

Caregivers, care work and the limits of healthcare: An ethnographic exploration into practices of community-based HIV prevention, treatment and care in a resource-limited setting in South Africa

by
Dillon Timothy Wademan

Thesis presented in fulfilment of the requirements for the degree Master of Sociology in the Faculty of Arts and Social Sciences at Stellenbosch University



Supervisor: Dr Lindsey Reynolds
Co-supervisor: Mr Jacob du Plessis

March 2016

Declaration

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof, that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

Date: March 2016

Copyright © 2016 Stellenbosch University

All rights reserved

Abstract

In just over a decade the South African government's response to the HIV/AIDS epidemic has gone from a position that could be described as adversarial to rolling out and sustaining the largest antiretroviral treatment (ART) programme in the world (Simelela & Venter, 2014). With the latest recommendations from international organisations supporting immediate ART initiation for all people living with HIV/AIDS and ART for people at high risk for HIV infection (WHO, 2015), the number of people to be incorporated into the programme is likely to grow exponentially. One unfortunate effect of these shifts in healthcare provision is the enormous strain it places on an already ailing public health sector (Coovadia, Jewkes, Barron, Sanders & McIntyre, 2009).

In order to cope with the growing pressures on the health system, the South African public health sector has increasingly relied on community- and home-based carers to carry out the everyday tasks of managing HIV-infected people's initiation on and adherence to ART. Despite their essential role in sustaining the health care system, little research has been done on the actual practices and experiences of community care workers in resource-poor settings (Zulliger, Moshabela, & Schneider, 2014). In this thesis I explore the care practices of two such groups of community- and home-based carers in one locality in the Western Cape. The first group are community care workers (CCWs) who work for non-governmental organisations in partnership with the public health sector. The second group, community HIV-care providers (or CHiPs), work for a population-based HIV treatment and prevention trial called HPTN 071 (or PopART). In addition, I engage with HIV-positive individuals introduced to me by the caregivers to draw out issues surrounding access to and provision of healthcare.

In this context, CCWs are responsible for providing HIV-infected community members with treatment adherence and psychosocial support only once they have initiated ART. The CHiPs, on the other hand, are responsible for a range of HIV treatment and prevention practices including door-to-door voluntary HIV-counselling and testing. The PopART trial protocol describes the CHiPs' work as delivering a "best practice" public health intervention" and points out that their work should be "separate from the 'research teams'" employed by the trial (Hayes & Fidler, 2012:33). However, at the same time as providing their clients with healthcare, both CCWs and CHiPs must also produce certain kinds of evidence of their care.

Providing care while producing evidence often requires caregivers to adapt protocols and standard operating procedures, to 'make do' (Livingston, 2012), in order to meet their client's healthcare needs. Further, everyday care work entails translating and negotiating between divergent and overlapping modes of healthcare and healing. This thesis explores how caregivers use their intimate knowledge of the challenges their clients face to help them navigate these complex layers of healthcare, knowledge and authority. Thus, rather than seen simply as intermediaries, I argue that caregivers should be seen as living in translation, as entangled in the everyday lives of their clients, tying together the loose ends of healthcare implementation in a resource limited setting.

Opsomming

Die Suid-Afrikaanse regering se reaksie tot die MIV/VIGS epidemie het oor die afgelope dekade verander van 'n aanvanklike teenstrydige posisie tot die implementering van die grootste volhoubare antiretrovirale behandelingsprogram (ART) in die wêreld (Simelela & Venter, 2014). Met die nuutste aanbeveling van die Wêreldgesondheidsorganisasie om ART te inisieer vir alle mense wat met MIV/VIGS leef of wat as hoë risiko vir MIV infeksie beskou word (WHO, 2015), sal die getal mense wat in hierdie program inskakel oor die volgende paar jaar eksponensieël toeneem. 'n Belangrike en onvermydelike gevolg van hierdie verskuiwing in gesondheidsorgvoorsiening is die enorme implikasie hiervan op 'n alreeds wankelrige openbare gesondheidsorgsektor (Coovadia, Jewkes, Barron, Sanders & McIntyre, 2009).

Om die groeiende druk op die gesondheidstelsel baas te raak, het die Suid-Afrikaanse openbare gesondheidsektor toenemend begin staatmaak op die toetrede van gemeenskaps- en tuisgebaseerde versorgers om die alledaagse taak van mense met MIV se toetrede en volhouding tot ART te bestuur. Ten spyte van hulle belangrike rol in die handhawing van die gesondheidsorgsisteem, is min navorsing gedoen oor die werklike praktyke en ervarings van gemeenskapsgesondheidswerkers in areas wat ondervoorsien is van bronne (Zulliger, Moshabela, & Schneider, 2014). In hierdie tesis word die versorgingspraktyke van twee sulke groepe van gemeenskaps- en tuisversorgers in een gebied in die Wes-Kaap, in oorweging gebring. Die eerste groep is gemeenskapsorgwerkers (CCWs) wat vir nie-regeringsorganisasies werk. Die tweede groep is gemeenskap MIV-versorging voorsieners (of CHiPs) wat werksaam is vir 'n bevolkingswye MIV behandelings- en voorkomingstudie, naamlik HPTN 071 (PopART). Daarbenewens gesels ek met MIV-positiewe individue, wat aan my bekendgestel is deur die versorgers, om kwessies rakende toegang tot en die voorsiening van gesondheidsorg aan te spreek.

In hierdie konteks, is CCWs verantwoordelik vir die voorsiening van behandeling en psigo-sosiale ondersteuning sodra hulle met ART begin het. Aan die anderkant, is CHiPs verantwoordelik vir 'n verskeidenheid van MIV behandeling- en voorkomingspraktyke, insluitend deur-tot-deur vrywillige MIV-berading en toetsing. Die PopART studie-protokol beskryf die CHiPs se werk as die lewering van 'n “‘beste praktyk’ openbare gesondheid intervensie” en wys uit dat hulle werk “losstaande [moet wees] tot die ‘navorsingspanne’” wat in diens geneem word deur die studie (Hayes & Fidler, 2012:33). Alhoewel, terselfdetyd as om kliënte met gesondheidsorg te verskaf, moet beide CCWs en CHiPs ook sekere bewyse van hulle versorging lewer.

Om versorging sowel as bewyse te produseer, behels dikwels dat versorgers protokolle en standaard operasionele prosedures aanpas om hierby ‘uit te kom’ (Livingston, 2012), om sodoende aan hulle kliënt se gesondheidsbehoefte te voorsien. Boonop behels alledaagse gesondheidswerk die vertaling en onderhandeling tussen uiteenlopende en oorvleulende wyses van gesondheidsorg en genesing. Hierdie tesis stel ondersoek in oor hoe versorgers hulle intieme kennis van die uitdagings wat hul kliënte in die gesig staar gebruik om hulle te help om die komplekse lae van gesondheidsorg, kennis en outoriteit te navigeer. Eerder as om gesien te word as blote tussengangers, is my argument dat die versorgingsvoorsieners gesien moet word as ‘lewend in vertaling’, soos wat hulle deel uitmaak van die alledaagse lewe van hul kliënte en poog om die losstaande aspekte van gesondheidsorg implementering in hulpbronbeperkte kontekste bymekaar uit te bring.

Acknowledgements

I wish to acknowledge my colleagues at the Desmond Tutu TB Centre who have taught me about clinical trial research. Thank you, for helping me gain access to my field site, for providing intellectual and emotional support and for sharing your knowledge with me. Thank you for your generosity and, most of all, your patience.

I wish to thank the Harry Crossley Foundation for generously funding my research, without which I would not have been able to complete this undertaking.

I would also like to thank my supervisors:

Lindsey; thank you for teaching me how to listen intently and to write creatively. I am indebted to you for introducing me to this field of research. You have taught me that writing is as much about learning as it is about teaching.

Jacob; thank you for walking this long road with me and, for seeing it through to its end. It has been a tedious journey. You have taught me that research is about more than the final product.

To my peers and colleagues in the Sociology and Social Anthropology Department at Stellenbosch University; my home away from home. Thank you for your guidance, wisdom and generosity. It has been *'far too short a time to live among such excellent and admirable folk'*.

To my participants who graciously shared their lives with me: You have inspired me to care about care. You have taught me about having compassion without apathy, an empathy without judgement and, shown me what it means to give hope to those who have lost it.

Dedication

To my God under whose continual care I live.

And,

To my family; your unfailing love and encouragement have helped me to persist. To the Dillen's; thank you for welcoming me into your lives with open arms. To Kat; thank you for being the voice of reason, the touch of comfort and, the embodiment of confidence in my life. To my friends who have shared in my tears, my laughter and my rage; thank you for your understanding.

Table of Contents

| | |
|---|------------|
| Declaration | II |
| Abstract | III |
| Opsomming | IV |
| Acknowledgements | V |
| Dedication | V |
| Table of Contents | VI |
| List of figures | VIII |
| List of Abbreviations and Acronyms | IX |
| Chapter 1 Introduction | 10 |
| 1.1 Locating the Research/Background | 12 |
| 1.2 The Provision of Care | 13 |
| 1.3 Key Research Questions | 15 |
| 1.4 Research Methodology | 16 |
| 1.5 Chapter Outline | 20 |
| Chapter 2 The landscape of care in Lwandle: Past, present and future | 24 |
| 2.1 A brief history of Lwandle | 25 |
| 2.2 Contemporary Lwandle | 28 |
| 2.3 Services provision in Lwandle | 30 |
| 2.4 Community Care Workers in South Africa | 32 |
| 2.5 The continuum of care and the PopART trial in Lwandle | 33 |
| 2.5.1 Lwandle as a trial site | 36 |
| 2.6 Conclusion | 37 |
| Chapter 3 Biotechnologies and the cost of care | 39 |
| 3.1 A meeting with the CHiPs | 39 |
| 3.2 Care as concept, the global to the local | 42 |
| 3.3 Exceptional populations: Intimate technologies, clientship, disclosure and responsabilisation | |
| 45 | |

| | | |
|-----------------------------|---|------------|
| 3.4 | Improvising technologies | 50 |
| 3.4.1 | Migratory patterns and infrastructural challenges | 51 |
| 3.4.2 | Stigmatisation, confidentiality and trust | 55 |
| 3.4.3 | Emotional, financial and, physical costs of care | 57 |
| 3.5 | Making-do, tinkering and ad-libbing care | 60 |
| Chapter 4 | Knowledge in translation..... | 63 |
| 4.1 | Knowledges and practices of care | 63 |
| 4.2 | Knowledge and healthcare in South Africa..... | 66 |
| 4.2.1 | Culture brokers: Empowering and connecting..... | 69 |
| 4.2.2 | Middle-figures: Negotiation and translation | 73 |
| 4.2.3 | Foot soldiers: Living in translation | 78 |
| 4.3 | Tending the line..... | 81 |
| Chapter 5 | Structural violence and the limits of healthcare | 83 |
| 5.1 | Possibility, freedom and choice..... | 83 |
| 5.1.1 | Meeting Diliza..... | 84 |
| 5.2 | In/capabilities, un/freedoms and structural violence | 87 |
| 5.2.1 | Economic facilities: Poverty and risky behaviour | 88 |
| 5.2.2 | Social opportunities: Social and personal violence..... | 92 |
| 5.2.3 | Transparency guarantees: Stigma and social death..... | 94 |
| 5.2.4 | Protective securities and the disability grant..... | 97 |
| 5.3 | Ending/s..... | 100 |
| Chapter 6 | Summary, conclusions and recommendations | 102 |
| 6.1 | Broad emerging themes and issues | 102 |
| 6.2 | Physical, Social and Economic Context..... | 103 |
| 6.3 | Practical and Moral Consequences..... | 104 |
| 6.4 | Some Implications..... | 106 |
| Reference List | | 108 |
| Addenda | | 124 |

Addendum A: DTTC Ethical Clearance 124

Addendum B: Good Clinical Practice Certificate 125

Addendum C: Map of Lwandle as Understood by Community Members 126

Addendum D: List of Participant Interviews 127

List of figures

Figure 2.1 Aerial photograph of Lwandle hostel, 1987 Copyright: Andrew Berman, Urban Design Services (Adapted from (Murray & Witz, 2013:53)..... 26

Figure 2.2 Two photos of illegal dumping sites in Lwandle 29

Figure 2.3 The HIV Continuum of Care Approach as it appears in the National Consolidated Guidelines: For the prevention of mother-to-child transmission of HIV (PMTCT) and the management of HIV in children, adolescents and adults (National Department of Health, 2015 34

Figure 2.4 Picture representation of active community HIV-care provider zones, July 2014..... 36

Figure 3.1 Two examples of 'backyard dwellings' in Lwandle..... 54

Figure 4.1 Posters of 'The Professor' and a Dr: 'Seeing is Believing', '100% Guaranteed' 68

Figure 6.1 Map of Lwandle as understood by my participants..... 126

List of Abbreviations and Acronyms

| Abbreviation/Acronym | Meaning |
|-----------------------------|---|
| AIDS | Acquired Immune Deficiency Syndrome |
| ART | Anti-Retroviral Treatment |
| ARV | Anti-retroviral |
| BBS | Broad Brush Survey |
| CCW | Community Care Worker |
| CHiPs | Community HIV-care Providers |
| DTTC | Desmond Tutu TB Centre |
| EDCs | Electronic Data Capturing devices |
| HIV | Human Immunodeficiency Virus |
| HPTN | HIV Prevention Trials Network |
| HSRC | Human Sciences Research Council |
| DoH | South African National Department of Health |
| MMC | Medical Male Circumcision |
| NGO | Non-governmental Organisation |
| PLWH | Person living with HIV/AIDS |
| PMTCT | Prevention of Mother to Child Transmission of HIV |
| PrEP | pre-exposure prophylaxis |
| RDP | Reconstruction and Development Programme |
| SANRAL | South African National Roads Agency |
| TB | Tuberculosis |
| UTT | Universal Testing and Treatment |
| VCT | Voluntary Counselling and Testing |
| ZAMSTAR | Zambia-South Africa TB and AIDS Reduction Program |

Chapter 1 Introduction

It's actually quite extraordinary that in 2004 we had only 47 000 people on treatment [...] By mid-2011, we had 1.79 million people. It's almost a city (Mbengashe, 2012 as cited in Bodibe, 2012).

As highlighted in the above comment made by the former head of the South African Department of Health's (DoH) HIV programme, South Africa's response to HIV has undergone a monumental transformation over little more than a decade (Simelela & Venter, 2014). Although antiretrovirals (ARVs) had already emerged as 'miracle' drugs in the late 1990s, they remained largely unaffordable to the majority of the South African population and largely unobtainable through the public health sector, in part linked to the South African government's questioning of the link between HIV and AIDS and effectiveness of ARVs (Levine, 2012). In October 2003, however, the government was forced by the Constitutional Court of South Africa to roll-out the first national antiretroviral treatment (ART) programme (Colvin & Robins, 2009). Between late 2003 and 2015, the programme expanded from providing treatment only to pregnant women with a CD4 cell count less than 200 to making antiretroviral treatment available to all HIV-infected people with a CD4 cell count ≤ 500 (Department of Health, 2015).¹ As a result, the number of South Africans on HIV treatment have increased from 47 000 at the end of the first year of the national ART programme to 2.3 million by 2013 (Mayosi, Lawn, Van Niekerk, Bradshaw, Abdool Karim, *et al.*, 2012; Simelela & Venter, 2014). Thus South Africa has gone from the position of having the majority of its HIV-infected population denied access to ART to moving towards offering ART to nearly all HIV infected people.

Yet, despite these successes, access to and provision of ART for the most vulnerable and high risk populations continues to be impeded by social, structural, and economic challenges (Bärnighausen, Tanser, Herbst, Mutevedzi, Mossong, *et al.*, 2013). To address these challenges, the South African Department of Health has made important efforts to reengineer the public health sector (Mayosi *et al.*, 2012). This response has included the adoption of 'task shifting' policies that see the burden of care shifted to lay- and community-based health workers (henceforth community care workers²) (Dennill, 2012). Community care workers (CCWs) are expected to provide their clients with holistic care which includes identifying and linking HIV and TB infected people to care, counselling HIV

¹ A low CD4 cell count means that the infected person's immune system is already severely compromised and, they are vulnerable to opportunistic infection.

² As with the South African Community care worker policy of 2009, the use of "[t]his term encompasses and replaces Community Health Workers" (Department of Health & Department of Social Development, 2009:6).

infected clients and providing moral and social support for clients on lifelong HIV and TB medication (Zulliger, Moshabela & Schneider, 2014). Research indicates that CCWs play an important role in helping to alleviate the strain of the HIV/AIDS epidemic on the public health sector (particularly in rural areas) and, contribute to improved ART initiation and adherence rates (Ayles, Sismanidis, Beyers, Hayes & Godfrey-Faussett, 2008; Naik, Doherty, Jackson, Tabana, Swanevelder, *et al.*, 2015). Although these changes have taken great strides to increase access to ART, almost 4 million HIV-infected people have not yet initiated ART in South Africa (Mayosi *et al.*, 2012).

At the same time that South Africa is struggling to meet the needs of its population, international guidelines are recommending an even greater expansion in HIV treatment programmes. These programs are predicated on the fact that high percentages of HIV-infected people are able to begin ART immediately and, that this early initiation of ART reduces the chances of HIV transmission. The aim is to locate 90% of HIV-infected people and have 90% of those eligible people on ART, with 90% treatment adherence rates, so that widespread viral suppression reduces incidence rates (UNAIDS, 2014). This is known as the treatment as prevention model (Bärnighausen, Eyal & Wikler, 2014). In October 2015 the World Health Organisation released important new guidelines on ART, drawing on an increasing body of evidence of both the preventive and clinical benefits of early ART initiation (WHO, 2015). The guidelines endorse two important changes to their previous recommendations. Firstly, all HIV-positive individuals should be initiated on ART immediately, irrespective of their CD4 count. Secondly, pre-exposure prophylaxis (PrEP), or ART for individuals not HIV-positive, should be offered to all individuals at high risk of HIV infection.

Despite these new guidelines questions revolving around ART initiation, such as how best to extend ART to all HIV-positive individuals and to those at risk of infection, continue to be pivotal in countries like South Africa, which has one of the highest HIV prevalence rates in the world and, where ART scale up has been fragmented and slow. Major challenges, therefore, continue to impede HIV testing uptake, linkage to and retention in care and, long term adherence. To help answer some of these questions, South Africa and Zambia are hosting an ongoing cluster-randomised trial that aims to test a new strategy to reduce HIV incidence and prevalence, referred to as the universal test and treat (UTT) approach. Underpinning the UTT approach is the hypothesis that the combination of population-based voluntary HIV counselling and testing, education and, the provision of a combination of HIV prevention methods with immediate linkage to care and antiretroviral therapy initiation, will reduce HIV incidence rates at the population level (Hayes & Fidler, 2012). The trial is referred to as the Population Effects of Antiretroviral Therapy to Reduce HIV transmission (or PopART) trial, and is being overseen by the HIV Prevention Trials Network (HPTN). The PopART

trial follows on previous trials to test whether their combined strategies (among others) could work to reduce HIV infection at the population level (Hayes & Fidler, 2012). On the 6th of February 2011 during a “public, fair and open randomisation event”, three of the nine communities in the Western Cape of South Africa were chosen as intervention arms of the PopART trial. These intervention arms will receive the full range of intervention strategies of the UTT approach. My research took place in one of these three intervention arms, to interrogate what changes take place in healthcare provision as a result of the trial.

The central concern of this thesis is to explore what care is, what form/s care takes and how care is provided by community care workers and clinical trial staff in the context of this massive ART scale up in a resource constrained community trial site. In attempting to answer these questions, I describe the challenges caregivers face in their labour of care and how these challenges can manifest in the everyday lives of both those attempting to access ART and those trying to provide ART. Thus the thesis interrogates complex layers of healthcare provision and perception, knowledge production and the cost of care, in order to explore the opportunities and limitations for care in resource constrained settings.

1.1 Locating the Research/Background

My research is located in a community called Lwandle. Lwandle is an informal settlement situated in the Eastern sub-district of Cape Town Metropole between Somerset West and Strand. Like other informal settlements in South Africa, Lwandle has high levels of crime, violence, unemployment rates, and poor sanitation and service provision. Unemployment rates in the municipal area within which Lwandle falls were roughly between 24% and 35% in 2011 (Strategic Development Information & GIS Department, 2013a,b). The area, also like similar sites in contemporary South Africa, has an extremely high burden of disease. A 2010 study³ revealed that the Cape Town Metropole, within which Lwandle falls, had the highest HIV rate in the Western Cape at 20.2% in 2010 and carried 59% of the TB burden of the Western Cape in 2009 (Western Cape Government, 2012:19). In the local clinic, 69% of TB patients tested HIV-positive in 2007 (National Council of Provinces, 2007:10), a clear indication of extremely high underlying HIV rates. According to preliminary findings in the PopART trial, the current HIV prevalence rate is between 10 and 15 percent (Haddinot, 2015). The combination of a high unemployment rate, stretched healthcare services and a high burden of disease feature as central concerns in this thesis. These challenges have

³ These estimates were calculated using the 2010 National Antenatal Sentinel HIV and Syphilis Prevalence Survey.

a profound impact on the ability of community care workers to provide care to people living in Lwandle, as much as they do on the ability of people living in Lwandle to access care.

My research revolved around the local community clinic, called Ikhwezi. Ikhwezi clinic was built in 1999 and provides primary healthcare services to people living in and around Lwandle. According to a 2007 report to the National Council of Provinces, the clinic provided primary health care services to a population of approximately 56 525 people living in Lwandle and adjacent areas (National Council of Provinces, 2007). As a primary health care centre, these services include healthcare for sexually transmitted infection (STI) management, prevention of mother to child transmission (PMTCT), voluntary counselling and testing (VCT) for HIV, reproductive health, antenatal care, baby clinic and adult curative and chronic illness management (National Council of Provinces, 2007). The provision of services is constrained, however, by shortages of human and healthcare resources in the clinic (National Council of Provinces, 2007).

I chose to locate my research here because the PopART trial has been underway in Lwandle since the end of 2013. Lwandle has the highest HIV prevalence rates and largest patient load of all the trial sites in South Africa. The PopART trial defines the boundaries of its intervention site as the catchment area of Ikhwezi clinic. What exactly comprises the clinic's catchment area, however, is unclear, as anyone can access services at Ikhwezi clinic. Working with caregivers in the area, I define the boundaries of my own field site in a more porous way. By following the movements and boundaries of caregivers themselves in the everyday labour of care, I allowed them to define the boundaries of my field site.

1.2 The Provision of Care

The success of population-based HIV prevention and care programmes depends centrally on the ability of health systems staff (both the CCWs and the CHiPs) to extend healthcare, primarily in the form of HIV testing, linkage to care, immediate ART initiation, and adherence support, to all people living with HIV/AIDS in communities like Lwandle. However, failure to link to care, loss to follow-up and high drop-out rates continue to plague the scale up of ART programmes across the globe (Gardner, McLees, Steiner, Del Rio & Burman, 2011; Van Rooyen, Barnabas, Baeten, Phakathi, Joseph, *et al.*, 2013). To address the challenges of retaining clients from testing to continued viral suppression, researchers have developed models that focus on moving people incrementally from step to step across a linear “treatment cascade” or “care continuum.” The model was originally conceptualised to integrate different healthcare programmes and prevent loss to follow-up for patients as they move from one form of healthcare programme/provider to another over the course of their

disease (Kerber, de Graft-Johnson, Bhutta, Okong, Starrs, *et al.*, 2007). The HIV treatment cascade or continuum of care generally involves 5 steps: learning of HIV-positive status (testing), entering into quality healthcare services (linkage to care), receiving CD4 cell count testing to determine eligibility to start ART, initiating ART if eligible and achieving viral load suppression by adhering to ART over time (Ogden, Esim & Grown, 2006; Micek, Gimbel-Sherr, Baptista, Matediana, Montoya, *et al.*, 2009). The final stage, ongoing viral load suppression, is achieved in most patients through adherence rates of approximately 80% (Gardner *et al.*, 2011).

In South Africa, the 2015 *National Consolidated Guidelines For the prevention of mother-to-child transmission of HIV (PMTCT) and the management of HIV in children, adolescents and adults* advocate such a step-wise approach to treatment and care provision. The Guidelines describe a continuum of care as an

integrated system of care that guides and tracks clients over time, through a comprehensive array of health services spanning from screening for HIV, to diagnosis and management of HIV, to initiation onto ART, retention in care and psychosocial support (National Department of Health, 2015:7).

This step-wise approach is in line with international guidelines on ART programmes that recommend early treatment initiation and viral suppression for the prevention of transmission to uninfected populations, as described above. Thus the continuum of care is not merely about the clinical benefits for the HIV-infected individual, but for population benefit as well. Also described above, a large portion of this programme is carried out by community-based care workers. How to best carry out this step-wise approach is one of the questions that the PopART trial seeks to answer—to determine the best practices for an effective continuum of care.

While the South African DoH is confident that this approach will help realise its vision of “a long and healthy life for all citizens” (National Department of Health, 2015:1), it recognises that the continuum is far from linear in practice. Difficulties exist at each level in the continuum of care, which prevent timeous linkage to and retention in care (Micek *et al.*, 2009). Not only is this process not linear, in that many people living with ART drop-out only to take up ART again at a later stage (Kranzer, Lewis, Ford, Zeinecker, Orrell, *et al.*, 2011), but many clients use their medication and the healthcare services of the caregivers in ways other than that which they were intended.

Further, healthcare provision is limited not only by the constraints of the healthcare system, but is also shaped by a continually evolving dialectic between protocol and practice, between optimum healthcare and structural constraints, between biomedical knowledge and local knowledge of

healthcare. In the context of the PopART trial, the community intervention programmes are carried out by Community HIV-care Providers (CHiPs), who are employed by the trial, but linked to the South African public health sector clinics. Once the CHiP links a client to care, the client accesses ART at Ikhwezi clinic and is assigned to a community care worker (CCW), who is employed through the clinic. CCWs then provide the client with ART support and care. The combined approach of the CHiPs and CCWs is unique to the PopART trial. Through their ongoing work of care provision, they help retain people in care and ensure high ART adherence levels which is integral to the success of the PopART trial, as I will explore in greater detail below. In providing healthcare, both the CHiPs and CCWs are called to stretch their job descriptions to better meet both their clients' healthcare needs and their employers' evidence production expectations, often at great personal cost. The caregivers⁴ serve as intermediaries and 'middle-figures' (Hunt, 1999), translating and negotiating between the biomedical healthcare practices of the trial and the public health sector, and the community context in which they live.

1.3 Key Research Questions

This thesis is thus about the varied means of providing and procuring care and what this provision and procurement of care entails in a resource limited setting like Lwandle. Steven Feierman and John Janzen argue that "[a]n ethnographer who studies the world from the point of view of patients or their lay attendants is likely to see a much more varied, perhaps chaotic, picture of therapeutic ideas and practices" (Feierman & Janzen, 1992:2). It is this chaotic picture of therapeutic ideas and practices that I engage with in this thesis. The key questions guiding this research are:

1. How do caregivers' everyday practices of care provision compare with how their practices are imagined and portrayed in each of their organisations' protocols and operational guidelines? In other words, what forms are their healthcare practices *made* to take as they both provide care and produce evidence for divergent actors?
2. In what ways are caregivers involved in translating, negotiating and reinterpreting divergent understandings and experiences of healthcare and disease, life and death?
3. What structural, economic and social factors exist in Lwandle that affect ART initiation and linking and adhering to care?

In a broad sense, I consider the differences between protocol and practice, between healthcare provision of community-based caregivers and trial staff and, healthcare access for HIV-positive

⁴ Throughout this thesis I often switch between the CHiPs and CCWs to illustrate both what distinguishes them from one another and what remains similar. I use the terms 'caregiver' or 'care provider' to refer to both the CHiPs and the CCWs, where their practices overlap.

individuals in one place in South Africa. In another sense, I consider the provision of and access to healthcare as compromised links and compromising linkages, where the caregivers are seen as links between their respective organisations and their clients and, where the linkages are the actual practices involved in linking clients to and retaining them in care. As the links between community members and their respective organisations, the caregivers often provide care and produce evidence at great personal financial, physical and emotional cost. After all, they too must find ways to live in a resource-limited setting.

1.4 Research Methodology

To explore these questions, I conducted ten months of research, from June 2014 to April 2015. In May 2014 I was introduced to the Social Science Team at the Desmond Tutu TB Centre (DTTC) by my supervisor, Lindsey Reynolds. DTTC is responsible for implementing the PopART trial across the nine study sites in South Africa. As part of their work, DTTC hired a group of social scientists to explore the social aspects of the trial. One element of their work is to “describe contextual, social factors in the HPTN 071 (PopART) study communities in relation to a diversity of community members’ experiences of HIV, ART, UTT, and related health/public health variables.” My ethnographic research in one study site fits well within this study aim, and thus my research was folded into the broader social science programme. Due to the similarity in research aims, my research project was subsumed under DTTC social science’s research ethics approval⁵. I was, however, required to complete a Good Clinical Practice course in order to meet randomised control trial standards for social science research, which I did in September 2014⁶.

To refine my study aims, between May and September of 2014, I met with the social science team to discuss what research had already been conducted in the different trial communities and what research still needed to be conducted. I also began attending interview training courses with the social science team and sitting in on their meetings. I was also able to sit in on training sessions with research assistants as they were taught how to use electronic data capturing devices, similar to those used by the CHiPs at each of the trial sites.

Once I completed these training and ethics courses and was given ethical clearance I began engaging in participant observation amongst various stakeholders involved in the PopART trial, focussing on Lwandle. This included attending Community Advisory Board meetings and general meetings amongst the social science team at DTTC, as well as accompanying them to Lwandle. It was during

⁵ See Addendum A for ethics approval document.

⁶ See Addendum B for Good Clinic Practice certificate.

one such research excursion, while accompanying social science teams members to a meeting at Lwandle library, that I was first introduced to the community care workers in Lwandle. At the end of the meeting, I was given an opportunity to introduce myself to the 27 community care workers in attendance.

At the next meeting between the social science team and CCWs, this time at Ikhwezi clinic, I introduced myself to the one of their supervisors. With the supervisor's help, I then contacted the CCW's coordinator and discussed my research with her. In mid-October I was granted permission by the coordinator to accompany the community health workers as they travelled out into the community. The following week I arrived at Ikhwezi clinic and reintroduced myself to the CCWs and their supervisors. They helped me to develop a schedule for which CCW's I would accompany and to which areas in Lwandle we would be going. From then on, I began to conduct participant observation with the caregivers as they provided their clients with adherence support. During these excursions, I followed the caregivers as they visited their client's houses, counted their clients' medications and performed recalls of clients defaulting their treatment regimen. I spent between 4 to five hours per day accompanying caregivers 4 and 5 days a week, over a five month period in and around Lwandle.

As a participant observer I was able to both observe how the caregivers performed their tasks as well as ask questions about their practices in real time. Moreover, as I often accompanied the caregivers into their client's houses, I was also able to engage with their clients. Where the client spoke English or Afrikaans, I was able to ask the client's questions about their access to and experience of care at Ikhwezi clinic. Where clients were isiXhosa, isiZulu or Shona-speaking, I relied on the community care workers to translate questions I had for the clients. During each trip into the community, I jotted down field notes as we moved from one client's house to another. At the end of each day I would type these notes out along with any other observations, questions or concerns raised throughout the day. These field notes form a major part of my research data and helped to shape my formal interviews.

It was also during these interactions and conversations that I began to see the pressure that caregivers were put under by both their clients and their employers. I also frequently observed the disparities between the caregivers' practices and what they said their protocol asked of them. The caregivers' role as 'middle-figures' (Hunt, 1999) was fully instantiated in those instances where they acted as my facilitators, interpreters, translators and even as guardians. Not only did they literally interpret and translate countless conversations between myself and their clients, they also translated local understandings of concepts related to health and healthcare. During these excursions, I was also able to determine which of the caregivers' clients would be willing to participate in formal interviews

following my initial participant observation period in Lwandle (spanning October-December 2014). I aimed to interview ten people living with HIV who had recently initiated ART. However, despite the mediation and assistance of the community care workers, I was only able to interview six people living with HIV.

Due to the participants' shifting working hours, organising interviews proved to be difficult with some clients, and it could take up to a month to organize the first formal interview. Once each participant agreed to partake in my research, we completed confidentiality forms together. I limited myself to interviewing only people fluent in English or Afrikaans. I completed six interviews with people living with HIV/AIDS in Lwandle⁷. The length of the interviews varied from 30 minutes to two hours. During these interviews, I asked respondents to tell me about their lives, both before and after they found out they were HIV-positive. We discussed their experiences with ART uptake and adherence. We also spoke about community life more broadly. Where possible, I allowed my participants to guide the interviews, only interjecting to ask for clarifications or to start another theme or topic of conversation. Most of these interviews were completed by the close of my first round of participant observation, in December 2014.

I returned to the field for a second round of participant observation (spanning January-April), focusing on observation with the community-HIV care workers (CHiPs). Though I had been introduced to the CHiPs early in my research, they were in the process of collating their years' worth of data at the time and were also in the midst of a move to new offices. For this reason I waited until my second round of participant observation before I engaged with the CHiPs again. At the start of my second round of participant observation the DTTC social science team introduced me to all the CHiPs supervisors at Lwandle. I was able to negotiate with them when and how much time I could spend with them.

On more than one occasion I was threatened by people the caregivers knew to be thieves while walking through Lwandle. These security concerns limited the ways in which I could participate with the CHiPs and the extent of my observations. Additionally, ethical concerns about being present while community members were informed of their HIV status weighed heavily on my decision to limit the amount of time I spent accompanying the CHiPs in the field.

With these concerns in mind, I was limited to spending time in the CHiPs office in Zola, Lwandle. Here I was able to engage with the CHiPs supervisors who, unlike the rest of the CHiPs, do not go out into the community unless they are needed to help resolve misunderstandings between community members and the CHiPs. Rather the CHiPs supervisors are responsible for managing how CHiPs are

⁷ One of the six interviews, conducted in Afrikaans, was conducted with the help of a research assistant from the social science team at DTTC.

allocated to each zone, tracking what percentage of each zone has been enumerated and, dealing with issues that arise between community members and CHiPs, and between CHiPs and DTTC management. Since all but one of the supervisors I spoke to had once been CHiPs themselves, they were able to relay many of the difficulties experienced in the community. Moreover, as the CHiPs reported to their respective supervisors at the end of each day, the supervisors were also privy to the many challenges CHiPs faced in each area in Lwandle.

Nearing the end of this participant observation period, I also conducted formal interviews with two CHiPs and one of the supervisors. I approached the CHiPs supervisors to ask which CHiPs would be willing to partake in my research before going ahead with the interviews. In addition I also conducted formal interviews with two CCWs. When I approached the CCWs' supervisor to ask who I could interview, he recommended several CCWs. However, only two volunteered to be interviewed at my request. During these interviews I asked the caregivers about the challenges they face as caregivers as well as personally. I also asked them whether or not they felt responsible for their clients' health and, what expectations their clients have of them regarding the care they provide. These interviews provided me with a clearer understanding of the more nebulous objectives of their practices which my participant observation among the community care workers failed to resolve.

All of the interviews were conducted at a time and place that was convenient for my participants—for community members this generally meant in their homes. Although informed of their right to privacy, many of my participants living with HIV preferred the CCWs to be present during the interview. This may be indicative of the trusting relationship the CCWs have with their clients. For the CCWs, interviews were conducted on the clinic's premises. Finally, the interviews done with the CHiPs were completed in or just outside the CHiPs office in Zola, Lwandle. Each of these interviews have been transcribed⁸ and each of my participants also completed an informed consent form. Besides the formal interviews, many informal discussions underpin much of the knowledge I gained of the history, healthcare provision and community life in Lwandle. As I mentioned, during my excursions into the community with both the CCWs and the CHiPs I was able to speak to them, take notes and even, on occasion, speak to their clients about health and healthcare.

Drawing on these various participants narratives' and the experiences I shared with them helped illuminate the many challenges involved in accessing and deploying healthcare in a resource-limited setting like Lwandle. In addition to the primary data, I was also granted access to some of the research

⁸ For the purposes of accessibility, where my participants spoke in Afrikaans, I have translated their scripts into English. Also, in order to ensure my participants confidentiality I have given all of them pseudonyms. See Addendum D for a list of my participant interviews.

completed by the DTTC social science team. These data included interviews conducted with community members, people living with HIV, clinical staff and other stakeholders.

As I shifted between these different actors, I was able to explore the context of care in Lwandle from a variety of perspectives. In doing so I explore “the relation between the real world and the concepts we form of it” (Danermark, Ekström, Jakobsen, & Karlsson, 2002:15) . Doing so means recognising an external reality to which I am able to direct my attention. It also means recognising that the reality of care is contingent and socially mediated, meaning that it is contextually specific (Newton, Deetz & Reed, 2011; Molapo, 2012). Not only does this allow for the ‘reality’ of an HIV-positive status but it allows for an investigation of the impact that this status has for individuals in their everyday lives. As much as I recognise that my research participants “are intelligent, reflective and wilful, and that these characteristics matter for how [they] understand the world,” I am not exempt from this subjectivity. I “recognise that [as a researcher I] do not just ‘experience’ the world objectively or directly” (Moses & Knutsen, 2007:10). Rather, my understanding of the world is constantly shifting and being channelled through my position in it. Similarly my understanding of my participants’ views of the world is affected by my position in relation to them. As an outsider of a different race and socio-economic class and gender, I am constantly attempting to interpret the world through my participants’ lenses rather than my own.

1.5 Chapter Outline

Before I begin to describe care provision in Lwandle, it is important to first understand the context in which this care is being deployed. I therefore begin the thesis by situating my research historically and geographically. In chapter two, I first describe Lwandle’s history, starting with the building of a migrant labour camp in the 1950s and continuing through the present day. I describe the ways that this history has contributed to the high HIV prevalence and overall disease burden in contemporary Lwandle, drawing on published literature and on research completed by the social science team at Desmond Tutu TB Centre. The high levels of structural inequalities and resource scarcity sometimes relegates healthcare to a lower priority for people living in Lwandle, as they focus all their energies on securing an income. This has an impact, I argue, on the way that people respond to ill health and limits the capacity of care providers to extend care through the public health sector as it currently exists in Lwandle.

I then describe how the provision of healthcare has been envisioned in places like Lwandle and how it has transformed over the years, particularly in response to HIV/AIDS. Thus I describe the broader landscape of HIV care in South Africa and some of the slippages that occur across the various

healthcare providers that appear in Lwandle, namely; non-governmental organisations, the public health sector and, more recently, the PopART clinical trial. When these organisations are conceptually held together, they form separate parts of the distributed landscape of care provision in Lwandle.

In chapter 3 I begin to explore the practice of care provision in Lwandle. That is, I describe the different forms and shapes that care takes in Lwandle. I begin by considering how care is understood more broadly. As I describe in the chapter, care as a concept has a long history. It is also a concept that is in constant flux, changing as it shifts from one context to another. By considering how care is understood, I show how conceptions of care are in fact intimately tied up in the present political moment, as neoliberal economic policies dictate in some ways who provides care and who bears the weight of care provision. By juxtaposing CCWs and CHiPs' care practices, I aim to elucidate the different forms of care and the costs that come with this care.

As one important element of these forms of care provision, I also consider how each of the caregivers' care practices in fact go far beyond the bounds of their duties as described in protocol and operating procedures. That is, they often provide more than merely biomedical healthcare. Rather, they offer a full range of care practices such as praying for their clients, or counselling family members, which often come with physical, emotional and sometimes financial costs. At the same time as the caregivers contend with the financial and emotional costs of their care practices, they are expected to meet the evidence production expectations of their respective organisations. That is, monitor and record their clients' ART uptake and adherence and, report these data to their respective organisation as proof of their care work and success of their respective HIV-care programmes. These twin obligations (to provide care and produce evidence) race to garner particular care practices from the caregivers.

In chapter 4 I describe the ways in which the CCWs and the CHiPs mediate the tensions that arise between their respective organisations demands and their clients' physical, emotional, social and biological needs (Schneider, Hlophe & Van Rensburg, 2008). To help understand the sometimes contradictory roles that caregivers play, in the chapter, I draw on the scholarship of Mary Ann Jezewski (1995) and Digby and Sweet (2002) to describe the caregivers as cultural brokers. As cultural brokers, the caregivers help empower and educate their clients to make the best decision to secure good health. In doing so I argue, following Nancy Rose Hunt (1999), that caregivers act as middle-figures between their clients and their organisations. As middle-figures, the caregivers are involved in translating different forms of healthcare and knowledge of health as well as negotiating healthcare practices with their clients in order to promote appropriate understandings of health and disease and, appropriate healthcare practices. It is through the process of translation and negotiation

that the caregivers attempt to ensure their clients properly understand biomedical technologies and disease. Yet translation is never fully complete. Finally, following Steven Robins (2009) I describe the caregivers as foot soldiers who translate and represent biomedical knowledge and healthcare practices to people living in Lwandle. However, I take this construction one step further to describe how the caregivers also carry with them personal beliefs and understandings of health and healthcare. Sometimes the caregivers engage their clients through these excess forms of knowledge, or through personal beliefs in order to provide their clients with social, emotional or spiritual care.

The boundaries between each of these functions, however, are fluid and overlap one another in interesting and complex ways. Similarly, different forms of healthcare and knowledge about health appear alongside one another, in complex ways. I argue that caregivers' must navigate through these various forms and understandings of healthcare in order to meet their clients' needs. In their deployment of care, they carry, as well as confront, particular knowledges or understandings of medicine and health, which they must carefully navigate if they are to provide their clients with appropriate and effective care. Again, this sometimes entails adapting their protocol. Thus, the caregivers' local practices are reflected in their clients' needs and are refracted by the protocol, even as their protocols allow for improvisation.

In chapter 5 I consider how HIV-positive people's inclusion into and retention in care can be disrupted by structural, social and economic inequalities and realities. I begin with the story of one man, whom I call Diliza, who was diagnosed with HIV, initiated ART and died within six months. I argue that some of the factors which contributed to Diliza's untimely death are a combined lack of economic opportunity, lack of access to social services provision and a lack of social support. I draw on his story alongside several others to describe how such structural, environmental and social challenges can infringe upon possible life choices for people living in Lwandle. Using Amartya Sen's (2005) notion of *poverty as capability deprivation*, I describe how the structural, environmental and social issues in Lwandle combine to restrict people's choices in life and their sense of possibility for a better future. Sen's notion (2005) revolves around the idea that particular unfreedoms (or the inaccessibility of certain ways of being) leads to further unfreedoms. In other words, it is a multidimensional view of poverty, where for instance financial poverty prevented Diliza from accessing transport to and from the healthcare centre. Presented in this way, I am able to move beyond a 'barrier-resolving' conception of these constraints to illustrate how they accumulate and compound on one another. Conversely, as more freedoms are extended to people so other freedoms are made available to them. Thus I present Lwandle as an area of constrained agency, limited in opportunity and shaped by

context. Yet, even among people living in Lwandle, inequalities exist and continue to restrain some people more than others.

In the concluding chapter, I pull together my argument regarding what forms care takes in Lwandle. I consider how these various forms of care are often responses to the caregivers' relationship with both their clients and their respective organisations. That is, as long as the caregivers are required to produce certain forms of evidence, their care work will continue to be shaped by this requirement, often resulting in adaptations or alterations to their standard healthcare practices and/or protocol. Similarly, the caregivers respond to the situations their client's face in their everyday lives. At times like these, the caregivers are also moved to alter their care practices in order to better meet the healthcare needs of each client. However, I consider how, in spite of caregivers dedication to healthcare provision, structural limitations hinder the implementation of ART scale up, adherence and HIV/AIDS intervention programmes. I conclude by considering how understanding the ways in which the context of care affects the successful implementation and daily practices of care provision will, perhaps, help unblock knowledge flows to future global health programmes.

Chapter 2 The landscape of care in Lwandle: Past, present and future

South Africa is considered to have one of the highest HIV rates in the world, at 11.2% across the population (Statistics South Africa, 2015). Similarly, the place where I conducted my research, has an HIV prevalence of between 10 and 15 percent (Haddinot, 2015). Not only does Ikhwezi clinic have the highest HIV prevalence rate of all the community clinic sites in the PopART trial, it also has the largest patient load. Further, numerous structural inequalities impede access to healthcare and contribute to ill health in Lwandle⁹. As this chapter will draw out, many of these structural inequalities are historically embedded and find their roots in migrant labour and the accompanying forced, poor living conditions. Lwandle's own history is located within and shaped by the broader history of South Africa.

In this chapter I describe how Lwandle emerged around the establishment of a migrant labour compound during the early Apartheid era, through present day. Lwandle and its surrounds gradually came to be recognised by the local municipality, as national legislation and government changed. However, the effects of the uneven distribution of resources during the Apartheid era continue to shape healthcare in Lwandle. I then describe how these effects have come to influence service provision and community life in Lwandle. Part of the response to the massive healthcare and human resource shortages in South Africa has been to fund community care workers (CCWs). I describe the role that CCWs are expected to play in the public health sector. Lastly, I describe how in Lwandle, CCWs work in tandem with Community HIV-care providers (CHiPs) from the PopART trial. Their care work is PopART's attempt to introduce a new form of the continuum of care into Lwandle and, suggests ways to retain HIV-infected people in care in resource limited settings.

In a sense, this chapter outlines the development of the Lwandle's response to the HIV/AIDS epidemic. It also considers how the national response has gradually emerged so that it now closely resembles that of the PopART trial. However, operational, social and economic challenges impact the ability of people living with HIV to initiate and adhere to ART. The implementation and success of the PopART trial aims to provide a form of 'best practice' for the continuum of care. In the chapters to follow I look at the particular practices involved in care provision and procurement for people living in Lwandle.

⁹ Here I refer to the area of my study which included the combined catchment areas of the PopART trial and Ikhwezi clinic.

2.1 A brief history of Lwandle

Lwandle, the isiXhosa word for ‘sea’ or ‘ocean’, is an informal settlement just a few kilometres north of False Bay in the Western Cape of South Africa. Lwandle is situated between Somerset West (to the north and west) and Strand (to the south), two of the wealthiest areas in the Western Cape. Somerset West Business Park and Somerset West CBD are a few short kilometres away to the west. To the east is Gordon’s Bay. Each of these surrounding areas are significantly wealthier than Lwandle and attract a considerable number of tourists over the course of the year. Lwandle’s relative poverty is a stark contrast to the wealth of these areas. Whereas most of Lwandle is comprised of row upon row of informal housing, Somerset West, Strand and Gordon’s Bay are lined with supermarkets, golf courses and free standing formal housing.

Lwandle came to life in 1943 with the selling of C.PJ van Vuuren’s farm to the Stellenbosch Divisional Council (Heap, 1993). Even then it was a desolate, arid area, with little opportunity for growing crops. Noëleen Murray and Leslie Witz describe the area as a “windswept harsh environment near to the sea [...] a marginal farming area” (Murray & Witz, 2013:55). It was originally established as a midpoint for migrant labourers. These labourers had already begun to migrate to the area from the Eastern Cape in the early 1900s (Murray & Witz, 2013). Lwandle was officially declared a ‘location’ or ‘native village’ after the construction of 22 hostels for single men in 1958 (Murray & Witz, 2014:19). The hostels were seen as temporary housing for short-term contract ‘African’ workers seeking employment in the Helderberg Basin area (Huggins, 1992:21). The hostels were built close enough to “growing fruit and canning industry” that workers could easily travel to and from work, but far enough away so that the hostels would go largely unseen by white urban surrounds (Witz, 2011:373). Murray and Witz go on to describe Lwandle as an area of ‘profound dislocation’ “precariously perched, hidden even, between buffer areas as a form of planned temporary encampment” (2014:19).

The hostels were upheld and legalised by pass laws implemented by the Apartheid government. These laws restricted labour migrants to living in the hostels where they could be monitored¹⁰ (Witz, 2011). They were also not allowed to work without permits. This coercive form of (labour) migration legally sanctioned racial and gender segregation (Mgijima & Buthelezi, 2006; Barchiesi, 2008). Although women were eventually allowed to join their husbands in the hostels during the 1960s/70s, find a job and contribute to the family bed-hold income, Mamphela Ramphele found that many women (and

¹⁰ Hostels of this kind started emerging as early as 1923 (with the first draft of the Native Urban Areas Act) and were sustained by means of Section 2 of the Native Urban Areas, Act 25 of 1923, 1930 and 1945 (Xulu, 2012; Murray & Witz, 2013).

men) continued to migrate between rural homes and the hostels into the late 80s because of the poor living conditions in hostels and “the undesirability of the hostels as a place in which to bring up children” (Ramphela, 1989:402). During the early stages of the HIV/AIDS epidemic, this migratory pattern was also linked to high HIV incidence rates among mainly Black South African migrant workers who were believed to engage in extramarital sexual relations while living in urban areas away from their families (Marais, 2011:272). This view has been critiqued by Mark Hunter (2002) who points to the intimate role that gifts (in the form of material goods or money) play in sexual relations. I return to this point later.

In 1986 the abolishment of influx controls across South Africa combined with the relaxation of regulations and control over hostels allowed migrant workers and their families to move freely between rural and urban areas. It also saw the government have a “total disregard of the hostel[s]”, as it withdrew from social services provision, allowing hostels to become decrepit and unliveable dwellings (Xulu, 2012:99). Due to monetary constraints in rural areas many people began to move to and live in urban areas.



Figure 2.1 Aerial photograph of Lwandle hostel, 1987 Copyright: Andrew Berman, Urban Design Services (Adapted from (Murray & Witz, 2013:53).

In the 1980's, increased urbanisation, low wages and the state's refusal to be seen as responsible for providing housing combined with the collapse of strict policing of hostels led to a huge influx of migrant labour into Lwandle. The general lack of infrastructure and social services provision, as well

as the inability of many migrant workers to afford the costs of formal housing, resulted in a rapid expansion of squatting¹¹ around Lwandle migrant compound (Huggins, 1992).

In 1986, Lwandle—which had been strategically positioned to be out of sight and out of mind—started to draw attention because of the poor living conditions. On two occasions, the poor living conditions in Lwandle were reported in local newspapers:

On 11 April 1986 the Helderberg District Mail reported on how the Mayor of Somerset West, Walter Stanford, had described the *'disgusting concentration camp type conditions in Lwandle'*¹² (Witz, 2011:376, *emphasis in original*).

Soon after these articles were published, in October 1986, the Strand Municipality used the poor living conditions and overcrowding as motivation to draw up plans to “demolish Lwandle and [...] move its population to Khayelitsha” (Mgijima & Buthelezi, 2006). Bongani Mgijima and Vusi Buthelezi (2006) argue that underlying the plans to demolish Lwandle was a desire to remove the ‘black spot’ Lwandle had become, from a ‘white area’. The plan was, however, foiled by the combined protest actions of community residents and employers in the Helderberg Basin. In July 1989, Lwandle was declared a local authority and began the process of being incorporated into the local municipality (Emmett, 1992:67).

By this time, the original compound was dwarfed by the size and growth of the informal housing around it. One of the largest informal settlements, Nomzamo, had already begun to emerge to the west of Lwandle in the 1980s. Nomzamo was recognised as an informal settlement by the local municipality in 1994. Between 2002 and 2005, the area surrounding Lwandle increased in size yet again with the introduction of two government housing developments; namely, Greenfields and Asanda Village (Sondlo, 2012:4). Lwandle has and continues to grow at a rapid pace as people continue to migrate from all over South Africa in search of work. The expansion of shopping malls, business parks and housing complexes just a few kilometres away in Strand, Somerset West and Gordan’s Bay signal a growing economy and the presence of money. Despite major growth and development in the area, Lwandle continues to manifest severe inequalities in housing, income and social services provision.

¹¹ Squatting, according to Heston Phillips (1992:1), is the illegal occupation of land, while “the term informal settlement is reserved for the legal(ized) shack settlements”.

¹² Leslie Witz (2011:376) notes that “all the emphases and italics are in the original” newspaper articles.

2.2 Contemporary Lwandle

One of the most striking things about Lwandle today is that it is teeming with life. People are continuously on the move, no matter the time of day. During the early morning many people leave Lwandle either going to work or in search of work. Work mobility to other areas in the Western Cape is increased by access to Metrorail, the National railway service provider, which provides transport to and from Cape Town several times a day. During the day older people and the unemployed sit outside watching children play in the streets, do their laundry or visit neighbours. Entrepreneurs line the streets selling goods and services to passers-by and, taxis zip in and out of Lwandle at all times of the day carrying passengers to and fro Somerset West, Strand, Gordons Bay and other nearby areas. Finding your way around Lwandle can, therefore, be tricky as the different areas are not well demarcated and do not seem to be separated from one another by any logical order. Even community members struggled to come to agreement when I asked them about the boundary lines between areas in Lwandle¹³. Moreover, Lwandle and the many informal settlements around it are defined differently by community members, clinic staff and the PopART trial. As I illustrate in the chapters to follow, the porous nature of these boundaries makes the work of the CHiPs and the CCWs profoundly more difficult.

In order to better understand the contemporary dynamics that come with living in Lwandle it is useful to draw on the data collected by the DTTC social sciences team. Before the PopART trial began, the DTTC social sciences team conducted what they call Broad Brush Surveys (BBS) at each of the trial communities, to help determine some of the nuanced structural, social and economic challenges that either contribute to high HIV prevalence rates, or inhibit community members' access to healthcare. The BBS methodology included focus group discussions with different age groups of both genders; interviews with community leaders, community clinic staff and community members; and, participant observation. Here I draw on their research report and my own fieldwork in the area to illustrate some key dynamics that shape the HIV landscape in Lwandle.

As highlighted in my brief historical review above, Lwandle continues to be an area of high mobility and informality. Because of the informal structure of much of the housing, disasters like flooding or fire breaks can cause havoc on the size and shape of areas in Lwandle. For example, in 2007 a fire broke out and destroyed much of the area referred to as Wag 'n Bietjie (Etheridge, 2014a)¹⁴. The 2011 Census indicates that 19.9% and 32.9% of people in Ward 085 (Nomzamo and surrounds) and

¹³ See Addendum C for a map of the area as understood by community members and CCWs I spoke with.

¹⁴ For other examples of the changing nature of Lwandle and its surrounds, see Jenna Etheridge (2014a,b,c,d) and (South African Press Association, 2014) for more on the evictions that led to the formal establishment of Siyanzaela.

086 (Lwandle and surrounds), respectively, live in informal dwellings¹⁵ (Strategic Development Information & GIS Department, 2013a,b). Informal housing is also tied to a host of healthcare concerns.

Living in informal dwellings, particularly those with a high population density, increases one's exposure to environmental pollution and poor sanitation. Tashlin Govender, Jo Barnes and Clarissa Piper (2010) argue that exposure to environmental pollution, poor sanitation and, a lack of fresh water are also linked to poor health outcomes, particularly for people living with HIV/AIDS. Below are two pictures I took of illegal dumping sites in Lwandle. One of my interviewees pointed out that children often play in these illegal dumping sites.



Figure 2.2 Two photos of illegal dumping sites in Lwandle

Larry Sawers and Eileen Stillwaggon extend this argument to say that HIV-infected people living in poverty-stricken areas and in informal dwellings are exposed to opportunistic infections and other diseases. This is a particularly crucial health concern for HIV-infected people who have compromised immune systems. They continue to add that these conditions not only expose HIV-infected people to ill-health but can in fact lead to higher transmission of HIV:

There is a substantial body of evidence that [suggests] poor sanitation, nutrition, and inadequate health care for people living in single-sex barracks and squatter settlements can increase the transmission of HIV (2010:198-199).

As I have already noted, Lwandle is not only home to former single-sex barracks but consists of large areas of 'squatter camps'. These areas, in particular, are very poor and receive little in the form of social services provision. Like other research then, the BBS report pointed to the well-known

¹⁵ These statistics include: 'Informal dwelling/shack in backyard and informal dwelling/shack not in backyard' (Strategic Development Information & GIS Department, 2013a,b).

intersection between poverty, inequality and large disparities in health and health care provision (Barnett & Whiteside, 2002; Whiteside, 2002; Shisana, Zungu & Pezi, 2009).

The more malign effects of poverty have to do with the way that high levels of unemployment¹⁶, marginalisation and little room for advancement affect behaviour and healthcare decision making. The BBS report indicated that poverty may push people into making poor decisions regarding sexual behaviour (DTTC, 2013). Lwandle community members saw young, unemployed women as well as single mothers as particularly vulnerable to resorting to ‘transactional sex’ in order to secure financial security. In these relationships, women are often unable to negotiate the terms of sexual practices and, sometimes engage in unprotected sex with multiple partners, further increasing their chances of contracting HIV (MacPhail, Pettifor & Rees, 2007). Conversely, people with money (mostly men) who exchange money or gifts for sexual favours were also considered to be at higher risk of contracting HIV. I return to the notion of ‘transactional sex’ in Chapter 5.

Unemployment and poverty were also linked to crime, violence and alcohol abuse. Once again young people (particularly women) who abuse alcohol and frequent shebeens are understood to be at greater risk for HIV infection, due to impaired decision making. Young women were even believed to engage in risky sexual behaviour in order to access alcohol (DTTC, 2013:7). Young men on the other hand, were said to join gangs and turn to violence in order to survive. Gangsters were linked to violence and theft, particularly among the most vulnerable groups like older people.

Another point worth highlighting from the BBS report is the fact that HIV (and other diseases) is only one of many concerns for people living in Lwandle and, not the most pressing at that (DTTC, 2013). Instead the report argues that employment or income of any kind is the most pressing issue for many people living in Lwandle and, as a result healthcare is often relegated to something to be sought out only when absolutely necessary (DTTC, 2013). Clearly, structural, economic and operational challenges continue to shape the lives and health of people living in Lwandle. Economic opportunities, or lack thereof, constrain living conditions which in turn affect healthcare decisions and possibilities for people living in Lwandle. I return to this in chapter 5.

2.3 Services provision in Lwandle

It is important to understand the response from healthcare providers to living conditions in Lwandle. Research conducted by the Human Sciences Research Council (HSRC) in 1992 revealed that despite

¹⁶ According to Johannes Erasmus (2005:145), the unemployment rate in the 2001 Census for Lwandle was 38% while the unemployment rate for Nomzamo was 31%. During the 2011 Census, Wards 085 (Nomzamo) and 086 (Lwandle) had unemployment rates of 23.83% and 34.21%, respectively (Strategic Development Information & GIS Department, 2013a,b).

being included incorporated into the local municipality's responsibility, Lwandle continued to lack proper infrastructure, housing and social services provision (Emmett, 1992). Community members listed access to sewerage facilities and running water, electricity, enough land to extend housing and, a street light system as some of their most pressing needs (Kok & Motloch, 1992). Pertinently though, 92% of respondents living in Lwandle cited a community health clinic as their most needed social services facility (Kok & Motloch, 1992:155).

In the early 90s, the lack of healthcare provision within the public health sector prompted non-governmental organisations (NGOs) to find ways to offer some forms of healthcare to people living in the greater Helderberg Basin. One such NGO providing healthcare to people living in the Lwandle recruits and trains community care workers (CCWs) from among community members. Although the NGO started off small with only 8 CCWs in 1998, it grew exponentially to more than 100 by 2012. These CCWs are spread out among the various informal settlements in the Helderberg Basin. The growth of community caregivers in Lwandle is reflected in a nationwide movement towards increasing reliance on community and home-based care within the newly elected African National Congress (ANC) government's call for a preventative primary healthcare approach. This was as much a response to the looming HIV/AIDS epidemic (as well as other chronic and infectious diseases like TB) as it was a response to massive human resource shortages¹⁷ in the public health sector.

As a consequence of the simultaneous need to upscale HIV/AIDS treatment and overhaul and remedy the massive human resource shortages in the South African public health sector (Schneider *et al.*, 2008), "community members have increasingly adopted 'caring' roles in places where services are inadequate or unavailable" (Sips, Haeri Mazanderani, Schneider, Greeff, Barten, *et al.*, 2014). Limited by an understaffed and under resourced public health sector, the primary health care model adopted by the government focusses on decentralising healthcare through the district health system. The district health system was designed "to allow for a continuum of health care throughout a person's life. The system includes [sic] both public and private providers as well as adequate input from support services" (Dennill, 2012:60). The district health system is a ward-based system and promotes community- and home-based care through the employment of community care workers from within the community.

According to the South African *Human Resources Health Strategy for the Health Sector: 2012/13 - 2016-17* each ward is supposed to be provided with one Primary Health Care Team. Each team is

¹⁷ For example, Hoosen Coovadia and colleagues (2009:830) note a decrease in public professional nursing staff from 149 per 100 000 population in 1998 to 110 per 100 000 population in 2007. Similarly an increasing number of doctors switched from the public health sector to the private health sector, from 40% in the 80s to 79% in 2007.

made up of seven primary health care agents, comprised of six community care workers (CCWs) and one specialist/professional nurse. In 1999 Ikhwezi Community Clinic was built north of the old migrant labour compound, near the National road (N2). When it was initially built, Ikhwezi clinic was responsible for providing healthcare to more than 6000 households with an estimated population of 25 000 people between Nomzamo and Lwandle (in 1997¹⁸) (Coetzee, 2002:38). The large population size is partly due to the high density that comes with informal housing and, partly due to the fact that Ikhwezi clinic's catchment area "overlaps the council boundaries of two councillors [...]. One is responsible for Nomzamo [...] and the other one for Lwandle" (DTTC, 2013:1).

In this ward-based system, each CCW is responsible for approximately 270 families and, each primary health care team is responsible for an average of 7 660 people or 1 619 households (Department of Health, 2011). Due to the way that Ikhwezi clinic's catchment area spans two wards, using statistics produced by the Census is difficult. For instance, while Lwandle is situated in the middle of Ward 086, Ward 086 also includes Greenways, Helderberg Park and Sercor Park all of which fall outside of Ikhwezi clinic's catchment area. Similarly, while Nomzamo is situated in the middle of Ward 085, Ward 085 also includes George Park and Onverwacht. These areas also fall outside of Ikhwezi clinic's catchment area. Thus while the population size of Ward 085 during the 2011 Census was 33 367 and Ward 086 was 39 177 respectively, one cannot extrapolate the exact population size of Ikhwezi clinic's catchment area from these figures (Strategic Development Information & GIS Department, 2013a,b). In the 2007 report to the National Council of Provinces Ikhwezi clinic management estimated that it served 56 525 people (National Council of Provinces, 2007).

Thus although Ikhwezi clinic serves two Wards and therefore should have at least two PHC Teams serving 15 220 people, it actually serves a population in excess of 50 000 people. This massive human resources shortage adversely affects the ability of both HIV infected people and their caregivers to retain high linkage to care and retention in care rates in Lwandle, further impeding the success of ART scale up. In the chapters to follow I discuss how healthcare providers in Lwandle have tried to manage healthcare shortages and meet the needs of their clients.

2.4 Community Care Workers in South Africa

In order to understand the dynamics of care in contemporary Lwandle, it is necessary to understand a little more about the structure of care in South Africa. Within the, national health system, community care workers (CCWs) fall in and between two departments, the Department of Health and

¹⁸ These statistics were generated by WESGRO in 1998 as quoted in (Coetzee, 2002).

the Department of Social Development (Fakier, 2014; Hunter, 2014). Not only do CCWs provide the community in which they live with healthcare services, but in receiving stipends many of them are enabled to look after themselves and their families (Fakier, 2014). Although their care work and the stipend they receive is acknowledged as a livelihood strategy by the state, much ambiguity revolves around their formal status as civil servants (Patel, 2014). The *National Guidelines for Community and Home Based Care*, first published in 2001 provided guidelines “to assist in the development and implementation of nationwide home-based and community-based care programmes” (Department of Health, 2001:1). Yet the community care workers continue to be cast as volunteers, neither employed by the Department of Health nor the Department of Social Development.

In fact, the ambiguity surrounding community health worker’s employment relationship with the state has recently been criticised as being “uncoordinated, unregulated and unstructured, with [no policy] formally forming part of the country’s public health system” (Malan, 2014). According to Helen Schneider and Uta Lehmann (2010), the South African government’s ambiguity surrounding community-based health workers has had two effects. Firstly, as long as community-based care workers remain outside the formal public health system, they will continue to be marginalised, and, secondly, there remains “little obligation to define roles and normalise relationships with other health professionals” (Schneider & Lehmann, 2010:65).

The lack of a clear delineation between a ‘volunteer’ and a CCW has meant that community care workers continue to work for a stipend rather than a wage. Casting CCWs as unemployed ‘volunteers’ disregards the fact that many of them work under conditions, arguably, more difficult than those in a clinic. In addition to these conditions, many of them volunteer as their main source of income. However, “[p]olicy guidelines are being developed to bring [home- and community-based care] work in line with the Basic Conditions of Employment Act (No. 18491 of 1997)” (Patel, 2014:259). The policy guidelines should provide CCWs with a greater employment security and draw more people into the CCW programme.

2.5 The continuum of care and the PopART trial in Lwandle

Although not a new model, the CCWs and the PopART trial are introducing a novel spin to the continuum of care or treatment cascade in Lwandle. Figure 2.3 (below) graphically illustrates what the HIV continuum of care looks like and how it should work in South Africa.

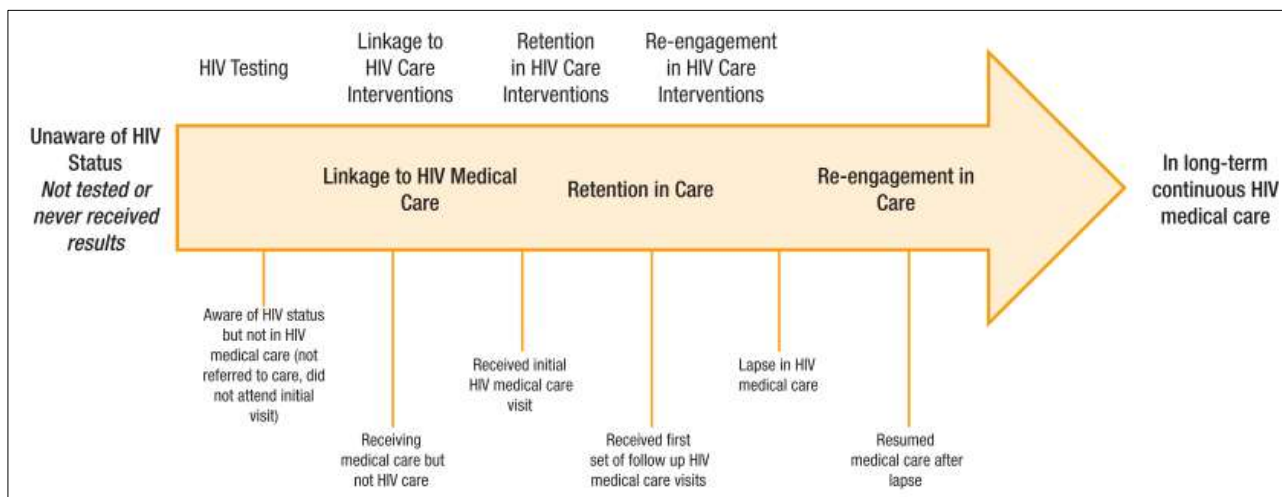


Figure 2:3 The HIV Continuum of Care Approach as it appears in the National Consolidated Guidelines: For the prevention of mother-to-child transmission of HIV (PMTCT) and the management of HIV in children, adolescents and adults (National Department of Health, 2015).

The PopART trial is the first population-based test and treat trial of its scale. Rather than waiting for people to find out their HIV status, the trial intervention includes active door to door voluntary HIV counselling and testing with the addition of linking HIV-positive individuals to immediate ART care in each of the trial communities. These interventions are carried out by Community HIV-care providers (or CHiPs). The CHiPs who I shadowed in Lwandle work from a building adjoining Anointed Church. The building is a rectangular hall about 50m by 20m and hosts more than fifty CHiPs every morning. The CHiPs start to arrive like patchwork, between 8 and 10am, depending on the time of year, as I explore in the next chapter. All the CHiPs wear a maroon uniform branded with DTTC's name. Each of the CHiPs signs themselves in with their respective supervisors noting their presence on an attendance list. To the right of the entrance are several chairs around a large table. To the left are the CHiPs supervisors, who arrive about half an hour to an hour earlier than the CHiPs. Dozens of red cooler boxes are stacked directly across the entrance of the hall, each one labelled with their owner's name.

Inside each cooler box is a small box of latex gloves and enough needles and HIV rapid tests for the day. Each team also takes a small biohazard bin with them, into which they throw used needles. The latex gloves are disposed of in a red 'bio-hazard' plastic bag. The CHiPs gather in small groups, and their respective supervisors double-check that they know which zone they are working in for the day. Slowly but surely, the CHiPs start to filter out of the hall, weaving their maroon-coloured way through Lwandle. Once a month the CHiPs dedicate time to 'follow-ups', where they visit individuals who tested HIV-positive to enquire whether or not they have successfully linked-to-care, initiated ART and been integrated into Ikhwezi clinic's ART support system.

In addition to deploying the CHiPs into the community, the trial strengthens the healthcare services offered at each of the trial site community clinic's by providing the clinic with additional professional nurses and CCWs (Hayes & Fidler, 2012). Once a community member is tested HIV-positive, the CHiPs provide the individual with a referral letter which ensures the client has the opportunity to begin ART immediately. It is at the point of initiating ART that CCWs working in each of the trial sites take up the continuum of care to ensure high retention in care rates by providing HIV-positive individuals with life-long medical and psychosocial support.

The CCWs in Lwandle work from Ikhwezi clinic. On my first visit to Ikhwezi clinic I was overwhelmed by all the commotion going on. Outside the clinic were several food stalls, selling sweets and cold drink to passers-by. People of all ages sat around the entrance, some on stools they had brought with them and, others on the floor. Children ran around screaming and playing while their guardians stood in line, patiently waiting for their turn to see a doctor, nurse or dentist. Entering into the clinic through the main entrance one is greeted by the lady over the intercom announcing the names of the next patient to be seen or to collect their medication. Nurses flitter to and fro the different sections of the clinic sometimes with patients following close behind. These sections, along with the entrance hall and other hallways, are often filled to overflowing with people leaning against every open gap along the walls, all the chairs having already been occupied. Many of the people in the clinic wear the tell-tale signs of TB on their faces—disposable paper respirator masks—either to protect themselves or others. I often had flashbacks of media pictures following the H1N1 outbreak of 2009. Turning immediately left takes one into the TB section (passed a TB mask dispenser), where all TB patients wait to be seen by the professional nurse or doctor on call. Again to the left is the CCWs make-shift office separated from clinic patients by a mobile clipboard and a large storage locker. In the far left corner is a cabinet with stacks of old adherence forms in it. Under the two desks, which take up the last wall, are empty condom and TB mask boxes. These, too, are overflowing with old adherence forms. The CCW supervisor also works from this desk, managing all adherence forms and CCW labour hours between a few books and folders. This small area is the hive of approximately 30 CCWs working for two NGOs out of Ikhwezi clinic. The CCWs range from 19 to over 50 years old. Most of them are isiXhosa speaking, but are fluent enough in English to easily converse with. One or two CCWs also speak Afrikaans. The CCWs arrive at 7:30 and leave before 9:00 every morning, visiting HIV/AIDS and TB clients¹⁹ in Lwandle for four and a half hours every week day.

¹⁹ The CCWs refer to the people they follow up on and monitor as their clients.

During these visitations the CCWs count their client's pills, write down their client's adherence rates and report these back to their supervisors at the end of each month. The clinic's nurses and the CCWs' supervisors check the client's adherence rates against their patient folder at the clinic to ensure that the client is taking the right amount of medication and has attended all scheduled blood and sputum tests. When one of the CCWs clients' is found to be non-adherent, or failed to present themselves at the clinic for blood or sputum tests, the CCWs must perform a recall. During a recall CCWs encourage clients to reengage HIV/TB care and treatment. As they leave the clinic, the CCWs usually walk in groups of two or three people (preferably where they have been allocated to nearby areas), both for company and for safety's sake.

2.5.1 Lwandle as a trial site

Each of the CCWs is responsible for providing care to people living in particular areas in Lwandle. These areas are usually defined by name of the area in which they work and, therefore more closely resembles how community members view Lwandle. Because the CCWs only visit those people who have initiated or defaulted their HIV or TB medication, they are often responsible for more than one area. During my time in Lwandle I shadowed CCWs and CHiPs as they travelled from one client to the next throughout the community. In doing so, I allowed them to determine which areas we visited.

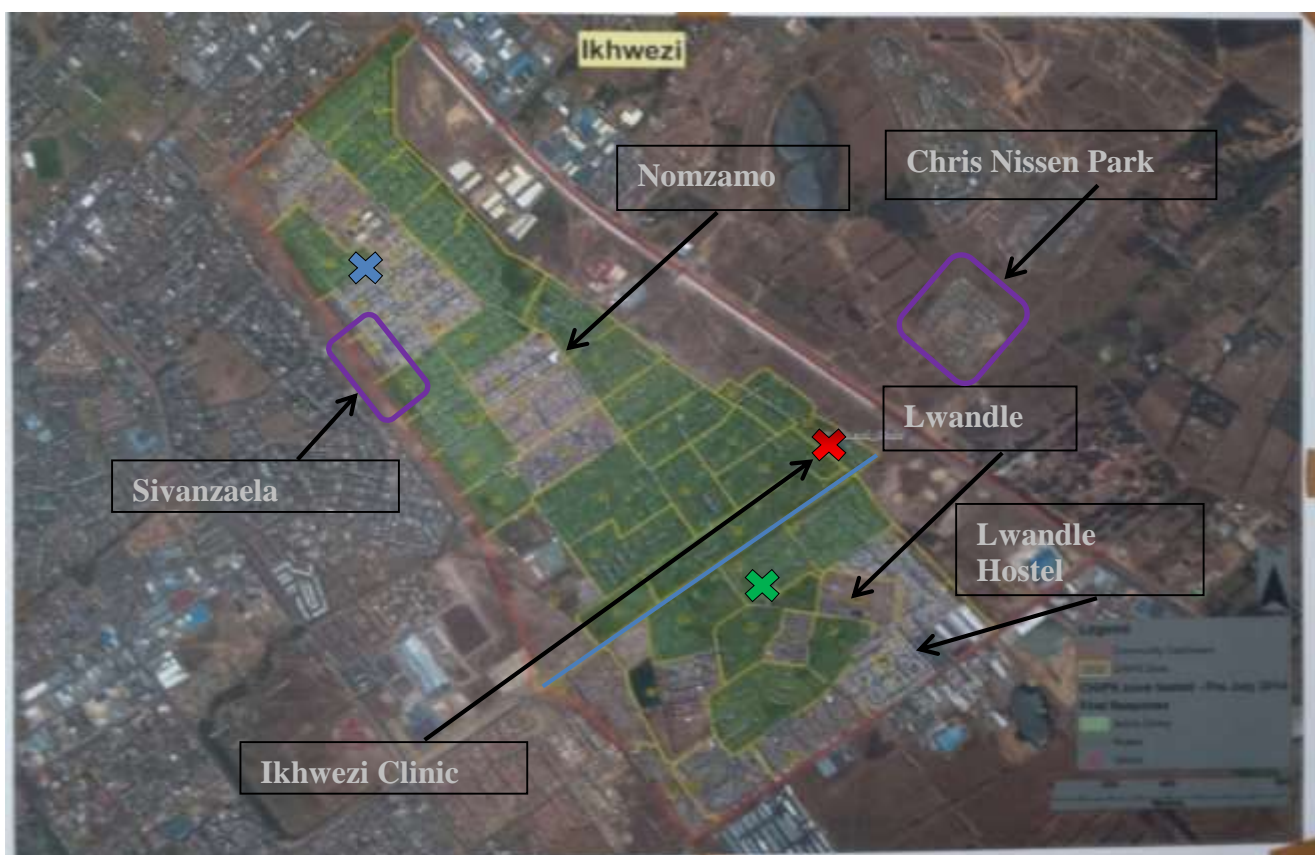


Figure 2.4 Picture representation of active community HIV-care provider zones, July 2014.

At the start of the trial, the CHiPs were stationed in a Methodist Church (indicated by a green cross) in Lwandle. During the second year of the trial, they moved to the Anointed Church in Nomzamo. Figure 2.4 (above) is a photo of a large poster that was stuck to the wall of the CHiPs office in Anointed Church (indicated by a blue cross), in February 2015. The picture indicates the CHiPs catchment area as ‘Ikhwezi community’, outlined in red. As the PopART protocol states; the research community, or *cluster*, is taken to mean “the catchment population of a local health unit” (Hayes & Fidler, 2012:28).

The CHiPs catchment area was separated (indicated by the blue line) into two general areas by the Desmond Tutu TB Centre; namely, Lwandle and Nomzamo. As I explained above, this was done because of the way that ‘Ikhwezi community’ actually spans two wards. Each of the CHiPs zones is indicated by the yellow markings. The zones shaded in green were active by July 2014.

‘Ikhwezi community’ as the PopART trial envisions it, does not correspond to the way that it operates in reality. It is much messier than how it appears in PopART’s imaginary of it. For example, Siyanzaela (see above) only came into existence after the PopART trial had begun²⁰ and was therefore inadvertently excluded from the CHiPs catchment area. Similarly, because Chris Nissen Park (see above) is situated on the other side of the N2, it technically falls within Hottentots Holland Hospital’s catchment area. Yet, many of the residents living in Chris Nissen Park use Ikhwezi clinic (indicated by the red cross in Figure 2.4) as their primary source of healthcare services. Indeed, many of the residents that go to the hospital are referred back to Ikhwezi clinic. As noted in the previous chapter, while people living outside of the CHiPs catchment area are excluded from their door-to-door testing, linkage-to-care and ART support, anyone can make use of Ikhwezi clinic’s services. In the following chapters I interrogate what practices are necessary to locate, test, link and monitor HIV-infected people in an area that has porous borders and is constantly changing shape and size.

2.6 Conclusion

In this chapter, I described the physical and geographic HIV landscape in Lwandle. I presented Lwandle as an emergent urban area, with a long and tumultuous history; envisioned as a thoroughfare between the Eastern Cape and Cape Town, between Somerset West and Strand. Historically, the physical location and aesthetic resulted in pejorative reactions from the affluent surrounds, but simultaneously existed as a necessary part of “the circulation of commodities” where the people living in Lwandle acted “as both labour power and the means of production and exchange” (Mbembe,

²⁰ See Jenna Etheridge (Etheridge, 2014a,b,c,d) and (South African Press Association, 2014) for more on the evictions that led to the formal establishment of Siyanzaela.

2004:377). Located in this peripheral area, people living in Lwandle continue to move between spaces and, as a result, Lwandle continues to be a place of ‘profound dislocation’ that experiences vast inequalities in social services provision (Murray & Witz, 2014).

Drawing on research conducted by DTTC’s social sciences team, I describe how the lack of general social services provision combine with rampant poverty and unemployment to amplify vulnerability to infectious disease and HIV in Lwandle. I then describe how the continuum of care in Lwandle rests on the leg work of the CHiPs and CCWs. Together they promote and provide HIV counselling and testing, linkage to care and immediate ART, as well as ART adherence support and retention in care. The layered provision of care through the trial and the public health sector intersect in the community and Ikhwezi clinic. However, the community is an ever-shifting space that resists clear definition of its borders.

As a field site and trial site, this ever-changing and shifting nature complicates the work of the CHiPs and the CCWs. As I moved in and around Lwandle with the caregivers I witnessed how the structural and geographic context of care provision complicated the nature of the caregivers’ work. Although they form part of a much larger healthcare programme, the caregiver’s work in Lwandle underpins the continuum of care model. The disruptions and challenges they face put the model in question. In the following chapter I consider how they attempt to overcome these challenges and how these challenges shape their care work.

Chapter 3 Biotechnologies and the cost of care

3.1 A meeting with the CHiPs

One Wednesday afternoon, I was sitting in the Anointed Church in Zola, after having spent the day walking through Lwandle with the community HIV-care providers (CHiPs). I followed the CHiPs as they visited community members all morning, testing people for HIV, screening for TB and, educating people about condom use, medical male circumcision and prevention-of-mother-to-child-transmission. The fifty or so CHiPs were waiting in the hall for the CHiPs Coordinator and the rest of the PopART data-capturing and management team. The team was to report back on the Annual General Meeting that had taken place in Zambia the week before. At the annual meeting, a few CHiPs joined trial management from both South Africa and Zambia, together with scientists, staff, and representatives of the trial funders to discuss successes and challenges of the trial. The meeting also served to make comparisons between the progress in each host country and trial site. These comparisons were made primarily in terms of intervention progress, which was defined primarily by the number of HIV-infected people who had been located, tested and linked to care.

The meeting began after the Coordinator arrived and stepped up to announce, ‘This is my meeting, my meeting’, compelling the CHiPs to settle down and pay attention. After a brief introduction, the Coordinator handed over the metaphorical microphone to one of the data capturing team managers who had set up a PowerPoint presentation in the middle of the hall. The presentation included statistics from all the PopART trial sites in South Africa and Zambia.

The presenter paused in reading these statistics to emphasise that half of all the known HIV-positive clients in South Africa were from Lwandle. However, while Lwandle registered more HIV-positive people than any other site in South Africa, the linkage to care ratio was relatively low in comparison to other sites. At that point, the CHiPs Coordinator stepped in:

I have told you to go out and get the HIV-positive people, and you listened, so give yourselves a round of applause. [Applause]. But we need you to follow up with these people now (Field notes, 20 February, 2015).

After presenting these statistics, the rest of the presentation included instructions on how to use the electronic data capturing devices (EDCs), the primary tool through which CHiPs teams capture data from clients. The CHiPs must complete a survey questionnaire, or enumeration as they call it, at every household they visit. Using the device, CHiPs record client’s HIV status, household structure, and linkage-to-care status.

During the meeting, the CHiPs were given specific instructions by one of the trial managers on the importance of collecting information accurately so that statistically sound data could be produced:

Get the truth from the client. Don't choose to make your life easy by accepting 'I don't know'; people know if they are on ART! Even if you have to figure out the closest date to when the client first went to the clinic, that is better than saying, 'I don't know'. You must get to a place with these people who you tested HIV-positive that you can have these kinds of conversations! We do NOT want the answer -1 [indicating that the client refuses to answer whether or not they linked-to-care]. We don't want this answer to dominate our statistics [...]. Don't tell me 'the people aren't there'; go find them! Only if they have dogs or a gun do you not have to go inside. Even if the person is linked or not linked, home or not home, you MUST capture everything through the EDC. (Field notes, 20 February, 2015).

The trial manager encouraged the staff to be diligent and work hard to ensure good follow-up numbers. A follow up entails visiting clients who the CHiPs tested HIV-positive, to find out whether or not they had linked to care and started antiretroviral treatment (ART). Follow ups also includes encouraging HIV-infected people not yet on ART, to initiate without delay. The trial manager then went on to promise that the site with the most follow-ups successfully completed will be rewarded with a party.

In the brief exchange described above, questions of power, of health, and of governance are brought to bear on how care is to be carried out in the context of this clinical trial. In order to increase numbers for the overall trial imperatives, CHiPs from different sites within South Africa compete against one another. Through these processes, HIV-positive people living in communities are transformed into statistics (figures)—as proof of the trial's operational success. In addition to serving the scientific aims of the trial, these statistics also double as material proof of the CHiPs labour. The call for CHiPs to seek out these figures (particularly in the statistical sense) seemingly reduces their care to mechanical arms of the larger trial technology.

In this context, the kind of care CHiPs are being asked to provide is a highly biomedicalised form of care, which relies on a series of set actions including both the HIV testing and counselling and enumeration processes. It is necessary in order to carry out the continuum of care model. The model relies on HIV-positive people to move along a series of linkages to prevent nonadherence to treatment. These linkages start at being tested for HIV, to being linked to care, initiating ART, remaining in care and achieving viral suppression. Further, it aims to produce certain forms of knowledge, as required by the mandate of the clinical trial.

Alongside this highly biomedicalised form of care, however, the trial managers insist that the CHiPs care practices go beyond mechanical actions to establish a relationship with their clients: “You must get to a place with these people who you tested HIV-positive so that you can have these kinds of conversations!” In defining the terms of the relationships created between the CHiPs and their clients, the trial manager effectively blurs the line between care provision and evidence production and, between job description and job expectation, encouraging the CHiPs to work for ‘love rather than for money’ (Folbre, 2008:376). The invocation of working for ‘love rather than for money’ appears as an inherent characteristic of the care provided by the CCWs living and working in Lwandle. Indeed, they are called to provide their clients with not only physical but psychosocial care as well (Department of Health, 2009). Unlike the CHiPs, the CCWs’ clients often ask them to provide psychosocial care over and above their healthcare practices. Rather than the request coming from the above (like the CHiPs manager asked the CHiPs to ‘get to a place with these people [...] so that you can have these kinds of conversations’) the CCWs are asked from below, from their clients, to provide them with emotional and social care. Time and again I witnessed and heard stories about instances when the CHiPs and CCWs were asked to go beyond their job descriptions in order to secure the best health outcomes for their clients. This ‘cost of care’ often goes unrecognised by the caregivers’ respective organisations; lost in the translation of their care into statistics and, subsequently into their stipends/salaries.

This human or relational side of the CHiPs care work serves to illustrate the fact that care manifests in diverse and shifting ways. In this chapter I argue that the biomedicalised forms of care that are necessary to carry out the continuum of care appear alongside more relational forms of care. Both modalities of care are necessary, I suggest, in order for CHiPs to meet both the caregiving and evidence producing expectations of the trial leadership, not to mention their client’s healthcare needs.

It is precisely these tensions that I wish to talk about in this chapter, where care provision is not only “both a burden and an expression of an attitude of dedication” (Reddy, Meyer, Shefer & Meyiwa, 2014:5), but where care is also highly biomedicalised and linked to research and income. This distributed form of care is of particular importance to global health research because it reveals something about the way that global health produces change in the way that people relate to one another.

Similarly the CCWs are called to go beyond their job descriptions by their clients. Yet, they too must produce certain forms of evidence through their adherence forms which they fill out when they visit and count their client’s ART adherence. These forms are submitted to their supervisors at the end of each month to collate and determine each CCWs performance. Although their practices are quite

different, both the CHiPs and the CCWs are involved in extending care to community members living in Lwandle. By holding the CHiPs and the CCWs care practices side by side, I interrogate the various forms care takes in Lwandle. I begin by briefly discussing ‘care’ as a concept as it appears globally, as well as how it is conceived in the South African context. Following this I describe the CHiPs and CCWs everyday care practices. I explore the manner in which their care is extended and received and how it is stymied and obstructed. I briefly argue, following Vinh-Kim Nguyen, that the type of care they provide acts as a form of policing, in the Foucauldian sense. I describe how this policing in the form of care helps transform their clients into responsabilised citizens. I describe how this form of care is not only limited by the context in which it is being deployed, but that other forms of care must appear alongside this policing form of care if the continuum of care model is to be successful. Thus, I argue that it is the other forms that care takes that may ultimately determine the success or failure of the continuum of care in Lwandle. Finally, I explore how caregivers attempting to extend care find themselves in similar circumstances to the recipients of their care. In this context, caregivers struggle to extend care at the same time as producing evidence—a struggle that comes at great personal cost.

3.2 Care as concept, the global to the local

Care is a difficult concept to define, and has been variously conceived and used within policy and practice over time (Moss, Boddy & Cameron, 2006; Reddy *et al.*, 2014). Although it has traditionally been used in feminist writing in relation to women’s unpaid work among family members, the concept of care has become increasingly diffuse in recent years as it spans across global/local, public/private, paid/unpaid and emotional/physical labour divides (Daly & Lewis, 2000). One of the broadest definitions of care is that offered by Berenice Fisher and Joan Tronto (1990) where they attempt to reconceptualise caring so that it “is comprehensive (including both the public and the private), integrated (not based on the separation of spheres [of love and labour]), and feminist (speaking to the ways in which caring often entails and perpetuates the oppression of women” (1990:37). Their pursuit of a suitable broad definition of care led them to define care as

a species activity that includes everything that we do to maintain, continue, and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web (Fisher & Tronto, 1990:37).

In drawing up a conceptual framework of care, Vasu Reddy, Stephan Meyer, Tamara Shefer and Thenjiwe Meyiwa (2014:4), put forward three general characteristics of care: care is an action, a mental state, and a moral value. These dimensions of care illustrate how care involves an intimate

morality of exchange that is both physically and emotionally demanding. In recent years, however, the division between emotional and physical labour has been challenged as carers and the cared for are increasingly considered to be in an interdependent relationship with one another.

Further, Parvati Raghuram argues that care is being ‘stretched’ globally, as it becomes “central to living responsibly in an increasingly interconnected world” (2012:137). This interdependence stretches across borders as people migrate both in search of procuring and providing care. The shift is also indicated by the increasing emergence of private- and state-run organisations like internationally funded non-governmental organisations (NGOs) and clinical trials, which reach across the North-South divide in order to either provide or procure health care. Raghuram goes on to point out that the ‘global stretch’ in care reflects not only its transnational nature but, also how

the forces and processes of globalisation (structural adjustment programmes, opening [developing countries] up to foreign capital and removal of state subsidies) have squeezed the lives of women in the global South, forcing them to pursue alternative survival strategies (2012:138).

The ‘squeeze’ on women’s lives, Raghuram (2012) refers to above, has resulted in what is called a ‘care deficit’ (Isaksen, Devi & Hochschild, 2008). The care deficit is thought to be caused by neoliberal policies that have seen an increase in the number of women moving out of the home and into the workplace (Raghuram, 2012; Tronto, 2013). There at least are two dimensions to the care deficit that are relevant here. Firstly, scholars argue that as an increasing number of women move into the workplace they leave a void of care (Isaksen *et al.*, 2008). Secondly, because women disproportionately bear the burden of care in households and communities, as caring needs rise among those who move into the workplace, other women step in to fill the void. Joan Tronto (2013) has recently argued that as working-, middle- and upper-class families are seen as less and less involved in the ‘dirty’/‘messiness’ of care, they create opportunities for the social and economic inclusion of new classes of people who are disproportionately women, people of colour and/or poor. Thus for some, usually the poor, caring becomes a source of income. For others, usually the well-off, care is outsourced. Tronto concludes that the ideology of personal responsibility in neoliberalism functions in such a way as to maintain “lines that reflect inequality and historic forms of exclusion” (2013:42).

Both dimensions of the care deficit appear in South Africa. Firstly, there has been an increase in the number of women entering into the workplace through public- and private-sector employment (Fakier, 2014). While it is true, however, that overall trends appear to indicate that more women are being ‘pushed into employment’, Daniela Casale and Dorrit Posel (2002) argue that this employment is largely unregulated, informal and/or self-employment. Secondly, there has been a simultaneous

increase in the number of healthcare workers in South Africa (Coovadia *et al.*, 2009; Schneider & Lehmann, 2010; Fakier, 2014). Khayaat Fakier (2014) shows how the simultaneous appearance of these trends is no coincidence, but reveals something about the nature of women's work. Indeed, women are expected to bear the brunt of care responsibilities either through volunteerism or through the public health sector's home- and community-based care work:

the role of the state as the employer of care work has changed as such work is increasingly outsourced to poor private individuals or communities, resulting in suboptimal conditions for carers and care recipients (Fakier, 2014:143).

As I described in the previous chapter, CCWs, in particular, are precariously positioned as volunteer-employees. They are not considered employees of the National Department of Health nor the Department of Social Development, despite the fact that their work is carried out and their stipends are acquired through these government systems. Rather than being cast as a form of employment, however, their care work is seen as a form of personal and community development.

As I have explored, in South Africa, the state's lack of social service provision has resulted in relying upon women, generally unemployed and needy themselves, to extend care to those the state fails to reach. This care work costs these caregivers a great deal. Ilona Sips and colleagues (2014) argue that so long as caregivers

link clients to the formal health system through consumption of their own limited resources, they may endanger themselves, their families and their communities. In so doing they threaten the social capital they are well positioned to build within their communities, and risk entering a downward spiral of poverty and destitution.

With unemployment rates among the highest in the world, and at its highest in 12 years in 2015, many South Africans simply cannot find work (Surender, Noble, Wright & Ntshongwana, 2010; le Cordeur, 2015). Any form of income, even under the guise of 'volunteerism' is better than none at all. Indeed, the need for a form of income is seen as one of the main drivers behind the increase in community care workers (Takasugi & Lee, 2012).

While recently Joan Tronto (2013:21) has described the definition provided by Fisher and Tronto above (1990), as an appropriate starting point for thinking about care, she acknowledges that care "needs to be further specified in particular contexts". Here, I draw on recent work by Reddy, Meyer, Shefer and Meyiwa (2014:2) who argue that:

If we want to understand care, we need to contextualise it in its proper dimensions. [...] A sophisticated understanding of care requires that we connect the universal existential

dimensions of care to the global and the national ones, and that we add to this a fine-grained analysis of particular practices, attitudes and values in diverse settings.

In this chapter, I seek to offer such careful analysis of the particular practices of care necessary to implement the continuum of HIV care in Lwandle.

3.3 Exceptional populations: Intimate technologies, clientship, disclosure and responsabilisation

As the CHiPs and the CCWs extend care to community members living in Lwandle, they deploy various kinds of technologies of governance. These technologies begin by incorporating community members into ‘exceptional populations’, where they are able to monitor their client’s ART adherence. This monitoring includes encouraging clients to initiate ART and to conduct themselves in particular ways, as well as physically counting their client’s pills. Together these technologies impart a ‘governmentality’ that fashions client’s into responsible and ART adherent individuals. “so that [they]‘do as they ought to’ without necessarily being aware of the conditions that influence their compliance” (Colvin, Robins, & Leavens, 2010:1184).

In order for clients to benefit from the PopART trial’s interventions they need to be incorporated into the trial’s exceptional population. There are at least three levels of being included into the CHiPs’ care programme. Firstly, anyone living in the ‘research community’ or cluster is included into the CHiPs catchment area. However, as I discussed in the previous chapter, these boundaries are porous and, living in particular areas in or outside of Lwandle means being excluded from the CHiPs catchment area. Secondly, anyone living in the area and is tested HIV-positive by one of the CHiPs leads to the extension of additional services, including provision of a recommendation letter to begin ART immediately and follow up on ART initiation and adherence. Thirdly, clients who have initiated ART are included into the CCWs adherence support programme. Enrolment into these populations “calls into being, maps and incites a population to participate” in an intervention (Nguyen, 2009:209).

For the CHiPs’ clients, inclusion into the PopART study population occurs at the point of being enumerated. The CHiPs are expected to enumerate every household in Lwandle. Each CHiPs team is allocated to a zone in Lwandle. Once the CHiPs have reached an enumeration level of 95% in their zone, they are assigned to a new zone.

When the CHiPs arrive at a community member’s house, they explain that they are representatives and implementers of the PopART trial. They offer all the people living in the household over the age of 12 voluntary HIV counselling and testing, screen them for sexually transmitted infections and tuberculosis, as well as provide them with information about prevention of mother to child

transmission and medical male circumcision. If the household members agree to be tested, the CHiPs perform pre-test counselling, test the client and, no matter what the result, perform post-test counselling. Because the CHiPs travel in teams of two or more people, after a household member agrees to be tested, one of the CHiPs will perform the pre-counselling service while the other begins the enumeration process.

All the CHiPs activities and their client's details are captured on electronic data capturing devices (EDCs) which send all captured data to a central database accessible to PopART staff. Some of the questions included in the enumeration survey are:

What is your name? How old are you? How many people live in your house with you? How old are they? Which area do you live in? What is your house number? What is your cell phone number? Have you been tested for HIV before? When last were you tested for HIV? Do you have TB? Do you use a condom when you have sex?

The data collected through their electronic data capturing devices is monitored by the trial managers—in great detail as the introduction to this chapter served to illustrate—and serves two purposes. Firstly, the data they collect helps to monitor the success of the trial, and, secondly, the data they collect is used to monitor their care work as they record every visit. Each visitation concludes with the CHiPs either providing the community member with a referral letter to Ikhwezi clinic stating that they are HIV-positive and should initiate ART immediately, or leave, only to return in a year's time to complete the same process. That is, if a community member is HIV-negative, the CHiPs come back once a year over the length of the intervention to check the persons' HIV status. In addition, once a month the CHiPs dedicate time to 'follow ups', where they visit clients who were previously tested HIV-positive to enquire whether or not they have successfully linked to care and been integrated into Ikhwezi clinic's HIV services, including the CCWs ART support programme.

The CCWs visit clients up to three times a week to count their pills to ensure that they are correctly adhering to their treatment regimen. Inclusion into the CCW's population follows a somewhat different route. One of the CCWs I interviewed whom I will call Vuyokazi²¹ an isiXhosa woman in her mid-thirties, explained the process an individual goes through from finding out they are HIV-positive to becoming a client as follows:

If the patient [is still going to] go [for] counselling on ARVs he's not starting ARVs yet. They will wait for that patient [...]. They will give that patient a weekly pill so that he can come

²¹ In order to ensure my participants confidentiality I have given all of them pseudonyms. See Addendum D for a list of participant interviews.

[to] the clinic for his counselling sessions, and then when he finish the counselling sessions, they will give that patient a monthly supply. And us as a CCW, we go visit a patient (CCW1, 2015).

At this point the client is allocated to a CCW by the counsellor with the assistance of the CCW supervisors. This allocation is determined by where the client lives. The CCW working (and usually living in that area) is provided with the client's housing and contact details, in order to visit them. During their first visitation with clients, the CCWs complete an initial assessment form. The questions in the CCWs assessment form are similar to those in the CHiPs enumeration survey. However, some of the questions directly address pill-taking and, health and healthcare seeking behaviours:

How do you remember to take your tablets? Who can support/remind you with/about your treatment? Do you ever go to a traditional healer? Where do you keep your medication? Do you smoke or drink?

Once the CCW has completed this initial assessment form, the CCW submits the form to their supervisor and continues to visit the client until the client is considered 'adherent'. The kinds of questions asked by CCWs and CHiPs are examples, I argue, of 'intimate technologies' (Nguyen, 2009). These 'intimate technologies,' Nguyen argues, drawing on the work of Michel Foucault (1991), aim to change the "way in which we care for our bodies, constitute our families, talk to our lovers, raise our children, as well as our sexuality" (2009:205). The deployment of these technologies, which question the most intimate and secret matters of people's lives, is subsumed under the client's enrolment into the exceptional populations involved in the trial. Clients are expected to provide caregivers with information regarding their public and private lives in exchange for free and, at least theoretically, seamless access to ART.

This 'morality of exchange' creates a long-standing relationship between caregiver and care receiver. Susan Reynolds-Whyte, Lotte Meinert and Jenipher Twebaze (2014) use the term 'clientship' to describe the relationships involved in accessing and dispensing care to clients. Clientship involves a contractual relationship that offers "proper examination, diagnosis, and monitoring over time" (Reynolds-Whyte *et al.*, 2014:57). In exchange for knowledge about themselves, clients are able to access goods and services through the caregivers. In these spaces, Reynolds-Whyte and colleagues (2014:64) explain, "to be a good client and to realise the benefits of clientship one must tell about one's bodily and social situation."

Some of the questions asked by the CCWs directly relate to disclosure, seeking to include the client's family and friends in helping to maintain the client's ART adherence. The issue of disclosure was

regularly brought up by CCWs as they encouraged their clients to talk to family members about their HIV status, or to disclose to at least one person in their household. Disclosure, Nguyen (2009:208) has argued, appears alongside ‘confessional technologies’ which “train ‘Africans’ to ‘come out’, [...] to disclose their status”. In my conversations with CCWs, disclosure was also caught up in religious and cultural discourses that cut across epidemiological reasoning. A CCW once told me that people living with HIV who are unable to accept their status will not get well: ‘they can eat all the pills they want but they will not get better.’ Non-acceptance and non-disclosure worked hand in hand for her. Conversely, disclosure indicated a huge step towards physical and emotional recovery, i.e. ‘living positively’²².

Non-disclosure is not only linked to emotional distress, but to practical difficulties as well. Without disclosing to at least one other person in a household, taking medication consistently could be compromised as it requires secrecy (Bogart, Chetty, Giddy, Sypek, Sticklor, *et al.*, 2013). It also affects the CCW’s capacity to monitor their client’s ART adherence in two ways. Firstly, disclosure ensures that at least one person in the household is able to remind the client to take their medication. Secondly, it eases the caregiver’s access to their client’s pills, in the event that the client is away when they visit. Clients who appropriately adhere to their medication are eventually released from CCW monitoring. In our conversation, Vuyokazi explained the process thus:

V: At the first week, we visit the patient three times a week. Then the second week twice, then the third week once, and once a week till [they have] finished the treatment. [...].

DW: Okay, and then do you see them all the time from that point onwards or do you stop after a time?

V: [...] On the ARV side, we visit that patient for six months also but in that six months if you see that [...] this patient is not compliant you continue. But if you see that the patient is compliant and everything goes well, you just stop, and here at the facility they [take] that patient to a club. To club, yes.

DW: What happens at club?

V: At club, they only come here to collect their medication and go. They only see the sister when they [are] supposed to [give] blood [...]. They are not supposed to come to the clinic every month [...] they are giving [the people living with HIV] a three month’s supply [of ARVs] (CCW1, 2015).

²² See (Opollo & Gray, 2015), (Tsarenko & Polonsky, 2011) and (Deacon, Uys & Mohlahlane, 2009) for more on HIV-positive people ‘living positively’.

What is made clear in this excerpt is that there is an incremental loosening of the reins for clients on ART as they prove that they are ‘compliant’. Those who are deemed compliant (or responsible) are granted more and more freedom as they successfully navigate the bureaucratic maze required to access ARVs; while those deemed non-compliant (or irresponsible), continue to be closely monitored, seemingly indefinitely. In some cases of ‘non-compliance,’ the CCWs have continued to work with the same client for years.

As much as CCWs and CHiPs are in a relationship with their clients then, they are also in a relationship with their respective organisations. Working in their respective organisations involves converting their clients' testing, linkage-to-care and/or adherence forms into statistics and those statistics into stipends, or salaries (Reynolds-Whyte *et al.*, 2014). Much like is done with the CHiPs electronic data capturing devices, at the end of each month, the CCWs hand in their client's adherence forms to their respective supervisors, for monitoring. This process entails copying their months' work onto separate sheets of paper, one for each and every client, recording every visit and how many pills the client had at the time of the visit. As I sat in the corner of the CCW's office watching this spectacle, I was reminded of school children copying down their homework assignments before class. It occurred to me that it is completely possible that the CCWs create fictitious stories of visiting clients, a question Gala True, Leslie Alexander and Kenneth Richman (2011) have also raised about counting and making clients known in global health. Fabricating data is less likely among the CHiPs because their devices are linked to the internet and therefore all data (including their physical location) is immediately captured and sent to the trial's database.

These digital or paper-based trails incorporate people into intervention populations and provide them with what Lindsey Reynolds has called “documentable ‘services’” (2014:126). These services are as much self-serving as they are in service of their clients. On the one hand, they “enable program implementers and policy makers to count ‘successes’ and thus to continue to expand their programs and funding streams” (Reynolds, 2014:126). As I have already suggested, this counting also entails monitoring the caregivers' practices and, as a result, the organisation's success. On the other hand, the act of being enumerated, documented, and monitored provides clients access to resources which would otherwise not be available to them.

Through this careful ‘documentation, quantification, evidence, and accountability’ (Reynolds, 2014:116) the caregivers deploy a form of governmentality which promotes the creation of ‘responsibilised citizens’. Steven Robins (2006:321) describes ‘responsibilised clients’ as those who are able “to demonstrate [...] treatment adherence, disclosing their HIV status, using condoms, abstaining from alcohol abuse and smoking, and having healthy diets and lifestyles”. In Lwandle,

when clients are deemed irresponsible and unable to properly take care of themselves, they are denied freedom from being monitored. In some ways, the ‘responsibilisation’ process is similar to Foucault’s notion of population and social control. João Biehl, Denise Coutinho and Ana Outeiro (2001:93), following Ian Hacking, describe “[t]hese strategies and actions” as a “new and automatic functioning of power [...] inducing a state of conscious and permanent ‘interior’ visibility and bodily control”. It is through these moralising behaviours that their clients become “‘good’ self-reflecting, self-regulating subjects” (Coveney, 1998:462). These behaviours are eventually normalised and internalised, resulting in an alignment between the client and the caregivers’ moral order, in which clients “*actively and productively* seek out the ‘correct’ course of action which will *positively* fulfil their ethical concerns” and their health concerns (*emphasis in original* Coveney, 1998:462)

While providing care and producing evidence in the ways required by their respective organisations the caregivers consistently perform actions which fall outside of their organisations’ standard practises. These different forms of care, which more closely resemble clientship, as described above, appear as necessary to retain their client’s within the continuum of care and adherent to ART. In the following section, I explore some of the ways that these other forms of care appear alongside the formal, biomedical care I have described above. In some cases, these other forms of care are necessary to enable caregivers to include more people into the intervention populations to meet their organisations’ statistical quotas. I describe how the cost of this care not only comes to influence the monitoring of their populations but that it stems from demands from above and below.

3.4 Improvising technologies

Wherever technologies appear, they are transformed by the people they come in contact with (Wynne, 1988; Lock & Nguyen, 2010). As Lock and Nguyen have argued, while biomedicine is commonly administered on the assumption that it is “standardised for universal application,” in fact it “must be individualised for use in actual clinical [and spatial] practice” (Lock & Nguyen, 2010:22). The biotechnologies of HIV testing, linkage to care and, ART adherence deployed by the CHiPs and the CCWs (describe above) are no exception. The caregivers improvise their care practices in order to better meet their client’s needs. In the same way that biomedicine and biotechnologies more generally are adapted and individualised in order to accommodate the settings in which they are being deployed, so too does care need to be context-specific. In the previous chapter I situated the care practices of the CCWs and the CHiPs within the global dimensions of care. In this chapter and the one to follow I provide a more fine-grained analysis of care practices as they appear in the context of the PopART clinical trial in Lwandle. Below I extend this analysis to consider the difficulties encountered by CCWs and CHiPs in their attempts to provide this kind of care in Lwandle.

Initially, I expected the practices of the CHiPs and the CCWs to be identical—that is, I expected each of the CCWs and each of CHiPs' practices to be exactly the same as the next. Instead, over the course of my fieldwork, I came to understand that each of the CCWs and CHiPs adapted their protocols in order to provide their client's with effective care. This was in part informed by the vast differences in their training and experience. While each of the CCWs and CHiPs underwent at least the same minimal level of training, respectively, older and longer serving caregivers had acquired both more training over the years and more experience. In this section, I draw out some of the regular adaptations of care among each group of caregivers in Lwandle. I describe how caregivers must contend with economic, social and structural challenges at the same time as they attempt to meet the evidence production expectations of their respective organisations. Thus, the forms of care provided adapt to and change with the context in order to meet community member's healthcare needs.

For the caregivers; adapting or altering their care practices sometimes comes at great personal financial, physical and emotional cost. Care is cast as a job and a way of being which, although sometimes burdensome, is also an act of dedication. There exists a tension here, between caring out of concern and caring as a necessary condition of employment—both of which are emotionally taxing. Caring, as I describe it, thus blurs the margins between physical and emotional labour: the wilful caring for community members and the necessary deployment of care. One of the CCWs I interviewed who I call Nesiwe, captured this tension, succinctly, saying, “It is difficult but you must, because this is your work” (CCW2, 2015). However, the imperatives of providing care and producing evidence are sometimes irreconcilable.

3.4.1 Migratory patterns and infrastructural challenges

Both internal and cross-border labour migration have long been linked to higher HIV prevalence in South Africa (Sawers & Stillwaggon, 2010; Marais, 2011). While the dynamics of migration have shifted in post-Apartheid South Africa. Many people continue to migrate in search of work and a better lifestyle, sending remittances to family members living 'at home' (Casale & Desmond, 2007). Daniela Casale and Chris Desmond (2007) have argued that the economic and political changes in post-apartheid South Africa have seen female migration increase. Not only have informal settlements 'mushroomed' as a result, but mass unemployment has transformed both support and care-taking relationships (Fakier & Cock, 2009). These changes and patterns affect the ability of CHiPs and CCWs to provide their clients with care, to police their ART adherence and result in exclusion from the exceptional population of the trial.

In the previous chapter, I described Lwandle as a community with a long history of migrant labour which remains an area of ‘profound dislocation’ (Murray & Witz, 2014). As in many places in South Africa, migration between the rural Eastern Cape and areas closer to large cities continues to be a key feature of life for many people living in Lwandle. Some of my interlocutors and interviewees spoke of the Eastern Cape as their ‘real’ homes: a women living with HIV in her mid-thirties whom I call Kuhle, described this feeling thus:

Lwandle is not home, Lwandle is [...] somewhere, where we stay, where we work, we save money and then we go back. Eastern Cape is our home (Community Member1, 2015).

While moving between the Eastern Cape and the Western Cape was regarded as normative, it often came with serious implications for medication adherence. To properly adhere to medication, clients were required to retrieve sufficient medication for long trips (usually up to two months’ supply of medication). Or, in the case of more permanent moves (three or more months), clients required technologies in the form of paperwork to ease their transfer from one healthcare facility to another. However, clients would sometimes leave without letting the caregivers know and would thus forego their medication, or they would fail to properly adhere to their medication while they were away. Describing her experiences with one client, Vuyokazi, explained:

When I came back from holidays, and my patient came back also, when I go see the patient, my patient was bed-ridden. I was very surprised because [when] I left that patient, [he] was very fine. There’s nothing wrong with [him]. When I asked the patient, ‘where’s that lady you were staying with?’ he said, ‘she left me because she, she can’t stay with a person that is sick’ [...]. That patient was staying alone, no one in the house making him breakfast or something to eat, and he was bedridden at that time. When he get up, he just fall down. I came here at the clinic immediately and report that [he was bedridden]. The sister here in the TB room [...] made then the referral form to hospice, and then at hospice they said that the space is full. He must wait [...]. When I go to see that patient the next week, to see how [he is] doing [...] I found that the patient is not there. But I did [take] his brother’s phone number. I contact his brother, ‘where is my patient now?’ He says, ‘we just take him to Eastern Cape because here we saw that this patient can die anytime’. I asked them, ‘did you take a referral form, so that there they can continue with his treatment, not to start?’ He said, ‘No. I was very confused and I was very stressed because those hospice people that you were talking about, they are not coming. So I can’t wait so long. He must go to Eastern Cape so that my mother can take care of him’ (CCW1, 2015).

She described how many clients who go ‘home’ (to the Eastern Cape) for the holidays return having defaulted their HIV/TB medication and become extremely ill. In some cases, because they are thus unable to look after themselves or to work, they are sent back to the Eastern Cape where they are cared for by their parents or grandparents, usually women. While the CCWs can encourage their clients to adhere to their medication and help make provision so that they are able to do so over the holiday period, they cannot force their clients into adherence. Without being under the watchful eye of CCWs, it seems that many clients fail to adhere to their medication.

Another form of migration is that which occurs between houses in Lwandle. These internal migrations make it difficult for CHiPs to find their client’s when performing follow ups. One of the CHiPs supervisors whom I call Cebisa explained that clients often ‘rented’ shacks on someone else’s property, thus tying their household to a stranger, sometimes creating forms of instability and impermanence:

C: A lot of people move from here to there, from here to there...

DW: Why, why does it happen so much?

C: Like I said before, it depends, because of the situations, either them or problems with the owner, or them with the owner, or both. Then they have to move, or they get thrown out (CHiPs1, 2015).

In some cases, problems emerged because the owner or the tenant abused alcohol, the tenant failed to pay or could no longer afford to pay rent and/or sanitation facilities were inadequate. The result was that when caregivers tried to follow up on the client, the client had often relocated. Not only does this affect future follow-ups, but also future and/or prior enumerations, particularly if the client moved to another area in Lwandle that had already been enumerated. Moving around like this also affected the ability of the CCWs to follow up on their clients.

Together, these migratory patterns hindered the caregiver’s ability to follow up on their clients’ ART adherence. Moreover it put their work at risk. As I observed during my time working with them, the CCWs often spent hours of their work day walking from one house to the next looking for clients. These ‘wasted’ hours presented a challenge for them: because the caregivers could not record any client information during this time, their job performance could be questioned.

While following up on clients could pose an immediate concern for many caregivers, in biomedical terms missed diagnostic tests and non-compliance with treatment regimens also raised a concern with biological vulnerability and/or drug resistance. Nguyen has argued that this issue is “certain to spur the development of more sophisticated strategies to track and monitor patients” (2010:180).



Figure 3.1 Two examples of 'backyard dwellings' in Lwandle.

Although not necessarily highly sophisticated, both the CHiPs and CCWs have developed measures to help counteract these issues. To accommodate for the long and variable working hours of many community members, the CHiPs start work at different times of the day during different times of the year. During summer when the sun is up for longer, instead of working from 8am to 5pm, they start working at 10am or 11am and work until 7pm or 8pm respectively. This greatly increases their chances of finding people at home to enumerate, test and link to care. In addition, the CHiPs also sometimes work on Saturdays to reach those people who work late hours on weekdays.

The CCWs were also frustrated by this aspect of their work. Their normal working hours are between 8am and 12:30pm, but they would often see clients after hours in order to accommodate their client's working schedules. However, visiting clients at their homes outside of working hours was seen as a potential safety concern, particularly if the client was male and the caregiver female. As a result the CCWs would sometimes organise to see clients at the clinic, or even invite the clients over to their own houses. This was particularly helpful for clients who felt vulnerable or were afraid of being stigmatised.

These adapted caregiving practices are reactions to the context in which they are being deployed, in order to retain clients in the continuum of HIV care model. The CHiPs brought the difficulties in locating clients during working hours to the attention of the trial management team. Together the CHiPs and the management team came up with a strategy to ensure the CHiPs have a better chance of locating their clients. The CCWs, on the other hand, made these adaptations of their own accord, each CCW choosing a different approach to ensuring higher retention in care rates.

3.4.2 Stigmatisation, confidentiality and trust

Adaptations in healthcare practices were not necessarily labour intensive, as those mentioned above. Sometimes they required the CHiPs and the CCWs to understand community members' emotional and social needs. This awareness often meant building a trusting relationship with the community and their clients. The trial protocol explicitly recognises that since the CHiPs conduct HIV counselling, testing and linkage to care, it is important that clients come to trust them (Hayes & Fidler, 2012).

However, one of the biggest concerns voiced about the CHiPs amongst community members and CCWs I spoke to was the confidentiality surrounding community members' HIV status. CCWs and community members were concerned that since the CHiPs live in Lwandle, they would share knowledge of their client's HIV status with other community members. Similar issues were raised by Reynolds, Cousins, Newell and Imrie (2013:118) in their research on 'dried blood spots' during "an ongoing prospective population-based HIV surveillance programme" in KwaZulu-Natal. They found that a central issue of concern for the HIV-positive research participants involved in the surveillance programme, was the proximity of the community-based researchers to the participants in terms of social ties and locality (Reynolds *et al.*, 2013:123). Their research points to important questions around trust and confidentiality. When I asked a CHiP, whom I call Sandile, about how community members felt about their care work, she admitted that community members continued to fear that the CHiPs would share knowledge of peoples' HIV status:

But we [...] try to explain to them that we [are] not going to talk about them when we come to a house. I am doing two streets in my zone [...]; can you imagine how many people we are dealing with every day? [...] So I can't remember that person [...]. You see so there is no way I can always keep them in my mind (CHiP 2, 2015).

Sandile pointed to the fact that she saw too many people in a day to remember each and every community member's HIV status. However, as suggested by Reynolds *et al.* (2013), because of the CHiPs physical and social proximity to many of their clients, it is possible that they are able to note some people's HIV status.

While it is interesting to note that many people did not want to be tested by the CHiPs, the converse also occurred. This would work both ways then, some clients would prefer to be tested by someone they know, while others would prefer to be tested by someone they do not know. Some CHiPs even tested their own family members. Sandile continued to explain that the deciding factor was whether or not the community member trusted the CHiPs conducting the HIV test:

S: Some of the people want to be tested by me if they know me. So they, they have that trust [...] but some of the people, they say they are not gonna be tested by me because I know them.

DW: Okay, and what do you do if there is someone who wants to be tested but they don't want you to test them?

S: Sometimes if I um, if I have a closer zone and we are working in this same street, so we exchange, I'm taking another CHiP to work there, in that house, then I am going to work in her zone (CHiP 2, 2015).

Although the practice of swapping areas with another CHiP is technically in contradiction of their protocol, it ensures that another community member is extended healthcare. It is also indicative of the trust that CHiPs build with community members.

Building trust between caregivers and community members is also an integral part of 'clientship' and, helps to secure not only buy-in from clients but also the wider community, making the CHiPs follow-up and evidence production work easier. Building trusting relationships with their clients sometimes meant a change in the CHiPs identities in relation to their clients. Recent work by Philister Adhiambo and colleagues (Madiega, Jones, Prince & Geissler, 2013) suggests relationships between healthcare provider and clients that traverse the formal and informal boundary may allow for better evidence production, but also came with personal responsibilities. In some cases like with Sandile, these relationships proved to be beneficial for both her and her client:

The friendship that I have with my clients is making because I can see I am making a difference, because some of the houses you find a person is positive. I mean I tested the person positive [...]. At first they didn't want to take ARVs but when I am going there several times, I am making a difference because now they can go to the clinic, they can be healthier again (CHiP 2, 2015).

In Sandile's case, the informal and trusting relationship she had with her client helped them to seek out healthcare and initiate HIV treatment. In other cases the CHiPs preferred to establish a formal relationship with community members, presenting themselves as researchers and/or DTTC employees. On one such occasion I accompanied the CHiPs into the field we stopped outside of a house. Just a few moments before we arrived we heard people chatting away happily inside. The CHiPs told me that sometimes people will completely ignore them and pretend not to be home—a common occurrence amongst CCWs as well. After standing outside for a few minutes, a gentleman emerged from inside the house and let us in. After leaving (having completed three HIV-tests and enumerations with members of the household) the CHiPs thanked me, saying that they had visited this family a few times before but every time they had refused to be tested. The CHiPs said that the

household members changed their minds because I was with them. My presence seemed to imbue their work a sense of authority or formality. Although in this case my presence seemingly had a positive outcome, I often considered my presence, as a white male (the only white male I saw in Lwandle besides policemen) carrying a small backpack accompanying two, sometimes three black women (known by some to be CCWs), to be a dead giveaway that the person we were visiting was ill.

One day while walking with the CCWs we stopped mid step and turned around. One of the CCWs told me that they would have to return the following day to see the client we were on our way to, when I was not with them. She went on to say that the client had not yet disclosed her HIV status to either her friends or her family. In order to follow up on the client, the CCW would visit the client under the guise of being a friend. Madiega, Jones, Prince and Geissler's (2013) insights are helpful to understand what this change in identity, from a CCW to a friend entails:

introducing oneself as close relative or sister was not merely about hiding institutional affiliations and maintaining HIV confidentiality. It also pointed to an important dimension of follow-up work: the forging of close personal relationships during many encounters, often in the privacy of the home, over several years (Madiega et al., 2013:26).

The practical implications of donning the façade of 'friendship' entailed finding out when the client would be alone at home. Only then was the CCW able to count the client's pills and check her adherence forms. In the event that any one of the client's family members' is home the caregiver would sit down with the family and visit her as if she were the client's friend. If I had accompanied the CCW to the client's house, it is likely that my presence would have raised too much suspicion to explain away. The CCW's sensitivity to her client's non-disclosure serves as yet another example of the ways in which CCWs had to care about their clients and not just provide care.

3.4.3 Emotional, financial and, physical costs of care

As I have already illustrated, clients often make other kinds of claims on caregivers, sometimes using their illness/es to make appeals to the caregivers' emotions. Claims are made for emotional, financial or biomedical support, calling caregivers to go beyond their protocols. In much the same way that the manager called the CHiPs to know their clients, clients appeal to their relationships with caregivers to provide them with forms of care. The distinction between 'caring for' and 'caring about' collapsed in cases like this, which required both physical and emotional labour.

Emotional labour, Arlie Hochschild (2012:7) says, "requires one to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others [...] the

sense of being cared for in a convivial and safe place”. Emotional labour has three general characteristics, it must involve personal contact with the public; it asks of the worker to produce a particular emotional state in another person and, it “allows the employer, through training and supervision, to exercise a degree of control over the emotional activities of employees” (Hochschild, 2012:147).

The care work of the CCWs and the CHiPs fulfil all three of these characteristics. They engage with the public during their everyday work. CHiPs, in particular, must be proficient at producing a feeling of ‘being care for’ in community members if they are to be successful in helping people link up to ART. Finally, both caregivers are monitored to ensure that they are involved in an appropriate level of emotional activities. Unfortunately the only way that these activities can be monitored is through the digital/paper trails of the CHiPs electronic data capturing devices and the CCWs’ adherence forms. In order to provide these ‘activities’, care sometimes appears in twisted forms as CHiPs and CCWs react to the needs of their clients.

Both sets of caregivers often felt that they were, at times, emotionally compromised when confronted by level of impoverishment among their clients. Cebisa described these circumstances as ‘disturbing’—she said, ‘maybe you can see the child is crying, not for the sake of crying, but because he might be hungry’. As a result of these circumstance, providing care sometimes literally meant giving money to clients, something which caregivers were well aware would be frowned upon by supervisors and trial staff.

More generally, care provision often entailed far more than what was understood as being within their protocols. Sandile recounted,

when you go into a household and you see that a child is hungry, you end up giving them your last money so that they can buy something to eat because you see that, here, it’s not good. And also sometimes you see that the mother is being abused by the father, you try and help them out, even in your spare time on a Sunday; I go to that person and tell that person about social workers and all that (CHiPs 2, 2015).

In this excerpt, the cost of Sandile’s care was dispersed across an emotional reaction to the abject poverty in the household where a child is hungry. She also noticed social issues within the household and attempted to address these issues through both the technical side of her care work, by providing the client with information on social workers, and the emotional side, by counselling and going out of her way to see this client. Significantly, this care was extended in her own time.

Although expressing sympathy for their clients' situation and a desire to help, CCWs also complained about being exposed to TB, largely because they visited people known to be infected with TB. One CCW explained:

Because sometimes I go to the house, and see a patient to visit [...] and this patient is very sick; he cannot walk, he cannot do anything so I am supposed to go. If he is lying on the bed, I am supposed to go there inside. And uh, sometimes I cannot use mask, this person is coughing, you can hear from when you enter the door, he or she is coughing too much (CHiPs2, 2015).

Setting aside concerns around appropriate healthcare practices for the moment²³; when I asked the CCWs why they cannot use their masks, they often said that family members complained that they were discriminating against the ill. The desire for CCWs to acknowledge their family members' healthcare needs, which may be social and emotional rather than physical, correlates with research conducted by Homan and colleagues (2005), who found that emotional and spiritual support figures first among HIV-infected people, followed shortly thereafter by their physical needs. Often this form of care—this social, emotional and physical recognition of a living person—was expected to extend to people other than the CCWs clients. Community members would rally around the caregivers and ask them to visit their bed-ridden relatives or neighbours and provide them with care. While the CCWs would usually oblige, they were rarely able to materially assist those too sick to help themselves. Instead, they would leave the premises, promising to mention the sick person to the social worker responsible for that area. This prevented them from taking on too many responsibilities, as well as formed a defence mechanism against emotionally burdening themselves.

On more than one occasion I accompanied the CCWs into the houses of these desperately ill people who were too sick to get out of bed. The healthier ones would emerge from a dark corner of the house somewhere, thin as stick figures and weak as reeds, clinging on to their family members helping them to cross the room to where the CCW would be sitting. They reminded me of the figures in *Vita*, which Joao Biehl (2005:2) speaks of as the “end-station on the road of poverty”. Yet, they were not abandoned, disowned, or forgotten. They continued to be cared for, loved even. Patricia Henderson has written about how family member's ‘touching the bones’ of the emaciated does not ignore their physical appearance, but rather serves to uphold their “humanity and the valued threads of interconnection between” them (Henderson, 2011:18-19). Here the physical act of caring, of

²³ This issue has been raised in research conducted by Olagoke Akintola and Lydia Hangulu (2014:391), who found that overcrowding and poor living conditions, combined with improper use of “protective devices such as masks and gloves” leads to greater risk of infection for community members.

acknowledging the person, provided clients and their family member's with social, physical and emotional care. But the provision of this care also requires caregivers to be physically and emotionally exposed to disease and potentially death.

Although many of the CCWs and CHiPs expressed a desire to help people in the community, they sometimes felt unprepared to deal with the situations they experienced in the 'field'. Cebisa captures this problematic when she talks about some of the difficulties surrounding linking clients to the clinic:

If they say they don't want to go to the clinic, just let them be and give them space, because I believe that it's not because they don't want to, I think it's just the way they are trying to deal with their inner feelings of shock and you know, stress and everything. And then at the same time it's worrying and stressing [...]. And also the fact that there are reasons; cause we only see the surface part but, sometimes the reasons for them to refuse have all the underlying, you know. [...] Because there's lots of things that's happening, it could be anything, I don't know. [...] And so we must always not only look at the surface [...] and think about the underlying reasons that we don't know of. And we are not trained to get to that stage or and get enough information about those things, we are only trained to do what we are doing (CHiPs1, 2015).

This way of understanding her clients is diametrically opposed to the views expressed by the trial manager in the introduction to this chapter. Cebisa scarcely feels that CHiPs are well enough trained to deal with the everyday situations they encounter in the field, let alone continue to carry out the care practices that they are 'trained to do'. Yet the trial manager expects the CHiPs to go beyond this framework, to create a relationship with their clients and to use that relationship to ensure high linkage-to-care rates—in effect, to produce good evidence. The difficulty in both providing care and producing evidence is that they often require opposing actions by the CHiPs. Providing their clients the best care may entail leaving 'their clients be' rather than continually following-up on them and encouraging them to link to care sooner than they are ready—foregoing good evidence production. The limits of both their professional expectations and their training resulted in the caregivers 'making do'.

3.5 Making-do, tinkering and ad-libbing care

In this chapter I have illustrated how care takes place in a distributed form in Lwandle. Care provision has emerged out of complex layers of interactions between the global and the local, the public and the private and, the paid and the unpaid sectors. In Lwandle, some forms of care are provided in and through the PopART trial and, while the trial's protocol is quite strict, caregivers show a remarkable

ability to work at the fringes of the protocol to retain clients within the continuum of HIV care. Through the CCW and CHiPs' policing, a particular kind of governmentality is deployed which engages with both its employees and their clients. In both policing and being policed, the CCWs and CHiPs help convert their clients into 'responsibilised citizens' through intimate-technologies and consistent monitoring (Nguyen, 2009; Reynolds-Whyte, 2014a).

At the same time as providing this form of care, the caregivers are expected to build and extend relationships with their clients that are in fact necessary for their provision of care and the production of evidence required by their jobs. Standing outside of the formal protocols, these relationships and practices often incur financial, physical and emotional costs. Similarly, the deployment of these diffuse forms of care within the parameters of their protocol is made profoundly complex by both their own and their clients' environmental, financial, and social circumstances. By acknowledging the emotional, physical and financial cost of care I have highlighted the complex and various forms that care takes in places where global health technologies like clinical trials meet the context-specific healthcare practices of research-caregivers. I have focussed on the adaptations and alterations the CCWs and CHiPs make to their protocols when extending care to clients in Lwandle. In doing so I take after Julie Livingston (2012:21) who encourages us to examine the "processes of making do, tinkering, and ad-libbing [...] to better understand the nature of biomedicine in Africa and the work of African healthcare workers, for whom improvisation is inevitably the *modus operandi*".

Providing their clients with effective care requires the caregivers to individualise their protocols. Brian Wynne has argued that rather than rules determining the use of technologies, practices determine the rules. Indeed, he argues that "a formal public image of technology as mechanical, rule-following behaviour belies a less clearly rule-bound and determined world of real technological practices" (Wynne, 1988:148). Taking after Wynne I argue, the adaptations and individualisations made by the caregivers are necessary in order to meet their client's needs—be they emotional, physical, financial and/or social.

By referring to 'emotional labour' I suggest that there lies a large disparity between what the protocol imagines caregivers' practices to be and, how their practices actually play out in reality. It is in this gap, between the "the 'what' and the 'how' [of providing care] lies the line between technical and emotional labour" (Hochschild, 2012:148). The cost of this form of care 'transcends the boundaries of the market,' as caregivers' emotional work is subsumed under their protocol without taking full consideration of the cost of this care (Folbre, 2008:376). Here, too, the traditional public/private divide between the state/organisation and the family, associated with care is broken down, as I described earlier in the chapter.

In this chapter, I have linked this breakdown to the demands made on caregivers to provide care and produce evidence. The caregivers were asked to provide care that is far more than merely ‘technical labour’, but to establish relationships with their clients, to create an emotional attachment—to care about care. The physical, emotional and financial costs of this care reach across the formal and the public into the informal and private lives of care workers and often creates informal, friendly, even loving relationships with their clients. Nancy Folbre (2008:376) has, I believe, rightly described care workers as ‘prisoners of love’.

Chapter 4 Knowledge in translation

4.1 Knowledges and practices of care

In conversations with Kuhle, a mother of four living with HIV who I met while working with the CCWs, she often stated that it was her belief in God that had helped her return to good health. She had been ill for some time, she explained, when the pastors from a local church visited her and prayed for her health. She had, at that point, just left her husband and was living by herself with her daughter. Through the support and prayers she received from the pastors and the antiretroviral treatment she received from Ikhwezi clinic, she told me, she regained her health and became more positive about her life. Since then she has remarried and had triplets, aged 2 and a half at the time I met them. God had blessed her with the triplets, Kuhle explained, so that she would know love again and so she would be able show her love. As we spoke, the children climbed over the furniture, asked to sit on Kuhle's lap and tried to play with my recording device. When I asked Kuhle if her faith would or ever had led her to discontinue taking HIV medication, she was shocked and said:

I never default my pills, I use my pills every day, each and every day. [...] No I didn't believe I must [leave] the pills and then pray, ahah [no]. I know the doctors and all [those] people that are here for me, they are sent by God. So together with me, we can work together and find myself, it's not up to one person [no] togetherness is important. To listen and do whatever the people said, [then] you are gonna be healthy, you must do it (Community Member1, 2015).

While Kuhle was receptive to the CCWs and open to speak with me about her beliefs, while walking around with the community HIV-care providers (CHiPs) of the PopART trial, I occasionally encountered individuals who were unwilling to speak with the CHiPs and CCWs about HIV. In one encounter, for instance, we approached a woman while she was hanging up her washing. As soon as she saw us, she immediately started shouting at the CHiPs in isiXhosa. Then, seeing me with the CHiPs, she suddenly started speaking English, "you must not feel bad for me; I know what I am doing. I have my reasons. I cannot tell you about them. My God will protect me." As we walked away, the CHiPs told me that this is the third time they have approached the woman. The first time they approached her, she had apparently tried to attack them. On the second visit, she completely ignored them. Despite her strongly negative response, they said they would continue to visit her with the hope that she will succumb to their continued efforts—"because maybe she knows her status and doesn't want to do anything about it," one of the CHiPs said. In addition to their concern for community members' well-being, it is important to point out that even though CHiPs struggle with dealing with resistance and may even be sympathetic of the beliefs of community members, they are

also confronted with the need to fulfil quotas in order to complete their work, as described in detail in chapter 3.

In this chapter, I explore how caregivers mediate between the demands of their job, focused on testing people for HIV and helping them initiate treatment, and the divergent responses they confront in the community. As I will show, multiple forms of healthcare exist in Lwandle. In this context, caregivers play an important role in helping community members navigate and negotiate between these entangled forms of healthcare. In doing so the caregivers become purveyors of more than merely biomedical care.

In the previous chapter, I describe how caregivers are tasked with providing a biomedicalised form of care that aims to create responsibilised citizens who adhere to their HIV medication. This description of the caregivers as purveyors of biomedicine is similar to how Steven Robins (2009) has referred to HIV activists as ‘foot soldiers of global health’. They carry with them potentially new forms of citizenship and agency, which do not necessarily reflect the hegemonic discourse of ‘biomedicine’. As I demonstrated, providing care in this form entails practices that sometimes contradict and sometimes adapt protocol, almost always at the personal cost of the caregiver/s. I demonstrated how the extension of these forms of care required deviation from protocols and upended the scientific knowledge production model. That is, I suggest, in these spaces, practice comes to shape protocol rather than the other way around. Richard Rottenburg argues that large-scale experiments like clinical trials are in fact a form of social experiment, requiring what he calls ‘translation’ in order to accommodate the context in which they are run:

Because one single process, contextual normalisation, is at once the presupposition for the working of a technology and a potential cause of accidents, the solution cannot simply be stricter adherence to the inscribed rules. One would rather have to live with experimental contextual normalisation or *translation* as I would call it (emphasis in original 2009:425).

It is precisely this ‘experimental contextual normalisation,’ or rather, the *translation* of biomedical modes of understanding health and care into the local context of healthcare practice in Lwandle, that I engage with in this chapter. Oliver Human (2012) has argued that without first contextualising protocols and practices in the particular context in which they are being used, their blind implementation could result in unintended consequences for their recipients. Human writes that people “will always have more complexity than can be modelled” in controlled settings, and that the use of what he refers to as ‘excess’ or ‘qualitative’ knowledge is necessary in order for appropriate care to be extended in the contingency of everyday practice (2012:29). In this chapter, I focus on how community HIV-care providers (CHiPs) of the PopART trial and community care workers (CCWs)

of the public health sector engage with community members' understandings of healthcare practices in Lwandle.

At times, as I draw out below, community members mis/use, mis- or re-interpret and/or explicitly resist biomedical forms of healthcare. Here, biomedicalised forms of care appear as only one alternative among many and, indeed are sometimes deployed alongside other forms of healthcare. The diffuseness and “translatability” of biomedicine has led Kaja Finkler to argue that biomedicine changes shape and form as it moves from one venue to another (2004:2037). Through the practices and procurement of healthcare in Lwandle, biomedicine itself becomes the target of entangled forms of care and knowledge. I consider how the caregivers' acts of translation allow them to span the gap between biomedical and local understandings of healthcare and healing—to extend forms of care that meet both the local expectations of healing and result in appropriate ART adherence. Here the caregivers can be viewed as ‘culture brokers’ (Digby & Sweet, 2002), representing at one and the same time the local and the global, the biomedical modes and alternative forms of care. Their role as culture brokers is essential in “helping the patient understand, gain access to, and negotiate different healthcare options” (Digby & Sweet, 2002:113).

However, as I have already begun to argue, biomedical and other forms of healing and care do not always appear neatly alongside one another. Instead the caregivers are often involved in navigating an eclectic and interwoven mix of different forms of healthcare and broader healing practices, as suggested in the opening anecdote to this chapter. They are thus often caught betwixt and between these various forms of healthcare, healing and knowledge systems, requiring them to function as mediators or ‘middle-figures’—to help their clients “negotiate a mixed social reality of coercive and alluring messages” (Hunt, 1999:21). I consider how their biomedical practices and adaptations/translations are informed by a sensitivity to what Hunt refers to as the ‘entangled objects of their work’. That is, their ‘excess’ knowledge of the local context in which they provide care, gives them insight to their client's social, emotional and physical needs. Lastly, I consider how the caregivers' practices sometimes include the extension of healthcare practices other than biomedical modes of care. While caregivers are expected to translate complex biomedical modes of healthcare into local understandings, and vice versa, they also live as part of the community and bring their own understandings of healthcare and healing into their practices. That is, rather than seeing caregivers simply as ‘foot soldiers’ (Robins, 2009) of exclusively biomedicalised forms of care, I argue that caregivers carry with them their own understandings of health and care which may influence how their practices are mis- or re-interpreted by community members.

In this chapter then, I extend the discussion on the different forms of healthcare that appear in Lwandle to discuss how caregivers are involved in empowering and negotiating with their clients to make the best healthcare decisions in their deployment of, particularly, HIV care. HIV care and treatment in Lwandle, I argue, can be seen as distributed, diffuse and multifarious in form and structure. I begin the chapter by considering the complex layers of medical, traditional and religious knowledges and understandings of health and care alluded to by the vignettes above.

4.2 Knowledge and healthcare in South Africa

South Africa's healthcare and healing context is often regarded as one of medical, cultural and religious pluralism (Feierman, 1985; Flint, 2008; Niehaus, 2014). Divergent imaginaries of healthcare often appear alongside or opposite to one another, and can coalesce and resist one another in unpredictable ways, making it difficult to draw clear boundaries between different knowledge systems and healing traditions. Similarly, the implementation of any one form of healthcare often remains ambiguous in practice and form, appropriating and adapting to particular contexts and circumstances of both the broader political economic setting, as well as the local situatedness of clients. This is particularly relevant in a country that has undergone massive political, economic and social change in the past two decades. In *The Social Basis of Health and Healing in Africa*, Steven Feierman and John Janzen (1992:5) argue that,

Healing is rooted in society; as society changes, healing changes with it. Health and disease are rooted in society; as society changes, these also change. Yet changes in healing must respond to changes in health. Neither of the loops can be understood in isolation.

Understandings and responses to the HIV epidemic have been similarly diverse, and have also been shaped by social, political and economic factors. In response to the epidemic, over the past decade, South Africa has undergone a major shift in healthcare practices. The initial response to the HIV/AIDS epidemic in South Africa was fragmented and confusing and contributed to mass scepticism and slow uptake of ART among HIV-infected individuals. Ebenezer Obadare and Iruka Okeke have described the politics of HIV in Africa as surrounded by “a deep suspicion of all things Western”—a suspicion which has become “a fundamental and recurrent component of the everyday imaginary” (2011:192). They provide three reasons for this. Firstly, the complex aetiology and ‘intractability’ of HIV/AIDS has made it difficult to treat biomedically, and ART has only in the past decade begun to be efficacious in fully treating the disease. In the South African context, it is also important to point out that a series of ‘alternative’ treatments and alleged ‘cures’ have been promoted through commercial channels, and have led to prominent public debates about effective treatments

and the regulation of medicines. For example, in her research on healthcare provision in Worcester, Susan Levine (2012) explores how sangoma's in the area, despite having received training on HIV care, continue to prescribe traditional/alternative medicines to their clients. They do not deny the efficacy of ART, but said that in order to take ART people need to eat and, many people in the community simply cannot afford food. Thus the sangomas, argued that "local herbal medicines are better for people living with compromised immune systems" (2012b:66). Levine goes on to make the argument that these forms of healthcare provision should be understood "within a context where the majority of South Africans do not have access to adequate healthcare services, and where HIV and AIDS is placing additional pressure on an already strained public health sector" (2012b:66).

Secondly, confusing and, indeed, inconsistent information provided on the HIV virus by various actors in the healthcare sector has resulted in a "garbled" understanding of the disease (Obadare & Okeke, 2011:198). Thirdly, the moral environment, particularly in South Africa, where AIDS denialism permeated political and healthcare agendas contributed to increased scientific scepticism and uncertainty (Obadare & Okeke, 2011).

Rather than necessarily addressing these concerns, Adam Ashforth has suggested that the presence of what is perceived to be 'Western science' in poor communities in South Africa can serve to highlight existing structural inequalities and thereby exacerbate the uncertainties and scepticisms surrounding AIDS (2005). Ashforth describes postcolonial South African townships, in particular, as places of profound "spiritual insecurity" (2005). These insecurities manifest in various ways—as accusations, as rumours, as spiritual doubt and as scientific scepticism. In this context, it becomes difficult for one model of healthcare to be trusted entirely.

When individuals align themselves with different modalities of healthcare and healing, they neither deny nor reject the efficacy of others. Rather divergent understandings and practices of care are held together—suspended alongside one another, even if they sometimes seem contradictory. As Christopher Colvin argues "[s]uch a description of medical pluralism sometimes reads like a 'supermarket' approach to treatment, where customers pick and choose between discrete and competing possible approaches and see what happens to work at any given time" (2012:40). Rather, Colvin insists, the approach people have towards healthcare practices is often far "more fluid, contingent, sceptical, sometimes even baffling" (2012:41) than such a consumerist, rationalized description would suggest.

During my visitations with the CCWs in Lwandle, I often noticed posters and pamphlets advertising the services of different healers and care providers. In many of these, including the two pictured below, a seemingly incoherent mix of knowledge forms plays out. However, these ads also often draw

on ubiquitous symbols of legitimacy and authority, as in ‘Dr’ and ‘the Professor’ in the two examples below²⁴. In some ads, the claim appears to be quite clinical, for example ‘safe abortion’ in the second image below. However, the promises made—‘same day, pain free,’ sometimes seem far-fetched or unclear. In many advertisements, claims are made to cure a whole host of afflictions from penis size to marital problems to many forms of disease. While references to HIV/AIDS are generally avoided (due to legal regulation), materials often reference immune system strengthening or make general claims to cure all ailments, as in the first image below, which claims “No Problem is Too Big or Too Small.”



Figure 4.1 Posters of 'The Professor' and a Dr: 'Seeing is Believing', '100% Guaranteed'

In contemporary South Africa, a complicated space exists in which ‘traditional’ and ‘modern’ healing practices intersect and are mediated by capitalist markets. John and Jean Comaroff argue that at the turn of the century, ‘millennial capitalism’ and mass unemployment have given birth to new forms of income in South Africa:

the two sides of millennial capitalism, postapartheid style, come together [where] on one [side] is the ever-more-distressing awareness of the absence of work [...]; on the other is the constantly reiterated suspicion [...] that it is only by magical means, by consuming others, that people may enrich themselves (2002:792).

In this context, the traditional healer is held as the ‘apotheoses’ or culmination of these circumstances, promising clients a better future, for cash, and doing so through claims of efficacy and legitimacy, and the ability to heal any disease, or malady²⁵.

More recently, Diana Gibson and Estelle Oosthuysen have proposed that “[a]s people seek wellness and healing, they engage, sometimes in messy and contingent ways, with different ways of knowing”

²⁴ Jo Wreford (2009:10) has quoted one of her traditional healer-interlocutors comparing her professional standing as ‘almost on the same level as a medical doctor’.

²⁵ See also Levine’s (2012) discussion on packaging and marketing of traditional medicine.

(2012:93). Their argument leads them to conclude that as people seek out diagnosis and treatment of healthcare, they embody and enact heterogeneous realities that correspond to the different knowledges being activated at different stages of the disease lifecycle.

4.2.1 Culture brokers: Empowering and connecting

The caregivers with whom I worked were often asked to help their clients navigate these nebulous spaces, where the limits of biomedicine meet an eclectic mix of options for healing. Thus, in some sense, CCWs and CHiPs act as a bridge between divergent systems of healthcare, between “traditional African and biomedical practitioners [who] operate in parallel, but largely separate, arenas, in which collaboration is largely absent” (Wreford, 2005:1). This work of bridging is important because, as Maheshvari Naidu and Gabriel Darong (2015) have argued, biomedicine has often overlooked the impact of “cultural” beliefs on both patients’ and local healthcare practitioners’ health practices and beliefs. In addition to a concern with patient perceptions, Naidu and Darong point out, it is also important that “due consideration [...] be taken of how nurses’ explanation of aetiology and patients care is being influenced and affected by their cultural constructions of health and illness” (2015:104).

In Anne Digby and Helen Sweet’s work on black community nurses working in 20th Century South Africa, they describe how community nurses often acted as “culture brokers.” Operating as they did “within a cultural context where the claims of Western medicine [confront] entrenched traditional values, customs and practices” (2002:123;126), nurses were expected not only to translate linguistic differences, but also to identify with ‘cultural divisions’. By using the term ‘culture brokers,’ they imply that these healthcare providers effectively move between two distinct cultures.

Digby and Sweet (2002:122) go on to depict ‘culture brokers’ as able to navigate South Africa’s complex medical pluralist healing terrain and provide “transcultural” care, bridging “two [or more] cultures in order to empower the ‘lay’ recipient of that care”. For Digby and Sweet, the idea of ‘empowering’ recipients of care remains a central concern for ‘culture brokers’. Doing so requires providing clients with the knowledge and the freedom to make informed healthcare decisions, rather than enforcing biomedical models of healthcare with “its associated, culturally limited explanations for the aetiology of disease” (2002:123).

While the concept does capture some of the challenging roles that care workers take on, viewing the work of the caregivers as mediating between two distinct cultures (one of ‘entrenched traditional values’ and the other of Western medicine’) also reifies essentialised views of culture. As illustrated above, ‘traditional values, customs and practices’ are anything but entrenched. Rather, much like biotechnologies and biomedicine, they are shaped by broader political-economic changes as much as

they are shaped the context in which they are practiced, and intersect with ‘biomedical’ systems in complex ways.

Drawing on the likes of Eric Wolf and Clifford Geertz (Jezewski, 1990), Mary Ann Jezewski’s describes culture brokering as “the act of bridging, linking, or mediating between groups or persons of differing cultural systems for the purpose of reducing conflict or producing change” (1995:20). In particular, she describes it in relation to healthcare as “brokering between patients and representatives of the orthodox health care system” (Jezewski, 1990:497). Two key factors underpin Jezewski’s construction of culture brokering. Firstly, that caregivers share an intimate knowledge of their client’s cultural background and, second, that this cultural sensitivity nurtures a mutual connection between the client and the caregiver. Jezewski emphasises that the connectedness between culture brokers and their clients is what allows the caregivers to link clients to healthcare in ways that secures the best health outcomes. Thus the relationship that ‘culture brokers’ establish with their clients, empower their clients to maintain their medicinal adherence and ensures that their clients are able to access other forms of healthcare where necessary.

Early in December 2014, while walking around Lwandle with the only male CCW (apart from a supervisor), he confided in me that he was concerned that one of his newest clients, Ndileka, was on the brink of becoming disillusioned with ART (and biomedical care more generally). The CCW and I had visited Ndileka just two weeks before then. At the time the CCW told me that she was his best client and that she perfectly adhered to her HIV-medication. Today, however, he informed me that Ndileka was continuing to experience liver and kidney problems despite having visited a private doctor twice in the past two months. Having recently attended a training seminar about adverse-effects associated with different types of ART, the CCW suggested that Ndileka’s problems might be related to the ART she had been receiving, for the past two months. He intended to give the information sheet from the training to Ndileka, he told me, with the hope that it might answer some of the questions she had about her health, and reaffirm her trust in biomedicine.

The timing of his training session seemed providential, as I had organised to interview Ndileka that morning. During the interview Ndileka briefly told me about her life. The first time we visited Ndileka, I noticed a large poster on the fence running round the outside of the house. The poster was a sketch of a traditional healer. The poster boasted the ability to fix any problem, similar to the posters in the previous section. As we entered the house, I was greeted by a woman dressed in the attire of a traditional healer, who I later found out was Ndileka’s aunt. When I met her at the house, the aunt was brewing traditional beer—another reliable source of income in the community (DTTC, 2013). Upon our arrival, she immediately retreated into the house. A few minutes later, Ndileka emerged

from the house carrying a small yellow material cooler-box inside of which she kept her ARVs and other medication. She handed cooler-box to the CCW who took it and counted her ARVs to ensure that she was properly adhering to her regimen.

On a subsequent visit, Ndileka described the tensions she experienced in engaging in both biomedical and traditional healing medical systems,

My Auntie is a traditional healer, yes. People [are] coming here, insulting her and all that stuff when [other] people are entering to come and get some help [...]. The reason I get sick most of the time; some of them say they know why, and we don't know why. And then, since I firstly got the bladder infection and I went to the doctor and they say 'it's a bladder infection' and [I] got some pills. And after I got that [...] then I go to the doctor again but the doctor could not find anything, and then one of my family members told me that I have eaten a poison. Which is, I don't know about that (Community Member2, 2014).

For Ndileka, the tensions around health were particularly significant because of her Aunt's vested interest in both Ndileka's healthcare and her vocation as a healer. For Ndileka, the prospect that the root or cause of her illness remaining unknown at best and, poison at worst appeared to introduce doubt about the efficacy and appropriateness of the biomedical care she received from the doctor for at least two reasons. Firstly, the doctor was unable to identify the cause of her ailments and, secondly, these HIV-related symptoms share many similarities with "the malicious assaults of witches," and were linked to poison by family and community members (Ashforth & Natrass, 2005:289). Thus when Ndileka remarks how she is unsure about being poisoned, it could be that she is measuring the doctor's ability to heal her by the same yardstick as community members would of her aunt's practice. As Levine writes "[t]he measure of [a sangomas'] success rests [sic] on the client's satisfaction with the treatment outcome" (2012b:67). Since Ndileka was unsatisfied with the treatment outcome arrived at through the initial medication given to her by the doctor, I wondered whether or not she considered switching to her aunt's traditional healing practices:

DW: I find that quite interesting; that your aunt is a traditional healer but you still go and get other medication?

N: Uh since the doctors [told me to] firstly go to the clinic, [...] they told my aunt not to treat me with the medicines that she is using. I must firstly be treated with the medicines that they give me at the clinic.

DW: Okay. And was your aunt okay with that?

N: Yes, she was, but since she heard one of my community members telling me about the poison she was not happy at all.

DW: Oh Okay. So she wants to help you now?

Yes she does but I don't want to be helped by her. I just want to finish the medicine firstly and see where it puts me (Community Member2, 2014).

Here, Ndileka is not denying the possibility of poison nor is she writing off the medication that she got from the doctor. Instead she is testing the efficacy of the doctor's treatment using her own body. The CCW hoped that by bringing the sheet of paper explaining the possible adverse-effects of ART to Ndileka, she would be encouraged to continue taking her treatment and not interpret these symptoms as a sign of the medicine's failure.

Ndileka's response is similar to what Christopher Colvin witnessed in his work with people living with HIV/AIDS in similar communities, many of whom chose to use alternative medicines in the form of nutrients instead of ART. Colvin notes how HIV-infected people's approach to treatment had "a kind of narrow, embodied experimentalism in which people use their own bodies to test and understand the efficacy of various treatments but are reluctant to extend these experiences and knowledge claims to the bodies of others" (2012:40). Steven Feierman (1985:73) made a similar point almost 30 years earlier, when he said "multiple authorities co-exist [in Africa], and therefore no one healer decides the cause or cure of illness in a way which others accept as beyond challenge".

In Ndileka's case, she chose not take the doctor's medication unquestioningly. Further, her family has played a central role in deciding what healthcare procedures she should follow. When Ndileka expresses doubt about the possibility of being poisoned and the desire to wait and see where the doctor's medicine 'puts me', it appears as if she is attempting to consolidate these medical systems. However, I argue that she is not discounting the physical possibility of being poisoned, but is rather asking an epistemic question—"why should anyone want to poison me?"—concluding, "I don't know about that". Allowing time for the doctor's medicine to work will effectively nullify claims of poison and bring about physical and potentially social and emotional healing as well. Yet the vagueness of the doctor's diagnosis and her continued illness introduced an air of doubt and, the possibility of poison, particularly because community members professed to know the cause/s of her illness. Ndileka's refusal to allow her aunt to treat her, however, barred her from accessing other knowledge systems which may have provided her with answers to her existential questions, at the least, if not satisfied her treatment outcome desires.

Adam Ashforth's (2005) insights into the 'power of secret knowledge' and poison-as-witchcraft are pertinent here. The uncertainty with which the doctor was able to diagnose and treat her symptoms, combined with community members' supposed knowledge that she had been poisoned, introduces the suspicion of being poisoned. Fears surrounding the motives behind *muthi*, or whispers of secret knowledge, engenders what Ashforth has called "epistemic anxiety, a sense of unease arising from the condition of knowing that invisible forces are acting upon one's life but not knowing what they are or how to relate to them" (Ashforth, 2005:127). The CCW's role in his relationship with Ndileka was one of assisting her to navigate these tensions. By providing Ndileka with the list of possible adverse-effects of ART, the CCW hoped to alleviate her anxiety and, to encourage her to continue to take her medication. However, he failed to address the questions underlying the claims of poison and secret knowledge.

Following Robins (2009:102), I view the tensions Ndileka expresses between biomedicine and traditional medicine as being contingent on "observable evidence of their efficacy," rather than on passively accepting biomedicine. In Ndileka's case the CCW became a figure of biological and social security—presenting her with a reasonable explanation for her illness/es as well as potentially appeasing nagging questions about 'secret knowledge'. He, in effect, introduced biomedical knowledge into existing knowledge systems at precisely the right time in order to provide security and prevent disillusionment. His knowledge of Ndileka's need to navigate between her aunt's traditional medicine and her antiretroviral treatment serves to illustrate the broader translations that occur in attempting to extend healthcare in places like Lwandle.

In this context, the work of the CCW is in helping Ndileka navigate the medico-cultural-pluralist context in Lwandle. The CCW's sensitivity to and experiential knowledge of both the cultural and personal context within which Ndileka was accessing healthcare helped bridge the gap between her biological, emotional, social and epistemic needs. Here the caregiver does not merely exist as an entity with one foot in the 'culture of biomedicine' and the other in local culture/s, but helped provide his client with a translation of her biological symptoms that encouraged her to remain connected (or adherent) to ART.

4.2.2 Middle-figures: Negotiation and translation

Above I presented the caregivers as 'culture brokers,' as involved in translating biomedical ideas of health to ensure their clients remain connected to care, and/or empower their clients to make their own decisions about what kind of care they would like to receive. However, caregivers are also involved in more literal translations, particularly where mis/re-interpretations of healthcare are

concerned. Sometimes this entails renegotiating the terms of their client's healthcare or retranslating misinterpretations of healthcare. Indeed, Nancy Rose Hunt is quite explicit about the inability of caregivers to "control the circulation and remaking of the *terms*, neither the concrete objects" (Hunt, 1999:12). This requires a far more direct form of translation, where the caregivers literally translate the proper use of terms and healthcare objects. These translations often speak to different imaginaries of health and healthcare.

In addition to more literal forms of translation, Hunt describes caregivers being involved in acts of negotiation

in the classic sense of adversarial parties bargaining over contested ground, of mediation, arbitration, and sometimes even compromise [...] as is appropriate for rendering a situation of everyday 'making do' with its uncontainable meanings, chronic misunderstandings, and laughter (Hunt, 1999:23-24).

In some instances, these 'adversarial parties' negotiate over appropriate understandings of disease virology. At other times these 'adversarial parties' appeared to be irreconcilable as caregivers struggled to negotiate with client's understanding and use or application of biomedical technologies. Not only did these instances raise questions about the caregivers' knowledge of HIV/AIDS or their biotechnologies, but they also emerged as indicators of the indelible suspicions surrounding biomedicine I signalled in the previous section. In these moments, the caregivers help negotiate the terms of their client's healthcare practices as well as educate them on the appropriate use and construction of healthcare and its technologies. Yet this undertaking often meant that caregivers encountered resistance amongst community members.

Cebisa, the CHiPs supervisor I interviewed, told me about the days that she used to be a CHiP and what kinds of difficulties they faced early on in the implementation of the clinical trial. She recounted how a few of the clients they visited in the early stages of the trial confused their HIV status,

She said she is HIV-positive and then we asked her, was she referred [to the clinic to be initiated on ART?], and she said 'no'. So we asked her 'why', she said she doesn't know. 'Does your mother know?' She said 'yes', her mother does know. 'Okay then we are going to, can we test you', she said 'yes'. And then we tested her, and she was actually HIV-negative (CHiPs1, 2015).

Eventually, they came to understand, Cebisa explained, that to the client, to be HIV-negative was a positive thing, and therefore was interpreted to mean that she did not have the virus. As a result of such confusions, all CHiPs were urged to ensure that their clients understood what HIV-seropositivity

meant and to try to avoid such miscommunications. Cebisa suggested that correct education was the solution. However, like the vignettes told in the introduction to this chapter, sensitivity to the mis/understandings and negotiations occurring across health/healing constructs require not only correcting of misinformation, but also deeper understanding of divergent knowledge constructs.

At that time of the incident Cebisa was training a new set of CHiPs on how to engage with people living in Lwandle, test them and link them to care. She recounted a story about a traditional healer and his wife, where the traditional healer refused to be tested by the CHiPs for fear that the CHiPs themselves were going to infect him with HIV.

This man was a traditional healer [...]. He was actually outside, we were standing [at] the gate asking permission to get in, and he said, 'why', so we said 'we want to educate about HIV.' And he said to us 'ahh I'm not gonna do that, and I would advise you not to come in because I don't want to hear it, you are telling me that you are gonna cure HIV'. We didn't say that, you must remember. 'You're gonna cure HIV? I have lots of medication here that can cure HIV, and you are not gonna tell me about curing HIV. Who are you?' And, 'you have AIDS' and he didn't even say HIV, he said AIDS. 'Who are you? Go away with your AIDS [...] I don't want AIDS in my house'. You know all those kinds of things? [It was] very disturbing. [...] And I tried to soften him up, and I was more, at that time I was more aware of what to say and what to expect. And honestly I was in shock but I tried to get him. And we had people shadowing us so I didn't want to scare them, I tried to be as calm as possible. I was a bit hurt inside because I also felt sorry for the guy because he had no, he didn't have knowledge (CHiPs1, 2015).

As I indicated in the previous section, claims about 'miracle cures' to heal HIV/AIDS are prevalent in South Africa. Not only are these appeals often to the supernatural, relying on the insight and guidance of ancestors to intercede in the everyday lives of their kin, they can also call into question the legitimacy of science. Cebisa was quick to say that she did not tell the healer that she could cure HIV, rather that she was there to educate about HIV. His refusal, she said, was due to his lack of knowledge.

Another way to understand this exchange is to focus on the belief that the CHiPs themselves are living with AIDS. Rumours of this kind are common in clinical trial research (Fairhead, Leach & Small, 2006; Kingori, Muchimba, Sikateyo, Amadi & Kelly, 2010; Stadler & Saethre, 2010). Saethre and Stadler (2013) argue that such rumours are unpredictable and are employed in multifarious ways. In all instances, however, rumours expose existential truths which "embody the deep personal, economic, and social anxieties that suffuse the postcolonial world" (Saethre & Stadler, 2013:108)

and, “[u]ltimately rumours are one way in which foreign enterprises such as a clinical trial are rendered local” (Stadler & Saethre, 2010:345). The effects these viewpoints and beliefs have on the uptake and adherence to ART, as well as the effects they have on the ability of the caregivers to translate global health principles and practises into locally accessible knowledge, is difficult to gauge. Another important point to pick up on in the exchange between Cebisa and the traditional healer is the fact that Cebisa said that she was ‘more aware of what to say and what to expect’. Earlier on in her conversation with me, Cebisa said,

I know how to persuade a client now. I can’t just let them say ‘well I don’t want to test,’ I will have to ask why. They will tell me, ‘no I got tested’ [...]. And then I said, ‘but you can always get tested by us, participate in the study’, you know? All those things, I can do that. You, I can get you to get tested, I don’t care how much you refuse, I can get you to test with me (CHiPs1, 2015).

Cebisa is here referring to the skill of negotiation necessary to carry out care work. It is not enough to simply allow someone to refuse to participate, the CHiPs engage in a negotiation with community members over their healthcare and resultant participation in the trial. Part of the motivation for this negotiation process, as explained in the previous chapter, has to do with the pressure on caregivers to provide care and produce evidence.

In her study of the dynamics of consent in an HIV surveillance programme, Reynolds suggests that in addition to producing evidence, ‘liminal figures’ like ‘field workers’ play a vital role in mediating tensions between global health programmes and the production of knowledge at the community level, “between the norms and standards of global health research and local life worlds” (2014:128). “We suggested,” she goes on, “that ambivalent configurations of kinship, obligation, and trust crucially shape the conduct of HIV surveillance and thus the production of knowledge” (2014:128).

I believe her insights are equally applicable to the CHiPs and the CCWs care work. In these instances, they must remain cognisant of the fact that their care work requires the production of particular kinds of evidence. Yet, their sensitivity to local knowledge and healthcare practices often leads them to engage and negotiate with community members over the purpose of this evidence.

As another example of this negotiation between these ‘local life world’ and global health research, consider the misappropriation or the uncontainable use of the ‘objects’ of the CHiPs’ care work—the rapid HIV test. Community members who already knew their HIV status often asked to be tested. This occurred, the CHiPs told me, amongst both HIV-positive and HIV-negative community members.

I went to this lady, and she said to me, ‘I know my status, I am already on ARVs but I want to get tested’, but when I asked her why, she said ‘I am in this church that cures HIV’. And so I said to her before I tested her, I said to her ‘do you know the ARVs can suppress your viral load, so much so that it can be undetectable?’ and she said ‘yes,’ she knows that. So I thought, what’s the use then? Because if that happens it’s not because of the church, it’s because of the ARVs. But when we tested her [...] she tested positive (CHiPs1, 2015).

In the encounter I describe here, Cebisa explains to the client that adhering to ART can reduce her CD4 cell count to undetectable levels and, therefore, the test might come back negative. For the client, however, the central question was whether or not the church she attended had healed her. Here, the incorrigible ‘evidence’ of biomedical technologies meets the ‘evidence’ of faith and, questions of legitimacy, efficacy and knowledge are brought to the fore.

In this not so uncommon occurrence, it appears as if the rapid HIV test was supposed to lend the client’s faith credence. That is, she seems to be using the rapid HIV test to determine the legitimacy of her church’s ability to cure HIV. It is ironic that the very science she wished to use to verify the truth of her church’s claim, undermined that truth—since she tested HIV-positive. At another level, the client’s request could be indicative of a strange reliance on biomedical technologies to validate her hope, trust and of faith in the spiritual support of her church community. Yet Ashforth urges to recognise that as much as people no longer question the ability of science to effect change at a distance through imperceptible means (Ashforth provides the example of a cellular telephone), he argues that “[n]or would many doubt the power of God and the devil to transcend the ordinary laws of physics in performing their miracles” (Ashforth, 2005:146). The layers of health and healthcare activated in this instance are difficult to pull apart and, ultimately, it is unclear which of the form of healing is being ‘tested’. As a CHiP, Cebisa had very little influence over the motives or expectations of the client and merely played a facilitating role²⁶.

As I noted earlier, citing Hunt (1999), caregivers cannot control the way their practices, terms and objects are mis/interpreted by community members. However, they can attempt to help clients reinterpret these imaginaries in ways that more closely resemble biomedical models, in order to secure ART adherence. However, these reinterpretations are sometimes laden with the caregiver’s personal interpretations and practices of healthcare.

²⁶ This facilitating role is similar to the role played by counsellors at the HIV/AIDS Testing and Counselling Centre in Brazil, where Joao Biehl, Denise Coutinho and Ana Luzia Outerio conducted ethnographic research (2001).

4.2.3 Foot soldiers: Living in translation

Maheshvari Naidu and Gabriel Darong (2015) have recently considered the role of *isiZulu*-speaking nurses' construction of illness to illustrate how their beliefs regarding health and healthcare impact their healthcare practices and interactions with their clients. For Naidu and Darong, it is important that “due consideration [...] be taken of how nurses' [read healthcare workers'] explanation of aetiology and patient care is being influenced and affected by their cultural constructions of health and illness” (2015:104).

Here I draw on Steven Robins' (2009) construction of HIV/AIDS activists as ‘foot soldiers of global health’. I argue that the CHiPs' and the CCWs' healthcare practices fall in step with these soldiers, presenting new kinds of dialectics between biomedicine and traditional/alternative forms of health and healthcare. Like Robins' *Foot soldiers of Global Health* the caregivers “seek to ‘convert’ rural villagers into the acceptance of the fundamentals of ‘AIDS science’ through [...] persuasive arguments and translations that resonate with local idioms and discourses on illness and healing” (Robins, 2009:83). The lay counsellors in Robins' research tried to ‘convert’ their community members by appealing to “the authority of science and medicine, rather than God, to fight the pandemic widely attributed to ancestors, witchcraft and other ‘non-scientific’ causes” (Robins, 2009:96). Several years have passed since Robins' research and, South Africa's national ART programme has vastly improved. However, as with Naidu and Darong, I found that many of the CCWs I worked with, more so than the CHiPs²⁷, continued to show “particular understandings of what it means to be sick, which have been shaped by both [their] biomedical training and their cultural beliefs and practices” (Naidu & Darong, 2015:104). In this section I consider then how the caregiver's carry, together with biomedical forms of healthcare, their own ideas of health, healthcare and healing and, that they are not simply foot soldiers of global health but present their clients with various forms of care and healing.

While these forms of care and healing may appear to threaten or undermine their biomedical practices, they simultaneously appear to address more than mere bodily ailments—the site of illness for biomedicine (Lock, 2001). Throughout this thesis I describe the need for people living in Lwandle, and similar communities in South Africa, to receive holistic care which addresses biological, social, and epistemic maladies. In the previous chapter I illustrated how this sometimes entailed caregivers to deploy care at great personal cost, particularly because so much of their care provision is embroiled in evidence production. In this section, I argue that the caregivers carry with them their own beliefs

²⁷ Perhaps because the nature of CCWs work requires establishing a long-term relationship with their clients and, because of the CHiPs function within the PopART trial.

and practices. As much as they are purveyors of global health and biomedicine, they are also individuals with unique beliefs and understandings of the world. Anne Digby and Helen Sweet refer to this “pluralistic attitude [...] between the individual as a trained member of a respected health profession and the individual’s background, culture and belief system” as “latent pluralism” (2002:125). Each caregiver’s unique background, culture and beliefs are brought to bear in their everyday interactions with their clients.

4.2.3.1 *Prayerful Caregivers*

While walking around the community with a CCW and her supervisor early in 2015 we visited a woman whom I will call Esther. This was the second time I visited Esther. The last time I saw her was late November 2014. At the time she was healthy and cheerful, and was looking forward to spending Christmas with her family in the Eastern Cape. Her, her husband and five year-old son are all HIV-positive and have been the CCW’s clients for some time. Although Esther and her husband had been taking ART for more than six months before leaving for the Eastern Cape (which meant that they were considered adherent enough not to be followed up on by CCWs), the CCWs continued to check up on their son’s health. The CCW told me that upon returning from the Eastern Cape, Esther was hospitalised for a brief time. Like so many other clients, Esther returned from the Eastern Cape having defaulted and was very sick. The CCWs told me that Esther receives very little more than financial support from her husband, making it difficult for her to look after both herself and her son while in hospital. This lack of ‘care’ in the household is not uncommon in South Africa²⁸. As a result of her own illness, Esther’s son had also defaulted on his medication and had not yet been to the clinic for follow up tests and prescriptions—the reason for our visit. When we arrived at Esther’s house her son opened the door for us before running into the courtyard between the hostels to join his friends. Esther answered the CCWs from her bed to the left of the small ‘hostel-to-home’²⁹, and the CCW and her supervisor went inside. I stood in the doorway for some time, observing the conversation going on between them.

Esther looked worse for wear. She was much skinnier than when I last saw her. She was sitting on her half made bed, legs thrown over the edge with a CCW on either side of her. We all noticed immediately that a large bulge about the size of a tennis ball was jutting out from the one side of her neck. When the CCWs pointed it out, Esther kept saying, ‘stressed’, ‘stressed’. After a while the CCW supervisor turned to me, indicating for me to leave and started closing the door saying, ‘I just want to pray for her’. The prayer began quietly, at conversation level, but rose steadily until the

²⁸ See Debbie Budlender and Francie Lund (2012) for more details regarding household disruption and childcare.

²⁹ See Noeleen Murray and Leslie Witz (2014) for more details regarding the ‘hostel to homes’ project in Lwandle.

supervisor was shouting loudly. I was barred from this private, sacred, activity, left standing outside in the corridors between the old hostels. Later while we were walking back to Ikhwezi clinic, the CCW supervisor told me that Esther was emotionally and physically abused by her husband. The supervisor also said that two of the CCWs will go and visit Esther later that night to talk to the husband.

Although several issues related to health and well-being are raised in this exchange (including gendered care roles and intimate partner violence, migration, poor ART adherence, a general sense of powerlessness), what I wish to draw out is the way in which the CCW's religious beliefs intermingled with their work of providing biomedical knowledge and care. On the one hand, the CCWs were there to perform a recall on Esther's son—a form of biomedical care. On the other hand, they also brought spiritual, emotional and social healing through prayer.

As I have explored above, care workers are often called upon to provide forms of care beyond the biomedical in order to try ameliorate social and psychological (if not biological) traumas linked to disease and illness. In this way, they try to achieve both what they set out to achieve and fulfil the expectations of those implicated by the illness (Young, 1976).

Instead of merely acting as translators or negotiators of biomedical healthcare, or 'foot soldiers of global health', the CCW and her supervisor extended care in the form of prayer. The interpretation and latent effects of the CCWs' actions on their clients' healthcare beliefs and practices, although outside of the scope of this research to explore, is an interesting consideration. The CCWs became purveyors of both biomedical and spiritual healing. There are times when these beliefs may be seen as irresponsible; where the caregivers' 'latent pluralism' may introduce more doubt into their client's lives. For example, when I asked the CCW supervisor why she (along with many of the CCWs), does not wear her TB mask while walking from one client's house to the next, she said, "I am not afraid. I have my Jesus. I trust Him. Our Lord saves us a lot. We are walking, walking, and not getting sick". Concerns could very well be raised in instances where the CCWs' beliefs undermine appropriate and effective care of their clients—the CCW supervisor herself noted that the TB masks are there to protect the CCWs, their clients and the community.

While I am not suggesting that the CCW and her supervisor are governed by religious ideas and motivations, I do wish to signal the fact that by extending this form of care alongside biomedical healthcare practices there is a possibility that it provides opportunity for confusion, misunderstanding or reinterpretations of their healthcare practices. However valid these concerns may be, it is clear that the caregivers are endeavouring through these practices to provide their clients with context-specific translations and forms of care. Rather than necessarily being seen as conflicting then, combining these

practises appears to offer a holistic form of care. Fredrick Klaitz argues, for instance, that “[p]rayers and hymns communicate love from the bodies of the well to the bodies of the ill” (Klaitz, 2010:3). The assimilation of religious healing into biomedical practises can be seen as an attempt to overcome ideological and social divides between biomedical and local understandings of health and illness.

While I have borrowed Steven Robins’ (2009) portrayal of community caregivers as ‘foot soldiers’, I have done so to show the other side of this coin. Robins acknowledges that “the processes of embedding and translating biomedical discourses in particular places are anything but straightforward or stable” (2009:83-84). He goes on to say that although these foot soldiers appear as vanguards of biomedicine “it is not inconceivable that, were they to experience difficulties in accessing to modern medicines, they, too, could be driven to seek the services of traditional healers” (2009:100). It is possible that, given their knowledge of biomedical healthcare, these so-called ‘foot soldiers’ resort to ‘traditional’ forms of healthcare only in extraneous circumstances, however as I have set out to illustrate in this chapter, often an eclectic mix of healthcare practices is used as people “‘try everything’ in the hope that ‘something’ will eventually work” (Obadare & Okeke, 2011:194).

4.3 Tending the line

In this chapter, I have argued that CCWs and CHiPs can sometimes act as bridges to unite the perceived divide between the traditional and the biomedical systems, which are understood to “operate in parallel, but largely separate, arenas, in which collaboration is largely absent” (Wreford, 2005:1). By being aware of and responding to the local understandings of healthcare provision, the CCWs and CHiPs are able to negotiate healthcare options with their clients. The caregivers’ sensitivity to the context of their work and their client’s lives, provides them with a better understanding of health and illness aetiology in the area. Indeed the caregivers are able to “identify systematic blockages in the flow of medical information” which often take the form of “the pressing dilemmas—the harsh constraints on decision-making—faced by people who live and work far from the centres of policy-making power” (Feierman et al., 2010:125;123). I argue that we could, perhaps, usefully borrow and rework some elements of the figurations of culture brokers, middle-figures and, foot soldiers in order to come to a more nuanced understanding of how caregivers negotiate the many different forms of knowledge, healing practices and care needs they face.

In each of these formulations I have highlighted particular functions to signal instances where the caregivers’ translation of healthcare practices and biomedical technologies is required in their everyday care work. In reality, these formulations are far less concrete than I have perhaps conveyed. Indeed, they may overlap and converge. It is precisely this messy convergence of multiple layers of

knowledge, beliefs, and healthcare practices that form the backbone of this chapter. These divergent encounters and experiences necessitate constant acts of translation, and require the use of many different methods in order to mitigate misunderstandings of or resistance to HIV testing, linkage to care, and/or ART adherence. In this context, caregivers also bring their personal beliefs and practices to bear on the implementation of their healthcare practices.

Walking the thin line between providing only biomedical forms of healthcare and providing holistic forms of healthcare is made all the more difficult when this healthcare is tailor-made to meet each and every client's personal needs. This form of translation is more than a translation of protocol into practice or global into local, it is a translation that comes with experiential or excess knowledge, which Human defines as "a general body of knowledge in combination with the particular idiosyncrasies of the individual practitioner and his or her experiences with different medications, diseases and patients that may divert from orthodox" (Human, 2012:20).

In addition to divergent understandings and practices of care provision, access to and provision of healthcare is shaped by the physical, social and economic context within which caregivers and their clients live. As I have already indicated, Lwandle is a poor community that experiences many forms of these challenges. A common theme throughout the chapters thus far has been how care is deployed, accessed and understood in Lwandle. In the next chapter, I consider the limitations of healthcare and potential for living 'beyond bare life' in the face of these challenges, for people living with HIV.

Chapter 5 Structural violence and the limits of healthcare

5.1 Possibility, freedom and choice

Diliza was the very first person with HIV/AIDS I encountered in Lwandle. At the time, Diliza was co-infected with HIV and TB and had already initiated and defaulted his ART. Shortly after defaulting his medication, Diliza had a stroke. It was at this point that I met him. Yet, soon after we met, Diliza endured another stroke, was hospitalised and less than four months later, passed away. In the chapter, I describe his story, and our brief interactions in detail below in order to pose questions about the limits of healthcare in Lwandle. To understand how a man like Diliza comes to die of AIDS in the midst of a massive HIV treatment and care programme, I describe the structural constraints of life in this locality and its effects on health seeking. Further, I reflect on the concept of ‘poverty as capability deprivation,’ a notion coined by Amartya Sen (1999). This view of poverty transforms our understanding of and focus on poverty from merely lacking the *means* for existence (income/material goods) to that of achieving desirable *ends* (living a good life), and having the freedom to do so. As I will describe, for some people living in Lwandle, particular freedoms or opportunities have made achieving these desirable ends possible. For many others, however, these unfreedoms in the form of physical, social and structural violence have made these desirable ends unobtainable. They manifest in ways that seem to limit the possibility of a better future. I argue that a gap remains between achieving these ends and what is actually achieved. One of my participants, whom I will call Sara, summarised this quandary as follows:

Look here; the clinic is just down here. Why can you not; you go get all the people’s pills but [they] don’t help [themselves]. It is wrong (Community Member3, 2015).

Sara is here highlighting the possibility of accessing healthcare and the countervailing tendency of some people to default their medication. Without inadequately incriminating either the patient or the public healthcare sector, I explore why people living in Lwandle continue to die of AIDS when their access to ART, especially in the context of the HPTN 071 (PopART) clinical trial, should be seamless. What should be made clear by the end of the chapter are the limitations of healthcare (and life) for both self- and non-self-governing clients, restrained by the social and economic realities of living in a rural settlement in contemporary South Africa.

For individuals like Diliza, there exists a paradox; where the prospects of future choices leading to emancipation are held up by the seemingly fixed structures of social deterioration and, inadequate access to healthcare and economic opportunities. For although many had been extended the offer of healthcare, and thus been incorporated into the ‘exceptional populations’ cared for by the CHiPs and

CCWs, some clients somehow still fall through the proverbial cracks. Diliza was, for example, repeatedly urged to seek medical attention, to re-enter the CCWs care programme but, as I explore below, his physical, structural and social reality appear to have prevented him from doing so.

For other individuals, their access to care in the form of health services or other forms of assistance, such as social grants, often resulted in improved access to other opportunities. In most cases, access was secured with the support of the caregivers and other healthcare providers who were familiar with and sympathetic to the hardships that come with living in Lwandle. Simply put, these clients relied on their relationships with healthcare providers in similar ways to what Sean Brotherton has called ‘pragmatic subjectivities’, which help them manoeuvre “through the vicissitudes of the state’s crumbling welfare system” in order to secure access to healthcare and social grants (Brotherton, 2012:31). For both sets of individuals, the in/ability to invoke these opportunities, has resulted in different health and life outcomes.

5.1.1 Meeting Diliza

On the morning of Friday the 24th of October 2014, I arrived at the clinic for my first official day with the community care workers. The CCW supervisor paired me up with two CCWs. We walked for about 800m, taking a brief shortcut through an informal settlement cynically named ‘Wag-’n-Bietjie’³⁰ (Afrikaans for ‘wait a little’). Before arriving, the CCWs primed me for my first encounter with Diliza: ‘Diliza is on TB medication and ARVs. We are going to do a recall’. Like so many other clients that default their medication, Diliza had also stopped reporting to the clinic for TB sputum and CD4 cell count tests—the purpose behind our recall visit. As we arrived at Diliza’s house, a little boy showed us in to the lounge where Diliza was waiting for us. Diliza, in his mid-thirties when I met him, had been diagnosed with HIV in July 2014 and had initiated antiretroviral treatment shortly thereafter, in August 2014. When I met him a few months later, he was thin, frail and largely disabled on the right side of his body, the result of a stroke he suffered shortly after initiating ART earlier in the year. He walked with a cane and, was visibly in a great deal of discomfort.

As soon as the CCWs and I sat down, they began to berate him, accusing him of negligence in not adhering to his medications. They told him that since he had discontinued his medication for more than three months, he would be considered a new patient if he returned to the clinic. They also warned him that since he had defaulted, the clinic might change his ART regimen from First line to Second line ART. Later, the CCWs explained to me that Line 1 medication was taken once a day, and was

³⁰ So named because for years, government housing providers residents to ‘wait a little’ longer for their housing subsidies. In other research the area was referred to by locals as “‘ezimbacwini,’ literally meaning ‘places of refuge’” (Matholeni, 2012:62, *emphasis* in original).

usually only one or two pills, depending on the patient's CD4 count and viral load. In Line 2 ART, they explained, the patient would have to take two or three tablets twice a day³¹. They asked him why he had chosen to initiate ART if he was going to default on his medication anyway.

Diliza replied in short bursts of broken English, Afrikaans and isiXhosa, repeating himself several times, accusing the CCWs of not understanding his predicament. He could not walk to the clinic, he told them, because of how the stroke had impeded the use of his right side, nor could he afford to pay for transport to take him from his house to the clinic. Transport from his home, I was later told, could cost in excess of R15 per trip. At this point, one of the two CCWs pulled out a record of all the visitations they had made to his house over the past couple months and showed it to me. The CCW pointed to a particular entry while shaking his head in disbelief; he read aloud a quote of Diliza saying: 'I will go get my medicine when the weather is right'.

Diliza kept returning to the fact that he could not get himself to the clinic to fetch his medication. The physical effects of the heart attack and his inability to pay for transport impeded his ability to access further healthcare, he kept repeating. Finally, one of the CCWs said that they could write a recommendation for him to be taken to the local hospice where, according to the hospice website, "all persons who face a life-threatening illness and are referred to [...] with a predictable, restricted expectancy of life" can go to for palliative care, with the aim of reintegration into society ("Helderberg Hospice: About Hospice", 2014). Turning to talk to me the CCW justified herself by saying, 'he is not supposed to cook or use heavy/dangerous equipment', which he clearly had been doing.

While there is some evidence to suggest that institutionalisation "provides an opportunity to improve ART adherence," it comes with other challenges like "protecting [client] confidentiality, stigma, and transitions from institutions to the community" (Eaton, Saag, & Mugavero, 2014:361). Because being carted off to hospice can serve as a public form of forced disclosure, it is perhaps unsurprising that in some cases, it seemed to me as if the CCWs used the threat of being sent to the hospice as a 'scare tactic'—to scare clients into start taking their medication correctly. In Diliza's case though, the suggestion of hospice-based care was not used simply as a scare tactic, but seemed to be a genuine 'last resort'. Nonetheless, Diliza refused this offer.

Later in our conversation with Diliza, one of the CCWs offered to be at his house at 7h30 on Monday morning to help walk him to the clinic. After much deliberation, Diliza agreed that he would make a decision about whether or not to return to the clinic by Monday morning. When I saw them the

³¹ Taking more medication is often referred to as 'pill burden' and sometimes results in lower adherence rates (Peltzer, Friend-du Preez, Ramlagan, Anderson & Preez, 2010).

following Monday, I asked the two CCWs whether or not Diliza had visited the clinic with them. They evaded the question, making it clear that they had neither followed up with him nor accompanied him to the clinic that morning. They would not be able to visit Diliza today, they told me, as they had other clients to visit as well as other meetings to get to that afternoon.

About a month went by before I again followed up to inquire about Diliza's health. One of the CCWs and I tried to visit him but his girlfriend told us he no longer lived with her and had moved in with a friend down the road. She went on to say that he had been sent to Tygerberg Hospital³² after suffering another stroke earlier that week.

Two weeks later, while accompanying one of the two CCWs from my first meeting with Diliza into Lwandle, she asked quite casually, 'do you know Diliza passed?' I was so shocked by this information and the casual manner in which she relayed it, I do not remember what I replied. 'Ja' (yes), she said, 'when I last saw him he had a rash all over his body, with water coming out all over him'. She had implored him to go to the hospital, she told me. He was so sick that the people he had been staying with chased him out of the house. He was taken in by his friend, Xander, who we were in fact on our way to see. The CCW told me that Diliza had passed away while in hospital after suffering yet another stroke.

Before we got to Xander's house, the CCW briefed me on his illness and ART and TB adherence record—Xander was about to start his third round of TB medication, which meant that the CCW had to complete another assessment form with him. The CCW complained that he had received medication in the past, but stopped taking it after a month or two, or as soon as he started feeling better. She was puzzled by this because Xander has been on ART since 2007 and seems to adhere to his ART regimen without a problem. Xander's wife met us outside and led us into their home. She called Xander into the lounge from the back of the house, where the CCW and I were seated on the couch nearest the entrance.

As the CCW began the assessment form for new clients, which I describe in Chapter 3, I told Xander that I am sorry to hear about Diliza. At first he did not understand what I was trying to say. But between the CCW and me, I managed to convey my condolences, as much through action as through words. Xander initially said, 'Diliza is gone', absently pointing upward. He nodded, and said, 'Ai, Diliza was too much sick'. On the one hand, I wanted to press him for details about how and why Diliza deteriorated so quickly, on the other, I desperately wanted to respect his mourning. The CCW continued with the assessment. That was the last I heard or spoke of Diliza in the field. I have relayed

³² Tygerberg Hospital is a tertiary hospital located in Belville, Cape Town. It also acts as a teaching hospital for Stellenbosch University's Health Science Faculty (Western Cape Government, 2015).

his story in detail here because I feel it powerfully conveys some of the limits and opportunities of healthcare in Lwandle; where clients are able to and clearly do fall through the literal and figurative fingers of healthcare/rs. It also acts as a platform to exploring the finer structures and networks clients are entangled in, be they social, economic or personal.

5.2 In/capabilities, un/freedoms and structural violence

In this section, I try to make sense of Diliza's choices using Amartya Sen's (1999) capability approach, which offers a multidimensional view of development. Alongside the capabilities perspective, I also draw out the broadly defined concept of 'structural violence' as it has been used by Paul Farmer (2003). For Sen (1999) the extension of freedoms is necessary for development. Deprivation of these freedoms and/or poverty in any form impedes development. Farmer locates the failure of development and unfreedoms in broader political, economic and social structures that inhibit access to healthcare and other resources necessary for life. He defines structural violence as "social and economic inequities that determine who will be at risk for [human rights violations, HIV/AIDS and other maladies of various kinds] and who will be shielded from them" (2003:17). In his view, limited access to healthcare, income and education are the result of historically deep and geographically broad operations. Combined, these perspectives help us to locate Diliza's complaints within fractured state powers that struggle to provide sufficient opportunities to those living in impoverished areas like Lwandle. Indeed, as we have seen, "health workers regularly explain that the well-being of communities and the health of individuals are linked to 'structural forces', 'systemic factors,' and 'global circumstances' (Millen, Irwin, & Kim, 2000:6). I combine Sen's (1999) work on capabilities with literature that focusses on structural violence to illustrate how different people's different access to certain core freedoms leaves some people the ability to flourish, while others are left with little "capacity to choose to act rightly" (Tronto, 2013:40).

Amartya Sen's (1999) capability perspective contains five 'core capabilities'. I discuss four of these 'core capabilities' and, how they are shaped by structural violence and can lead to poor healthcare responses, ART adherence and life outcomes. The capabilities perspective essentially entails increasing people's freedom to choose ways of being they have reason to value. It invites us to examine what opportunities are available to persons to utilise or, indeed, choose not to utilise (Sen, 2005:154). One of the consequences of this perspective is that people who value certain ways of being, like good health for instance, have the opportunity to invoke this way of being without countervailing circumstances inhibiting this invocation. People should also have the freedom to choose not to invoke ways of being others might deem as valuable. For Sen, freedom ultimately

means having all the opportunities available to reach all possible ways of being, with the choice not to utilise these opportunities.

Here Sen draws a distinction “between *doing* something and being *free* to do that thing” (2005:155). For Sen, the “central issue [...] is the person’s freedom to choose how [they] should live” (2005:154). While having the opportunity to certain ways of being is important, having the freedom to choose to invoke them or not, is more important. Sen (1999:38) does, however, concede that all people should have access to at least five core freedoms which “contribute to the general capability of a person to live more freely, but they also serve to complement one another”, so that the sum of the parts are greater than the whole. Yet the opposite is also true; denial of any one of these core freedoms is likely to impede other freedoms. Development, according to the capability approach, therefore, requires increased access to opportunities and freedoms of various kinds. For this reason, the capability approach is often referred to as a multidimensional approach. I look at four of the five core freedoms; economic facilities, social opportunities, transparency guarantees and, protective securities.

I draw on literature concerned with structural violence as well as the Broad Brush Survey Report compiled by the Desmond Tutu TB Centre’s (DTTC) social sciences team, to describe how structural violence prevents people living in Lwandle from accessing the full range of freedoms. Although I describe them in relation to access to healthcare, failure to access these freedoms has far broader implications.

5.2.1 Economic facilities: Poverty and risky behaviour

The first of Sen’s (1999:11) core freedoms, economic facilities, is “the form of opportunities for participation in trade and production [which] can help to generate personal abundance as well as public resources for social facilities”. For Sen (1999), having access to economic facilities ensures that people are able to participate in the economy in a productive manner, not only providing for themselves, but contributing to the wider economy. Sen believes that having access to income will help to offset these physical needs as well as social anxieties and, ultimately, open up other freedoms. In this sense, poverty and unemployment not only impede peoples’ opportunity to participate in trade and production, but also prevents them from accessing goods and services necessary for everyday life. Lack of economic opportunity, Joan Tronto (2013) has recently argued, not only translates to the inequitable distribution of social opportunities, but produces unequal care. More often than not “these inequalities reinforce and fall along the lines of race, class, and gender,” further marginalising already marginalised groups (Tronto 2013:111). When viewed correctly, these decisions are located in

broader structural, social and economic conditions which contribute to poverty, unemployment and alcohol abuse.

In 2001, the unemployment rate in Lwandle was 38% while the unemployment rate for Nomzamo was 31% (Erasmus, 2005:145). During the 2011 Census, Wards 085³³ and 086 had unemployment rates of 23.83% and 34.21%, respectively (Strategic Development Information & GIS Department, 2013a,b). In this context, people living in Lwandle struggle to secure basic goods like food for themselves and their families. They are also often unable to afford transport costs to and fro healthcare centres, as we saw with Diliza. These material lacks powerfully shape their choices and possibilities of seeking care. Despite these difficulties, however, some still manage to access quality care and other opportunities.

In contradiction to Diliza, Kuhle's story is an amazing account of overcoming hardship. Yet it begins in alarming impoverishment and serves as a good example of how the inaccessibility of work led her to make risky decisions, while access to certain forms of income opened up the opportunity for improved living standards and other opportunities. I met Kuhle through the CCWs and, I was immediately taken by her positive outlook on life. Kuhle lived in the Eastern Cape with her mother and little brother before moving to Lwandle. Her father, the sole breadwinner, passed away when she was just thirteen years old. Her mother was an alcoholic and spent most of the money she got through an old-age grant, on alcohol. When she was sixteen Kuhle decided that she could no longer live with her mother and, decided to follow in the footsteps of an older brother who moved to Cape Town. Kuhle hoped that she and her younger brother would be able to live with their older brother and, that she would soon start attending school again. However, when she arrived, she found that her older brother had had a child of his own and was living with his girlfriend. She saw that he could scarcely provide for his own family, let alone another two mouths to feed. So she found a piece of land and built a shack for herself and her younger brother to live in. Next door neighbours would sometimes give them food, but she would often go hungry if she had only enough food/money to feed her younger brother. After living like this for some time, Kuhle managed to find some odd jobs and began to provide for herself and her younger brother. At about this time she met someone and had a child with him. They began living together. Because her partner was unemployed and unable to contribute to household expenses³⁴, she was compelled to go in search of better work. She found a job in Somerset West,

³³ Lwandle falls within Ward 085 and Nomzamo within Ward 086. See my discussion on these boundaries in chapter 1.

³⁴ A condition, Debbie Budlender and Francie Lund (2012:68) argue has a long history in South Africa, in which "women try and reconcile the need to be both carers and income earners".

I got the job from a man. This person was a rich man coming from Germany. [...]. Then I do the cleaning job for him for once a day, one day a week. Then I buy the food. Okay. But in in the meantime, this this man he was tricky to me [...] he wants to sleep with me in order [for] me to have another money. Not employing, or give me other days [to work]. So, because I, I was not having anything, I let that happen to me. I let that happen to me. I did that. I prostituted myself to him in order to have that money for food. Because the children, they didn't know why we don't have food. I have to provide (Community Member1, 2015).

For Kuhle, the critical factor contributing to her decision to agree to an unfavourable union was that 'the children [...] didn't know why we don't have food'.

Kuhle's story is also one that was told to the DTTC social sciences team during their Broad Brush Survey research in Lwandle. During their research community members told the team that poverty may push people into making poor decisions regarding sexual behaviour (DTTC, 2013). Lwandle community members saw young unemployed women as well as single mothers as particularly vulnerable to resorting to 'transactional sex' in order to secure financial security. In these relationships, women are often unable to negotiate the terms of sexual practices and, sometimes engage in unprotected sex with multiple partners. These risky sexual behaviours increase their chances of contracting HIV (MacPhail *et al.*, 2007). Conversely, Lwandle community members considered people with money (mostly men) who exchange money or gifts for sexual favours at higher risk to contracting HIV. While community members in Lwandle interviewed by the DTTC social science team recognised the vulnerability of unemployed women, they also recognised that men who engaged in these kinds of sexual relationships were at equally high risk for HIV infection. On the other hand, individuals that have a steady income, formal housing and senior citizens appeared to be safeguarded against HIV infection. Self-sufficient women were also considered at lesser risk to HIV infection, particularly when they did not rely on the income of a male partner to survive (DTTC, 2013:7).

More broadly, as much research has suggested, there is a clear link between 'risky behaviour' and poverty (Farmer, 2003; Sawers & Stillwaggon, 2010; Musumari, Feldman, Techasrivichien, Wouters, Ono-kihara, *et al.*, 2013). Didier Fassin describes the link as follows, "[t]he dialectics of AIDS and poverty are manifest in this biography in which the latter makes the former possible and in which the former in turn exacerbates the latter, in a vicious circle" (2007:194). For Kuhle, the inability to secure enough food for her daughter and younger brother drove her to make a decision she should never have had to make. Here food security, or lack thereof, directly contributed to risky sexual behaviour and exposure to HIV.

Such circumstances also challenge healthcare decision making and access in other ways. Beth Rachlis, Edward Mills and Donald Cole (2011) have suggested that not only does poverty increase high risk behaviour for HIV, but it also hinders ART adherence. Returning to Diliza's story, recall that shortly after learning of his HIV-positive status, Diliza suffered a stroke. We saw that while he had access to healthcare, through the CCWs, he was unable to go to the clinic because the stroke had left him partially disabled. His disability, therefore, restricted him from accessing further healthcare. Diliza needed access to public transport and rehabilitative healthcare.

As Hick (2014:296) points out, "people have differing needs, which means that they require different amounts of [different] resources to achieve the same capabilities" or ways of living worth valuing (Hick, 2014:296). Sen refers to these differences as 'conversion factors,' or 'personal heterogeneities' (Sen, 1999; Hick, 2014). This is a particularly important consideration when dealing with the chronically ill and disabled, like Diliza, who require more or at least, a different form of healthcare in order to remain as active in society as other people. The complex dynamic of opportunities and hindrances sees poverty increasing high risk behaviour for acquiring HIV and, restraining HIV-positive peoples' ability to appropriately adhere to their medication. On the flip-side of this, even the smallest financial and food securities, along with some good fortune, can greatly increase peoples' ability to adhere to ART.

Sara, a fifty year old Afrikaans-speaking women living with HIV who, like Diliza, also suffered a stroke, complained that she now struggled to walk long distances. Sara lives with her partner, who continues to provide for her biological and social needs. Although by no means wealthy, Sara has access to regular meals and other healthcare resources. Sara has also been able to establish long-term relationships with the CCWs and with a few nurses at one of the local public hospitals. These relationships provide her with access to additional healthcare resources which otherwise would not have been available to her:

I phoned the sister by the [hospital], I told her my stomach is running now and stuff like that. She say 'Sara, just wait there, just make yourself nicely dressed and everything, I will come fetch you now'. [...] And [she brought] a wheelchair for me. You know [...] people appreciate me a lot. The reason why, especially the nurses; because I cooperate with them a lot (Community Member3, 2015).

These relationships fill the gap where the state has withdrawn from service provision. No longer able to access healthcare (amongst other social services, like public transport and the social grant) through official channels, people living with HIV turn to social networks and healthcare providers (like we saw in the previous Chapters) in order to access these services. Brotherton concludes; these

relationships that “weave diverse groups of people together, crosscutting personal, institutional, familial, state-sponsored, and private spheres, constitute the micropolitics of health” (Brotherton, 2012:33). In Diliza’s case, the failure of the CCWs to follow up on him, his own failure to make use of their offer to recommend him to Hospice and, the general absence of appropriate service provision to meet his not so uncommon needs surely contributed to his death.

5.2.2 Social opportunities: Social and personal violence

Poverty and unemployment therefore not only impede people’s ability to secure the necessary means for survival but other freedoms, like social opportunities, as well. Social opportunities, “in the form of education and health facilities” are meant to provide people the capacity to “shape their own destiny and help each other” (Sen, 1999:11). As I illustrated above, differential access to healthcare, because of disability or poverty differently impacted the health outcomes of Diliza and Sara. Sara was able to draw on the help of nurses at the clinic to help transport her to and fro the clinic. Diliza, however, relied on the CCWs to help him, which they failed to do in the way that he wanted and needed.

Lack or access to education also shapes what job opportunities are available to people. For example, because Kuhle was unable to finish school, she has had limited job opportunities. After quitting her job with the German employer, Kuhle started working at a vinegar factory, where she was initially paid well, until her employment relationship changed:

In the meantime they said ‘[no] we can’t hire anymore people during daily, we gonna call you’. Once again, I came back to square one. I was called once a week [...], I was paid R150 per month (Community Member1, 2015).

Kuhle was reduced to a casual worker. This change in her employment relationship is reflected in the global shift towards increased externalisation, flexibilisation and feminisation of work as a consequence of neoliberal policies (Standing, 1989). David Harvey, in his seminal work on postmodernity (1989:150), describes this shift as involving high levels of structural unemployment, a rapid destruction and reconstruction of skills, and employers taking “advantage of [...] the pools of surplus (unemployed or underemployed) labourers to push for much more flexible work regimes and labour contracts”. In South Africa, these flexible work regimes are lawfully, albeit dubiously, constructed through the use of contract labour (Theron, 2009). One of the results of these policies is, the creation of the ‘working poor’ (Bezuidenhout & Fakier, 2006).

What is significant for people like Kuhle, the already marginalised ‘victims of structural violence’, is that “the legacy of apartheid is clearly fusing with the logic of the market to link the present outcomes and future possibilities for the working poor to the constraints of the past” (Bezuidenhout & Fakier,

2006:464). Thus, those who have historically been marginalised in South Africa, continue to be marginalised, leaving them little opportunity for either themselves or their children to escape a cycle of poverty. It is difficult for people in situations like this to think about a future, often resulting in the deterioration in social life. Gabriel Demombynes and Berk Özler (2006:290) argue, that “the lack of upward mobility in a society, combined with a high premium on economic affluence, results in anomie, a breakdown of standards and values”.

Throughout my research period, both the caregivers and community members bemoaned the high crime levels in Lwandle. They pointed to actions of gangs and the use of drugs, compounded by unemployment and poverty in Lwandle as explanation for the recent rise in crime levels. Sara noted that the combination of unemployment, drug and alcohol abuse has had deleterious effect on community life in general. She explained how the area she lives in has changed over time. Adults who she knew as children have grown up to be disrespectful and vulgar people. She does not trust anyone in the community and does not feel safe enough to share her HIV status with them either:

You see that girl whose coming here, she’s chew, [...] chew, tik. Yes, she was stealing too much clothes from me here this side [...]. I don’t have friends in this place, I don’t want to make friends [...]. I will go tell her, and she will go tell that one, and she will go tell that one. So the stories can just continue. [...] Then tomorrow, then look here, they turned the whole story around. [...] You see in this place, you can’t tell the people you have ARVs. You know why? Tomorrow they will chide you; AIDS this, AIDS that (Community Member3, 2015).

In a moment of fragility Sara recounted how she was beaten and raped one afternoon when walking back from the clinic. In this conversation, I was made acutely aware of how inaccessible this experience was to me. As Didier Fassin has acknowledged in his own work with people living with HIV in South Africa, “I can only see her body and listen to her sentences,” but “it is illusory to think [I] can know the meaning that her body and sentences have for her” (Fassin, 2007:26). Overt physical, social and emotional violence of this form constitute a violation of human rights, not to mention the concomitant biological risks (Milford, Barsdorf & Kafaar, 2007).

The toxic mix of unemployment, drug and alcohol abuse and crime results in the breakdown of social opportunities. For many, like Kuhle, attending school and studying is made extremely difficult, if not impossible, because of the immediate need for money for food. Even for those people who are able to complete school, the challenge of finding employment leads many people to turn to crime, violence, or alcohol and/or drug abuse. As an added consequence, the social fibre of the community is broken down. Sara only disclosed to her partner and one or two other people in the area, because people will ‘chide’ her if they found out about her HIV status. For Sen, it is important that people

have the freedom to engage with one another without fear of stigma or retribution of any kind. He refers to this as ‘transparency guarantees’. Not only does this create mutual respect and open up the possibility for development at the community level, but more specifically to the questions at hand, disclosure is seen as an important step towards becoming a responsabilised, adherent client. In this way, fear of disclosure due to stigma, discrimination or social exclusion hinders ART adherence (Hardon, Akurut, Comoro, Ekezie, Irunde, *et al.*, 2007).

5.2.3 Transparency guarantees: Stigma and social death

‘Transparency guarantees’ include “the freedom to deal with one another under guarantees of disclosure and lucidity” (Sen, 1999:39). Although ‘transparency guarantees’ hold implications for society at a broader level, in this section I focus on the implications for people living with HIV. As I suggest above, I believe the notion of ‘transparency guarantees’ could be usefully linked to stigma (both internal and external, perceived or felt) and disclosure. The ability to disclose one’s HIV status has the potential to transform one’s self-identities from being self-destructive, to self-constructive or to ‘living positively’. Achieving a positive lifestyle, after accepting one’s HIV-positive status, is usually assisted through social support (Dageid & Duckert, 2008; Daniel & Squire, 2009). This transformation reaches its crescendo in the disclosure of their positive status to partners, families and friends. A lack of social support or overt stigmatisation can result in fears of rejection, delaying HIV-testing and ART initiation and can also impede adherence and retention in care. Transparency guarantees which ensure “the right to disclosure” and include “some basic presumption of trust,” is undermined by the constant threat of being raided, shamed and/or rejected (Sen, 1999:39; 40).

When Luvellen, a coloured man in his early forties who I visited with the CCWs in his home before later interviewing him in the clinic after collecting his medication, first found out that he was HIV-positive in 2004, he ran away from the clinic, scared of what his friends and family might think if he was seen to be collecting ARVs. He immediately went home and told his childbearing wife, scared that their daughter might be born HIV-positive.

DW: So you first tested in 2004?

L: Yes, and then I run away, I never go back to the clinic because I was scared. And then my wife go to the clinic with our child, the child was born with not HIV [...]. She was born healthy, nothing HIV. And then she was use her treatment from this time [...] and she also tell me: ‘Luvellen, go, go’ and I never go. I didn’t listen to her.

DW: But why?

L: You know I was afraid [that] people [were] going to see me in the clinic, friends, people [...]. Now I am not afraid anymore. Because now I am a grown up person. I have to look after my children [...]. When I was sick, it was like I am dying. But it's only God's will that I'm still alive today (Community Member4, 2014).

For Luvelen, the fear of being seen in the clinic drove him to run away from the clinic and from ARVs. He went without ARVs for another 10 years before he became desperately ill. At the time of 'dying' he was co-infected with TB. The healthcare providers at Ikhwezi clinic helped him get to the local municipal hospital. After his blood tests reported that he had HIV, the clinic staff scolded him for delaying treatment. Despite the fact that his wife was already HIV-positive and that she encouraged him over the years to go to the clinic for ARVs (and that he supported her ART adherence by asking her: "Did you drink your pills?"), Luvelen feared the stigma attached to receiving ART at the clinic. Only when he was faced with his own mortality did he start taking ARVs. For Luvelen, fear of stigma is largely located externally. He feared what his family, friends and other people might think of his HIV status. This fear drove him away from accessing healthcare.

In one of our conversations, Sara also noted how stigmatisation is related to the number of people that die in Lwandle. She said that she knew of "about 20 [people] who died last week" (Community Member3, 2015). Steven Robins notes that where "[t]he 'smell of death' [exists in a community, it] may also heighten stigmatisation, ritualised avoidance, and social and physical isolation" (Robins, 2006:318).. It is clearly not merely biological death that community members feared. Social death, which is conventionally linked to abandonment, stigmatisation and, discrimination, has also emerged in many HIV burdened communities (Robins, 2006). The constant threat of social or biological death breeds insecurity, affecting the capacity of individuals to find meaning in and mastery over their illness, as well as impeding their ability to rebuild self-esteem through agency and social reintegration.

Kuhle, for example, recounted how she had isolated herself after disclosing her HIV-positive status to her husband:

When my husband came back from work, he find out I'm not myself and he ask me and because I was so honest with him, I told him. [...] Then for me, I was thinking [his family are] not gonna accept me, because I'm like this now. And I'm not gonna have children anymore, oh, I didn't have the information. I was got blank, nothing. I know. I got stressed, stressed, stressed, over and over. And then I left him. I came back to my house, to stay alone. While I was in here staying alone [...]. Because I was HIV positive, I didn't have the information, or, or what is happening to my life [...]. He did accept me, but eh me, it was me.

I was not accepting myself. I, I didn't believe it. I didn't accept myself (Community Member1, 2015).

Kuhle's fear of being judged and rejected by her husband and his family, combined with her inability to deal with her HIV-positive status drove her to into isolation. This effectively barred her from the social support that her husband and his family might have provided her—for she acknowledges that he accepted her. As we saw, Kuhle was forced to make choices that that may have exposed her to HIV. Although she does not say as much, it is possible that she blamed herself for her HIV-positive status. Internal stigma of this kind is often linked to withdrawal, isolation and, self-blame or shame (Bogart *et al.*, 2013).

As suggested by Cebisa, the CHiPs supervisor I spent time with in the CHiPs offices, it seems what is needed is time and space and, for people living with HIV/AIDS to feel free enough to disclose when they are ready. Sara acknowledged the intense stress she went through after finding out her status “if you do accept it, it's gonna take time. Then it it's like, it's all in the mind, really! It's all in the mind” (Community Member3, 2015). This can be aided by developing an accommodating, tolerant, even welcoming culture. Laura Bogart and colleagues suggest that “[s]uch interventions can include raising awareness regarding how discrimination is harmful to the community fabric, as well as dispelling myths about HIV due to lack of knowledge about how it is transmitted” (Bogart *et al.*, 2013:852).

For all three of these individuals I have discussed in this section (Kuhle, Luvelen and Sara), the challenge of coming to terms with their HIV-positivity was made more difficult by the social circumstances in which they live. The tenuous social relations in their community severely restricted their freedoms and augmented their suffering and isolation, delaying ART initiation and retention in care. Paul Farmer and Arthur Kleinman explain that suffering reaches across individual-social bounds, infringing upon the life of both the community and the individual: “If pain is distress of the body, suffering is distress of the person and of his or her family and friends [...] the ethical and emotional responses to AIDS are collective representations of how societies deal with suffering” (1989:138). In Lwandle, the physical proximity of people living together, combined with the amount of unemployed people walking around the community during the day makes it a difficult place to keep secrets from neighbours. When stigmatisation leads to social death, it is understandable that some people choose social isolation. It is clear that inaccess to economic facilities can contribute to social decline and increase exposure to personal and social violence and, constrains individuals' ability to access healthcare for fear of physical, social or emotional abuse and rejection. The unequal

distribution of resources, both social and material, among people living in Lwandle has a considerable impact on their health outcomes.

5.2.4 Protective securities and the disability grant

One of the mechanisms the South African state is using to address severe inequities in access to education, healthcare and economic opportunity is through the social security grant system. Amounting to approximately 3.5% (R94 billion) of the national GDP, these grants reach 14 million beneficiaries per annum (Fakier, 2014). I am linking the use of social security grants to what Sen describes as protective securities which are there to “provide a social safety net for preventing the affected population from being reduced to abject misery, and in some cases even starvation and death” (Sen, 1999:40). As I have argued, high unemployment rates results in fewer resources being available to those who desperately need them. Social welfare grants have quickly become, whether by design or not, one mechanism of poverty alleviation, particularly amongst people living with HIV (Booyesen & Van der Berg, 2005). Grant eligibility is, however, determined by means-tests; people have to ‘qualify’ for grant assistance. For the sake of brevity, I focus on the disability grant, and how the notorious “health-welfare tradeoff confronting South Africans living with AIDS” is manifesting in Lwandle (Leclerc-Madlala, 2006:250).

When the Disability Grant was first introduced, it was generally accepted that people living with HIV/AIDS having a CD4 cell count of, or below 200 (≤ 200 cells/mm³) were eligible for the Disability Grant (De Paoli, Mills & Grønningsaeter, 2012). This ‘means-test’ structure has been highly criticised, especially those ART adherent clients who no longer qualify for the grant as their CD4 cell count increases. As Suzanne Leclerc-Madlala (2006:251) notes, for HIV-infected people “accessing a state grant only when one was seriously ill with AIDS [does] not make sense”. Marina De Paoli, Elizabeth Mills and Arne Grønningsaeter (2012) have shown that the structure of the grant has, at the very least, resulted in some PLWHs practising a form of ‘circumstantial’ non-adherence; allowing their CD4 count to temporarily drop below 200 for their eligibility test in order to requalify for the grant before continuing with their treatment immediately afterwards. This is detrimental to public health in the long and short term. In the long term, encouraging this behaviour may lead to ART resistant forms of HIV. In the short term it is risky for those who come into contact with HIV-positive persons practicing ‘circumstantial’ non-adherence. Consequently, the means-test is seen as a disincentive for ART adherence (Kagee & Delpont, 2010).

In Lwandle, according to the care providers I spoke to, several changes have been made to prevent ‘circumstantial’ non-adherence with regards to the HIV means-test. The CCWs I spoke with said that

people living with HIV/AIDS are no longer considered eligible for the grant: ‘You have to have TB or TB and HIV.’ Although I was unable to verify this with policy documents, alterations of this kind have occurred elsewhere (Leclerc-Madlala, 2006). In addition, the CCWs said that South African Social Services Agency (SASSA) accredited doctors only visit the clinic once a week. Previously any of the clinic’s doctors were able to bestow the grant to clients. However, the CCWs argued, these doctors were easily bribed into bestowing the grant to ineligible clients. The SASSA accredited doctors are believed to be less likely to accept bribes because they rotate and are unknown to community members.

In addition, the CCWs told me that accessing the grant entailed not only being tested for TB, HIV and CD4 cell counts, but also required travelling back and forth from the local municipality-run community hall to the clinic. Once filled out and signed at the community hall, clients must return to the clinic to receive confirmation of eligibility from a doctor. If they are deemed eligible then they must go back to the community hall to submit their application and, then wait for final approval to arrive in the post between 4 and 6 weeks later. The challenges of navigating this bureaucratic maze may have been one of the reasons why Diliza failed to access the grant. This was certainly the case for Sara, who considered whether or not to apply for the grant, saying, “I [can’t] help myself, to go to [to get the grant]. But I don’t know. I must go, I don’t know, any help” (Community Member3, 2015).

Nonetheless, I observed many instances where grant accessibility and eligibility continued to be manipulated and, activated as a form of poverty alleviation. Diliza’s friend, Xander, for example, secured the disability grant through ‘circumstantial’ adherence to his TB medication. That is, Xander only takes enough medication to prevent from falling gravely ill but not so much that he will forfeit the Disability Grant he is able to access because of being TB-infected. The CCW responsible for his ART and TB adherence told me that Xander, who had been on ART since 2007, had adhered to ART without defaulting for more than six months. However, when I saw him shortly after Diliza’s passing, he was about to start his third round of TB medication. The CCW told me, ‘he has received medication in the past, but stops taking it after a month or two, or as soon as he starts to feel better’. Petryna (2002) illustrates how making biological claims of the kind being made by HIV-infected people, or as in Xander’s case co-infected with HIV and TB, is closely linked to their ability to both understand and manipulate the complex medico-legal frameworks upon which social grants are conferred. Often these rely on measurable biological indicators. In more exceptional cases, community members living with HIV/AIDS rely on emotional manipulation to invoke pragmatic subjectivities through an understanding of the medico-legal framework upon which grant eligibility is established. I

encountered cases where HIV- and TB-infected were able to draw on local discourses (of suffering, disability and poverty) which technically defy the means-test structure to be seen as ‘worthy’ or eligible grant access.

Ruth, a single mother living in a two bedroom RDP house told me how she had moved from one city to another in search of work, before settling in Mtata Hill with her husband. After her husband abused and cheated on her, she then left him and moved to Lwandle where she started looking for “simple jobs, because I don’t have any skill for jobs here” (PLWH5, 2014). After working as a street vendor for some time which failed to provide her and her son with sufficient financial security, Ruth decided to look for opportunities to up-skill herself. After doing a course, Ruth worked in a clinic as a lay healthcare worker. Yet Ruth continued to access a disability grant by portraying a narrative of suffering and pain:

I say to you guys I am working but to them I am not working because I want government also support me. I want money to support me as other people they get [...]. I was [with the] SASSA [South African Social Security Agency] doctor yesterday. He was getting very shocked when I told him that in 1992 I get four babies, quadruplets, three boys one girl, after this child [indicating to her son] who all died in hospital. The doctor was very shocked. [...] And then I see now that I’ve got [diabetes], but I’m starting getting weak, I’m having pains, pains, pains, all the time, and its worse when it’s winter. I see my bones is paining, cramps, lot of things, ulcers (PLWH5, 2014).

Ruth’s manipulation of her financial, emotional and physical conditions in order to retain grant eligibility reflects her understanding of the medico-legal framework of social grants. Her knowledge of healthcare and disease, gained through being a care worker, would also have proved helpful. However, her claim was made all the more compelling by the way she presented herself to the doctor. Ruth presented herself as needy, as someone who although did not technically qualify for the grant needed one.

The South African Social Security Agency disability grant qualification list provides doctors with no guidelines regarding HIV/AIDS CD4 count or viral load, or other disabilities like having suffered from a stroke. It simply states that grants are available to any adult legal resident of South Africa that is unable to work or provide for themselves (South African Social Security Agency, 2014). By intentionally leaving the grant application process without biological markers SASSA has allowed not only subjectivity into the grant eligibility process but has allowed this process to become a highly contentious one (MacGregor, 2006). Doctors have been allowed to make decisions regarding grant applications based on the circumstances of each client. Indeed, Marina De Paoli and her colleagues

(2012) argue that many doctors understand the deprivation felt by many PLWHs and decide whether or not to bestow a grant based on the ‘relative’ poverty of their clients. Oliver Human has explored some of the challenges in dealing with “conditions which do not match the idealised, scientific environments espoused by policies, in that they are under-resourced and the life conditions of their clients make their adherence to a medical regiment difficult” (Human, 2008:5). Human (2008:15) goes to great lengths to show ‘how doctors deal with protocols’ and how sometimes “the act of diagnosis is based on contingent, material factors rather than universal syllogisms”.

For those who are unable find work, are not ‘sick enough’ to qualify for the grant and, who do not have the resources or knowledge to successfully manipulate the grant application process, there appears to be little in the way of protective securities. For Xander, access to the grant rested on his ability to strike a balance between adhering to his TB medication long enough to prevent himself from dying (and becoming extremely drug resistant) to adhering perfectly to his medication, which he seemed capable of doing with his ARVs.

In their research in two community in the Free State province in South Africa, Frikkie Booysen and Servaas Van der Berg (2005) found that “social grants play an important role in alleviating poverty [...]; and that the expansion of the coverage of these grants has made an important contribution to softening the economic impact of HIV/AIDS”. However, it should be of great concern to policy-makers when these grants are granted on the basis of ill-health and “behaviours that could compound the HIV [and TB] epidemic[s]” (Leclerc-Madlala, 2006:255). Yet, when understood in the context of a community where food security, lack of education and a high prevalence of violence and crime are everyday realities, it is perhaps understandable that these circumstances “can lead individuals to make choices that might seem unthinkable to those who live more comfortable lives” (Leclerc-Madlala, 2006:255).

5.3 Ending/s

I have used the narratives of a few HIV-positive individuals I came to know to explore how particular unfreedoms in the lives of many in Lwandle are shaped by forms of structural violence. Although experienced at individual level, these unfreedoms find their roots in the social economic and political structures which lay outside of the control of people living with HIV/AIDS. What is clear is that the inaccessibility of even the opportunities that Sen refers to as ‘core freedoms’ has a cascade-like effect, hindering access to other freedoms. As we saw with Diliza; his poverty inhibited access to transport, which in turn impeded his access to healthcare. In addition, the social climate of the community hindered the ability of HIV-infected people to disclose their HIV-positive status and to make use of

social networks. Diliza was for example, traded off from one house to another—abandoned by the people closest to him at the time he needed them most. For others like Luvellen, fear of stigma delayed initiation on HIV treatment and compromised ART adherence. For Kuhle, these difficulties were reflected in a broken narrative which suspended any form of social support she may have been extended by her previous husband and his family. Likewise Sara lived in silence, without friends and in constant fear of being rejected and shamed. Yet she benefitted from the relationships she had been able to establish with the nurses at one of the local public hospitals. These ‘pragmatic subjectivities’ (Brotherton, 2012) play an important part in HIV-infected people’s ability to access healthcare and other social services.

Finally I argued that the medico-legal framework around which protective securities, in the form of the grants, are dispensed is complicated by its obvious poverty alleviating capacity. It is seen as a disincentive to ART adherence and uptake because of the way that it hinges on false assumptions about employment and disability. These concerns are particularly pertinent when held together with the lived realities of HIV-infected people, like Diliza, who are unable to access the grant because of the bureaucratic maze it requires one to navigate. Successful uptake and adherence to ART rests significantly on the shoulders of the state and its ability to redress broader political, social and economic unfreedoms that continue to impede the choices available to people living in communities like Lwandle. As Sen suggests, “[t]he process of development [...] has to include the removal of each person’s deprivation[s]” (Sen, 1999:37). Without bringing “life-denying consequences of chronic poverty” (Gupta, 2012:4) to the forefront of public discussion, we cannot hope to successfully implement effective, large-scale treatment and care programmes or eventually overcome the epidemic.

Chapter 6 Summary, conclusions and recommendations

6.1 Broad emerging themes and issues

I started the first chapter of this thesis with a quote from the former head of the South African National Department of Health, Dr Thobile Mbengashe, who remarked on the extraordinary progress made by the National HIV/AIDS programme through the public health sector. The programmes' progress is undeniable; in the past decade it has exponentially expanded to become the largest antiretroviral treatment (ART) programme worldwide, with more than one third of South Africa's HIV/AIDS-infected population on ART (Simelela & Venter, 2014). Dr Mbengashe went on to say that the South African government will continue to increase its spending on ART treatment provision in order to "ensure that it covers 80% of people who need ARVs by 2016" (Mbengashe, 2012 as cited in Bodibe, 2012).

However, as I have illustrated throughout this thesis, more biotechnologies or greater availability of ART do not automatically lead to better health outcomes for everyone. Here I draw on two points of concern raised by Margaret Lock and Vinh-Kim Nguyen (2010) regarding the misconception that increased access to biotechnologies will necessarily result in better health outcomes for all. Firstly, they argue, human bodies cannot be detached from their context. Instead, they should be understood as "the products of [...] ceaseless interactions among human beings, their environments, and the social and political milieu in which they live" (Lock & Nguyen, 2010:1). Thus, people are not only biologically different, but their environmental and social context plays an important role in how they react to biotechnologies. Second, they point out, "biotechnologies are not autonomous entities: their development and implementation are enmeshed with medical, social, and political interests that have practical and moral consequences". Biotechnologies are utilised in a particular manner with a specific purpose in mind. Divorcing biotechnologies from the purpose they are used for is thus disingenuous and can mask the oftentimes economic or scientific motivations that undergird their use. Through a thick description of the CHiPs and the CCWs' practices of care provision and deployment of biotechnologies, the thesis has aimed to reveal some of the challenges that lie beyond merely increasing the accessibility of ART to people living with HIV/AIDS.

As I argued at the start of chapter 1, the South African Department of Health is understaffed and under resourced. Increasing the amount of HIV-infected people receiving ART will, despite the benefits it may hold for HIV-infected individuals, increase the strain on an already strained public health sector, effectively decreasing the quality and availability of care. The HPTN 071 (PopART) clinical trial has been designed to address some of these challenges by attempting to introduce a new

continuum of HIV care into Lwandle, the site in which I conducted my research, and other trial sites. The trial organisers recognise that retaining people within the HIV-continuum of care over time has become the main challenge to ART scale up, and thus have aimed to develop ways to encourage linkage, adherence and retention in care, in part through the provision of new community care workers (the CHiPs) to help work with existing community care workers. This is already different to simply making more ART available, because it recognises that higher coverage of ART requires concurrent increases in the capacity and range of healthcare services to help manage the increased patient-load in the public health sector. Yet despite these support structures and the increased capacity to manage HIV-infected people's ART initiation and adherence, the CCWs and CHiPs' healthcare practices were often hindered by their client's physical, social and economic circumstances.

6.2 Physical, Social and Economic Context

In the thesis, I have described Lwandle as a 'landscape of constraint,' where the indelible effects of Apartheid continue to shape the face of healthcare and social services provision. Migration, unemployment and informal housing have led to high risk behaviour for HIV-infection and exposure to pollution, poor sanitation and as a result infectious diseases. In chapter 5, following Amartya Sen (1999), I go on to describe how particular 'unfreedoms' or restrictions on people's possible choices and opportunities in life can shape their future decisions and access to other necessary freedoms. For example, I considered how for some of my participants, the inability to participate in the economy restricted their access to appropriate healthcare practices and food security and, sometimes pushed them into making poor healthcare decisions or, prevented them from adhering to their medication. Sen's multidimensional understanding of poverty serves to illustrate how people often need access to a wide array of freedoms in order to be successful and productive citizens—or to benefit easier access to ART. The physical vulnerability that comes with living in poor housing conditions with poor sanitation combine with a lack of economic opportunity to constrain people's healthcare choices.

In addition to shaping choices and possibilities of individuals, I argue that CHiPs and CCWs' awareness of and sensitivity to their clients' physical, social, emotional, spiritual and economic needs led them to alter/adapt their healthcare practices and sometimes even their protocol in order to meet these needs. For example, the CHiPs altered their working hours in order to accommodate the vast number of people who were either at work or looking for work during their working hours. Similarly, the CCWs arranged to meet their clients outside of their working hours where their clients worked during the same hours the CCWs wanted to visit them. At other times these adaptations were a direct response to their client's immediate needs, such as when the caregivers gave their clients food or money. Although the caregivers adapted/alterd their care practices in order to meet their client's

needs, the client's themselves also used the caregivers' biotechnologies in ways other than which they were intended—for example, to test the efficacy of prayer as healing. These various forms of healthcare and healing appear alongside one another in sometimes uneasy, complex and layered ways and find their root, at least in part, in South Africa's slow and fragmented response to the HIV/AIDS epidemic at a policy level—resulting in considerable doubt and scepticism regarding the use of ART, particularly amongst poor, uneducated people.

As I argue in chapter 4, this political climate continues to shape the way that HIV/AIDS is understood and treated, particularly in places like Lwandle. In this context, CHiPs and the CCWs must negotiate between various healthcare and healing practices and knowledges in order to provide their clients with care. Thus, I argue, the caregivers often live in translation; by which I mean that they are involved in translating between multiple registers of understanding and priorities for action in their everyday encounters with their clients. Caregivers carry as well as confront these different understandings of health and healthcare, sometimes deploying more than biomedical forms of care. These various knowledges and forms of care appear alongside and overlap one another. In this space, caregivers not only encounter other modalities of health and healthcare, but also help guide their clients to make informed decisions about their well-being and offer necessary forms of support. The caregivers' sensitivity to both the diverse modalities of care with which their clients engage and to the broader structural constraints of life in Lwandle helps to mitigate the negative effects they might have on individual bodies as they negotiate appropriate healthcare practices with their clients.

6.3 Practical and Moral Consequences

However, as much as CCWs and the CHiPs are in a relationship with their clients they are also in a relationship with their respective organisations. Working in their respective organisations involves converting their clients' testing, linkage-to-care and/or adherence forms into statistics and those statistics into stipends, or salaries (Reynolds-Whyte et al., 2014:64). In addition to their care work, both CCWs and CHiPs' are expected to produce particular kinds of evidence. The CHiPs produce evidence by meeting their quota of HIV-tests and households enumerated for the month. They record this evidence on their electronic data-capturing devices which they carry with them into Lwandle. Similarly, the CCWs must conduct a certain amount of follow-ups and/or recalls every month. These data are recorded on their client's adherence forms which are collated and submitted to their supervisors at the end of each month. If they fail to follow-up, monitor and, enumerate the number of clients set out by their respective organisations, both sets of caregivers face the possibility of foregoing their stipend and/or salary and risk being fired.

As I suggested in chapter 3, the pressure to provide care and produce evidence sometimes led the caregivers to alter their healthcare practices in ways that not only worked around the fringes of their organisations' protocols, but in ways that came at great personal physical, financial and emotional costs. For example, caregivers often developed close relationships with their clients and spoke of them as friends or resorted to embodying identities other than being caregivers in order to protect their clients from stigmatisation or public forms of disclosure. These relationships must be maintained over disease lifecycle and, often requires further adaptations and discretion.

While I argue that these actions are necessary to retain high linkage to care and retention in care rates, and therefore are central to the success of the PopART trial, two ethical concerns need to be raised. Firstly, if caregivers provide care at personal cost they put themselves, their clients, and their families at risk, and potentially forego what personal/community development they have to offer their community (Sips *et al.*, 2014). The ethical concern here is amplified by the fact that most care workers are not in positions of permanent employment. During my time with the caregivers, particularly the CCWs, they expressed a great desire to be seen as permanent employees of the South African National Department of Health. They appealed to my experience of their care work to illustrate the difficulties involved in their daily labour and lamented the fact that neither the state nor the organisations they work for properly understood how much their care work cost them personally. I often asked them why they continued to work under these circumstances if it cost them so much. Some indicated that there was no other work available, while others suggested that being a caregiver, as was suggested by the PopART trial manager in chapter 3, is merely a stepping-stone to other forms of work.

Viewing their care work in this way links up with recent work completed by Dineo Seabe (2014) who argues that people often volunteer because it is temporary, it opens doors to learning a particular skill set and, provides them with experiences and expertise that will help them get a better job. Alongside this more pragmatic stance were many CCWs and CHiPs who were enthusiastic about their work, who felt that they were making a difference and who insisted that they would continue to work as caregivers for as long as they are able. The significant role the caregivers play in navigating between the different physical, social, economic needs as well as between different knowledge systems throughout the implementation of the PopART trial emphasizes the need for South African policy-makers to consider formalising the position of community- and home-based carers within the public health sector.

Secondly, following Madiega and colleagues (2013), the caregivers are tasked with negotiating the practical and ethical roles that come with both providing care and producing evidence. Not only does this undertaking often result “in erasing the ‘ordered separations upon which formal ethics and

scientific evidence rest” (Madiega *et al.*, 2013), such as when the obligation to produce evidence out of providing care becomes entangled with their personal social and moral obligations to provide care for the sake of caring. In this context, what evidence is produced and by what means is a central concern that needs to be raised. Similarly, the alterations or adaptations that caregivers make in order to both meet their client’s healthcare needs as well as produce evidence, are all the more complex when they are made in response to clients’ appeals to the caregiver’s humanity or emotions. At times like these the boundary between caring as a necessary condition of employment and caring as a condition of the heart fell apart. Not only does this indicate that the caregivers do not take up biomedical care practices unthinkingly, but adapt and change these practices as they see fit, often in order to provide their clients with care. It also indicates that caregivers, like their clients, are not complicit, ‘docile’ bodies that become the subjects of healthcare programmes; rather they take up their care practices with their own motivations. Sometimes these motivations align with their organisations’ motives, and sometimes they do not. This is an important consideration for global health programmes that hire local bodies to carry out their intervention programmes.

This thesis then begins to explore some of the practical implications of implementing international clinical trial research in resource limited settings in South Africa. Although the focus of this research is on the practice and access of healthcare, it signals much broader questions around, for example, the ethics of the simultaneous provision of care and production of evidence for both the care providers/evidence producers and the community members who become the subjects of this care provision and evidence production. Further, it speaks to broader ethical concerns about the inequalities inherent in global health research and intervention in resource constrained settings (Crane 2013). CCWs and other marginalised groups are relied upon to pick up the slack, to use their intimate knowledge of the local context in order to both provide care and produce evidence, to navigate between various forms of knowledge and to mitigate the effects of ‘structural violence’ to influence individuals’ ability to access healthcare.

6.4 Some Implications

At times this thesis may have appeared to be porous as I moved between different care providers and organisations, between care protocol and practice, between treatment provision and treatment reception. By drawing on the experiences and understandings of both healthcare providers and people living with HIV/AIDS, my aim has been to describe the convergence of complex layers of health, knowledge, authority and care to explore the hindrances and limits of extending and accessing a full spectrum of the healthcare in Lwandle.

Steven Feierman and colleagues (2010:127) have challenged global health programmes to make visible the local contexts of healthcare provision and to incorporate this knowledge into future programme development. To return to Lock and Nguyen's (2010) first point, I would argue more broadly that there is a need for a shift in focus from the provision of more biotechnologies of care to one that addresses a far broader landscape of care provision. That is, if HIV/AIDS researchers aim to curb the devastation that HIV has caused in these 'landscapes of constraint', it is necessary that they understand "that more biomedicine alone will not be enough to eradicate a given situation, and that a far more radical and far-reaching solution will inevitably be required" (Lock & Nguyen, 2010:109). My hope is that this research will serve to unblock the upward flow of knowledge of healthcare provision at the local level about the "realities of 'patients' lives" and the "conditions of treatment" to global health programmes and contribute to the development of future context-sensitive healthcare provision programmes (Feierman, Kleinman, Stewart, Farmer & Das, 2010:122;123).

Reference List

- Akintola, O. & Hangulu, L. 2014. Infection control in home-based care for people living with HIV/AIDS/TB in South Africa: An exploratory study. *Global public health*, 9(4):382–393.
- Ashforth, A. 2005. Witchcraft, violence, and democracy in South Africa. Chicago: University of Chicago Press.
- Ashforth, A. & Nattrass, N. 2005. Ambiguities of “culture” and the antiretroviral rollout in South Africa. *Social Dynamics*, 31(2):285–303.
- Ayles, H.M., Sismanidis, C., Beyers, N., Hayes, R.J. & Godfrey-Faussett, P. 2008. ZAMSTAR, The Zambia South Africa TB and HIV Reduction Study: Design of a 2 x 2 factorial community randomized trial. *Trials*, 9(1):63.
- Barchiesi, F. 2008. Wage labour, precarious employment, and social inclusion in the making of South Africa’s postapartheid transition. *African Studies Review*, 51(2):119–142.
- Barnett, T. & Whiteside, A. 2002. Poverty and HIV/AIDS: Impact, coping and mitigation policy, in G.A. Cornia (ed.). *AIDS, Public Policy and Child Well-Being*. Florence: UNICEF.
- Bärnighausen, T., Tanser, F., Herbst, K., Mutevedzi, T., Mossong, J. & Newell, M.-L. 2013. Structural barriers to antiretroviral treatment: A study using population-based CD4 cell count and linked antiretroviral treatment programme data. *The Lancet*. 382(S5):5.
- Bärnighausen, T., Eyal, N. & Wikler, D. 2014. HIV treatment-as-prevention research at a crossroads. *PLoS Medicine*. 11(6):1–4.
- Bezuidenhout, A. & Fakier, K. 2006. Maria’s Burden: Contract cleaning and the crisis of social reproduction in post-apartheid South Africa. *Antipode*, 38(3):462–485.
- Biehl, J.G. 2005. *Vita: Life in a zone of social abandonment*. Berkeley: University of California Press.
- Biehl, J.G., Coutinho, D. & Outeiro, A.L. 2001. Technology and effect: HIV/AIDS testing in Brazil. *Culture, Medicine and Psychiatry*, 25(1):87–129.
- Bodibe, K. 2012. NSP 2012-2016 Living with AIDS # 511. [Online]. Available: <http://www.health-e.org.za/2012/04/12/nsp-2012-%C2%80%C2%93-2016-living-with-aids-511/> [2015, November 10].
- Bogart, L.M., Chetty, S., Giddy, J., Sypek, A., Sticklor, L., Walensky, R.P., Losina, E., Katz, J.N., et al. 2013. Barriers to care among people living with HIV in South Africa: Contrasts between patient and healthcare provider perspectives. *AIDS Care*, 25(7):843–853.

- Booyesen, F. & Van der Berg, S. 2005. The role of social grants in mitigating the socio-economic impact of HIV/AIDS in two Free State communities. *South African Journal of Economics*, 73:545–563.
- Brotherton, P.S. 2012. *Revolutionary medicine: Health and the body in post-Soviet Cuba*. Durham: Duke University Press.
- Budlender, D. & Lund, F. 2012. South Africa: A legacy of family disruption, in S. Razavi (ed.). *Seen, heard and counted: Rethinking care in a development context*. Malden: Wiley-Blackwell.
- Casale, D. & Desmond, C. 2007. The economic well-being of the family: Households' access to resources in South Africa, 1995–2003, in A.Y. Amoateng & T.B. Heaton (eds.). *Families and households in post-apartheid South Africa: Socio-demographic perspectives*. Cape Town: HSRC Press.
- Casale, D. & Posel, D. 2002. The continued feminisation of the labour force in South Africa: An analysis of recent data and trends. *South African Journal of Economics*, 70(1):156–184.
- De Cock, K.M. 2014. Plus ca change ... Antiretroviral therapy, HIV prevention, and the HIV treatment cascade. *Clinical Infectious Diseases*, 58(7):1012–4.
- Coetzee, G. 2002. Formal retail as a strategy to enhance the quality of life in marginalised communities. Unpublished MA thesis. Stellenbosch: University of Stellenbosch [Online]. Available: <http://scholar.sun.ac.za/handle/10019.1/52851> [2015, October 18].
- Colvin, C.J. 2012. True believers or modern believers: HIV science and the work of the Dr Rath Foundation, in S. Levine (ed.). *Medicine and the Politics of Knowledge*. Cape Town: HSRC Press: 33–53.
- Colvin, C.J. & Robins, S. 2009. Social movements and HIV/AIDS in South Africa, in P. Rohleder, L. Swartz, S.C. Kalichman, C. Leickness (eds.). *HIV/AIDS in South Africa 25 Years On*. New York: Springer: 155–164.
- Colvin, C.J., Robins, S. & Leavens, J. 2010. Grounding “responsibilisation talk”: Masculinities, citizenship and HIV in Cape Town, South Africa. *The Journal of Development Studies*, 46(7):1179–1195.
- Comaroff, J. & Comaroff, J.L. 2002. Alien-nation: Zombies, immigrants, and millennial capitalism. *The South Atlantic Quarterly*, 101(4):779–805.
- Coovadia, H., Jewkes, R., Barron, P., Sanders, D. & McIntyre, D. 2009. The health and health system of South Africa: Historical roots of current public health challenges. *The Lancet*, 374:817–834.

- le Cordeur, M. 2015. SA's unemployment rate hits 12-year high. Fin24. [Online]. Available: <http://www.fin24.com/Economy/SAs-unemployment-rate-hits-12-year-high-20150526> [2015, August 24].
- Coveney, J. 1998. The government and ethics of health promotion: The importance of Michel Foucault. *Health Education Research*, 13(3):459–468.
- Crane, J.T. 2013. Scrambling for Africa: AIDS, expertise, and the rise of American global health science. New York: Cornell University Press.
- Dageid, W. & Duckert, F. 2008. Balancing between normality and social death: Black, rural, South African women coping with HIV/AIDS. *Qualitative Health Research*, 18(2):182–195.
- Daly, M. & Lewis, J. 2000. The concept of social care and the analysis of contemporary welfare states. *The British Journal of Sociology*, 51(2):281–298.
- Danermark, B., Ekström, M., Jakobsen, L. & Karlsson, J.C. 2002. Introduction, in B. Danermark, M. Ekström, L. Jakobsen, & J.C. Karlsson (eds.). *Explaining society: Critical realism in the social sciences*. London: Routledge: Taylor & Francis Group: 1–13.
- Daniel, L. & Squire, C. 2009. Experiences of people living with HIV, in P. Rohleder, L. Swartz, S.C. Kalichman, & L.C. Simbayi (eds.). *HIV/AIDS in South Africa 25 Years On*. New York: Springer: 255–271.
- Deacon, H., Uys, L. & Mohlahlane, R. 2009. HIV and stigma in South Africa, in P. Rohleder, L. Swartz, S.C. Kalichman, & L.C. Simbayi (eds.). *HIV/AIDS in South Africa 25 Years On*. New York: Springer: 105–120.
- Demombynes, G. & Özler, B. 2006. Crime and local inequality in South Africa, in H. Bhorat & R. Kanbur (eds.). *Poverty and policy in post-apartheid South Africa*. Cape Town: HSRC Press: 288-320.
- Dennill, K. 2012. Primary health care in southern Africa, in K. Dennill & K. Rendall-Mkosi (eds.). *Primary health care in southern Africa: A comprehensive approach*. Third Edition. Cape Town: Oxford University Press: 45–89.
- Department of Health. 2001. National guideline on home-based care and community- based care. Pretoria: Republic of South Africa [Online]. Available: <http://www.npi-connect.net/documents/592341/749044/R1+%26+2+SOTA+-+National+Guidelines+for+Home-Based+%26+Community-Based+Care>.

- Department of Health. 2009. Community care worker management policy framework. Tshwane: Republic of South Africa [Online]. Available: <http://www.cabsa.org.za/sites/default/files/2009%20-%20Community%20Care%20Worker%20Management%20Policy%20Framework.pdf> [2015, October 19].
- Department of Health. 2011. Human resources for health South Africa: HRH Strategy for the Health Sector: 2012/13 - 2016-17. Pretoria: Republic of South Africa [Online]. Available: http://www.gov.za/sites/www.gov.za/files/hrh_strategy_0.pdf [2015, October 13].
- Department of Health. 2015. National consolidated guidelines: For the prevention of mother-to-child transmission of HIV (PMTCT) and the management of HIV in children, adolescents and adults. Pretoria: Republic of South Africa [Online]. Available: www.kznhealth.gov.za/family/HIV-Guidelines-Jan2015.pdf [2015, July 24].
- Digby, A. & Sweet, H. 2002. Nurses as culture brokers in twentieth-century South Africa, in W. Ernst (ed.). *Plural medicine, tradition and modernity, 1800-2000*. London: Routledge: Taylor & Francis: 113–129.
- DTTC. 2011. Communities selected for groundbreaking research to reduce HIV transmission. Desmond Tutu TB Centre [Online]. Available: http://sun025.sun.ac.za/portal/page/portal/Health_Sciences/English/Centres/dttc/Read_more_2012/Pop_art_Feb_2013 [2015, October 14].
- DTTC. 2013. Brief Overview of Ikhwezi: Broad Brush Survey January-April 2013. Unpublished. Cape Town: Desmond Tutu TB Centre.
- Eaton, E.F., Saag, M.S. & Mugavero, M. 2014. Engagement in human immunodeficiency virus care: linkage, retention, and antiretroviral therapy adherence. *Infectious Disease Clinics of North America*, 28(3):355–369.
- Emmett, T. 1992. Origins and causes of squatting in the Hottentots Holland Basin, in T. Emmett (ed.). *Squatting in the Hottentots Holland Basin: Perspectives on a South African social issue*. Pretoria: Human Sciences Research Council: 27–70.
- Erasmus, J.C. 2005. Religion and social transformation: A case study from South Africa. *Transformation*, 22(3):139–148.

- Etheridge, J. 2014a. Evictees enraged by broken promises. [Online]. Available: http://www.iol.co.za/news/politics/evictees-enraged-by-broken-promises-1.1723089#.U_OdnPm4VCg [2014, August 19].
- Etheridge, J. 2014b. Lwandle evictions brutal: NGO. [Online]. Available: http://www.iol.co.za/news/politics/lwandle-evictions-brutal-ngo-1.1723209#.U_Odmvm4VCg [2014, August 19].
- Etheridge, J. 2014c. Sanral reprimanded for Lwandle evictions - Western Cape. [Online]. Available: http://www.iol.co.za/news/south-africa/western-cape/sanral-reprimanded-for-lwandle-evictions-1.1723960#.U_ObXPm4VCg [2014, August 19].
- Etheridge, J. 2014d. Sheriff tells of Lwandle interdict. [Online]. Available: http://www.iol.co.za/news/crime-courts/sheriff-tells-of-lwandle-interdict-1.1723764#.U_Odjvm4VCh [2014, August 19].
- Fairhead, J., Leach, M. & Small, M. 2006. Where techno-science meets poverty: Medical research and the economy of blood in The Gambia, West Africa. *Social Science and Medicine*, 63(4):1109–1120.
- Fakier, K. 2014. The community work programme and care in South Africa, in K. Fakier & E. Ehmke (eds.). *Socio-Economic Insecurity in Emerging Economies: Building New Spaces*. New York: Routledge: 133–146.
- Fakier, K. & Cock, J. 2009. A gendered analysis of the crisis of social reproduction in contemporary South Africa. *International Feminist Journal of Politics*, 11(3):353–371.
- Farmer, P.E. 2003. *Pathologies of power: Health, human rights, and the new war on the poor*. California: University of California Press.
- Farmer, P.E. & Kleinman, A. 1989. AIDS as Human Suffering. *Daedalus*, 18(2):135–160.
- Fassin, D. 2007. *When bodies remember: Experiences and politics of AIDS in South Africa*. Berkeley: University of California Press.
- Feierman, S. 1985. Struggles for control: The social roots of health and healing in modern Africa. *African Studies Review*, 28(2-3):73–147.
- Feierman, S. & Janzen, J.M. 1992. Introduction, in Feierman & J.M. Janzen (eds.). *The Social Basis of Health & Healing in Africa*. Berkeley: University of California Press: 1–29.

- Feierman, S., Kleinman, A., Stewart, K., Farmer, P.E. & Das, V. 2010. Anthropology, knowledge-flows and global health. *Global Public Health*, 5(2):122–128.
- Finkler, K. 2004. Biomedicine globalized and localized: Western medical practices in an outpatient clinic of a Mexican hospital. *Social Science and Medicine*. 59(10):2037–2051.
- Fisher, B. & Tronto, J.C. 1990. Toward a feminist theory of caring, in E.K. Abel & M. Nelson (eds.). *Circles of care: Work and identity in women's lives*. Albany: State University of New York Press: 35–62.
- Flint, K.E. 2008. *Healing Traditions: African Medicine, Cultural Exchange, & Competition in South Africa, 1820-1948*. Ohio: Ohio University Press.
- Folbre, N. 2008. Reforming Care. *Politics & Society*, 36(3):373–387.
- Foucault, M. 1991. Governmentality. In G. Burchell, C. Gordon, & P. Miller (eds.). *The Foucault effect: Studies in governmentality: With two lectures by and an interview with Michel Foucault*. Chicago: University of Chicago Press: 87–104.
- Gardner, E.M., McLees, M.P., Steiner, J.F., Del Rio, C. & Burman, W.J. 2011. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. *Clinical Infectious Diseases*, 52(6):793–800.
- Gibson, D. & Oosthuysen, E. 2012. Biomedical and traditional knowledge in the search for healing in Namibia, in S. Levine (ed.). *Medicine and the Politics of Knowledge*. Cape Town: HSRC Press: 79–97.
- Govender, T., Barnes, J.M. & Pieper, C.H. 2010. Living in low-cost housing settlements in Cape Town, South Africa—The epidemiological characteristics associated with increased health vulnerability. *Journal of Urban Health*, 87(6):899–911.
- Gupta, A. 2012. *Red tape: Bureaucracy, structural violence and poverty in India*. Durham: Duke University Press.
- Haddinot, G. Personal interview. 21 October, Tygervalley.
- Hardon, A.P., Akurut, D., Comoro, C., Ekezie, C., Irunde, H.F., Gerrits, T., Kinsman, J., Kwasa, R., et al. 2007. Hunger, waiting time and transport costs: Time to confront challenges to ART adherence in Africa. *AIDS Care*, 19(5):658–665.
- Harvey, D. 1989. *The condition of Postmodernity: An Inquiry into the Conditions of Cultural Change*. Cambridge: Blackwell Publishers.

- Hayes, R.J. & Fidler, S. 2012. HPTN 071: population effects of antiretroviral therapy to reduce HIV transmission (PopART): a cluster-randomized trial of the impact of a combination. (HPTN 071). HIV Prevention Trials Network. [Online]. Available: http://www.hptn.org/web%20documents/HPTN071/071ProtocolV1_26Oct2012.pdf [2013, October 28].
- Heap, P. 1993. *The Story of Hottentots Holland: Somerset West, the Strand, Gordan's Bay and Sir Lowry's Pass*. Third Edition. Cape Town: National Book Printers.
- Helderberg Hospice: About Hospice. 2014. [Online]. Available: <http://helderberghospice.org.za/about-hospice/> [2015, April 04].
- Henderson, P.C. 2011. *AIDS, Intimacy and Care in Rural KwaZulu-Natal: A kinship of bones*. Amsterdam: Amsterdam University Press.
- Hick, R. 2014. Poverty as Capability Deprivation: Conceptualising and Measuring Poverty in Contemporary Europe. *European Journal of Sociology*, 55(3):295–323.
- Hochschild, A. 2012. *The Managed Heart: Commercialization of Human Feeling*. Third Edition. Berkeley: University of California Press.
- Homan, R., Searle, C., Esu-Williams, E., Aguirre, M., Mafata, S., Meidany, F., Oosthuizen, C. & Towel, L. 2005. *Exploring the Role of Family Caregivers and Home-Based Care programs in Meeting the Needs of People Living with HIV/AIDS*. Johannesburg: Population Council. [Online]. Available: <http://www.popcouncil.org/uploads/pdfs/horizons/hbccrgvrsa.pdf>. [2015, April 14].
- HPTN. 2012. About the HPTN. [Online], Available: <http://www.hptn.org/AboutHPTN.htm> [2014, December 23].
- HPTN. 2013. Major Study of Combination HIV Prevention Gets Underway HPTN 071 (PopART) Seeks to Reduce HIV Transmission. Stellenbosch University. [Online]. Available: http://sun025.sun.ac.za/portal/page/portal/Health_Sciences/English/Centres/dttc/Read_more_2012/021. [2015, September 29].
- Huggins, G. 1992. Squatting in context, in T. Emmett (ed.). *Squatting in the Hottentots Holland Basin: Perspectives on a South African social issue*. Pretoria: Human Sciences Research Council. 17–26.

- Human, O. 2008. Between Policy and Patients Protocols and Practice in HIV/AIDS Treatment. Stellenbosch: University of Stellenbosch [Online]. Available: <http://hdl.handle.net/10019.1/2553> [2013, July 31].
- Human, O. 2012. The rings around Jonathan's eyes: HIV and AIDS medicine at the margins of administration, in S. Levine (ed.). *Medicine and the Politics of Knowledge*. Cape Town: HSRC Press: 15–31.
- Hunt, N.R. 1999. A Colonial Lexicon: Of birth ritual, medicalization, and mobility in the Congo. Durham: Duke University Press.
- Hunter, M. 2002. The materiality of everyday sex: Thinking beyond 'prostitution'. *African Studies*, 61(1):99–120.
- Hunter, N. 2014. Developing a model for analysis of home-based care activities using South African data, in V. Reddy, S. Meyer, T. Shefer, & T. Meyiwa (eds.). *Care in Context: Transnational Gender Perspectives*. Cape Town: HSRC Press. 228–245.
- Isaksen, L., Devi, U. & Hochschild, A. 2008. Global Care Crisis: A Mother and Child's-Eye View. *Sociologia, Problemas E Practicas*, 56:61–83.
- Jezewski, M.A. 1990. Culture brokering in migrant farmworker health care. *Western Journal of Nursing Research*. 12(4):497–513.
- Jezewski, M.A. 1995. Evolution of grounded theory: Conflict resolution through culture brokering. *Advanced Nursing Science*, 17(3):14–30.
- Kagee, A. & Delport, T. 2010. Barriers to adherence to antiretroviral treatment: The perspectives of patient advocates. *Journal of Health Psychology*, 15(7):1001–1011.
- Kerber, K.J., de Graft-Johnson, J.E., Bhutta, Z.A., Okong, P., Starrs, A. & Lawn, J.E. 2007. Continuum of care for maternal, newborn, and child health: from slogan to service delivery. *The Lancet*, 370(9595):1358–1369.
- Kingori, P., Muchimba, M., Sikateyo, B., Amadi, B. & Kelly, P. 2010. 'Rumours' and clinical trials: A retrospective examination of a paediatric malnutrition study in Zambia, southern Africa. *BMC Public Health*, 10:556.
- Klaits, F. 2010. Death in a church of life: Moral passion during Botswana's time of AIDS. Berkeley: University of California Press.

- Kok, P. & Motloch, J. 1992. Squatters' needs and preferences, in T. Emmett (ed.). *Squatting in the Hottentots Holland Basin: Perspectives on a South African social issue*. Pretoria: Human Sciences Research Council: 149–202.
- Kranzer, K., Lewis, J.J., Ford, N., Zeinecker, J., Orrell, C., Lawn, S.D., Bekker, L.-G. & Wood, R. 2011. Treatment interruption in a primary care antiretroviral therapy programme in South Africa: cohort analysis of trends and risk factors. *Journal of Acquired Immune Deficiency Syndromes*, 55(3):e17–23.
- Leclerc-Madlala, S. 2006. “We will eat when I get the grant”: Negotiating AIDS, poverty and antiretroviral treatment in South Africa. *African Journal of AIDS Research*, 5(3):249–256.
- Levine, S. 2012a. Medicine and the politics of knowledge: Beyond the microscope, in S. Levine (ed.). *Medicine and the Politics of Knowledge*. Cape Town: HSRC Press: 1–12.
- Levine, S. 2012b. Testing knowledge: Legitimacy, healing and medicine in South Africa, in S. Levine (ed.). *Medicine and the Politics of Knowledge*. Cape Town: HSRC Press: 55–76.
- Livingston, J. 2012. *Improvising medicine: An African oncology ward in an emerging cancer epidemic*. Durham: Duke University Press.
- Lock, M.M. 2001. The tempering of medical anthropology: Troubling natural categories. *Medical Anthropology Quarterly*, 15(4):478–492.
- Lock, M.M. & Nguyen, V.-K. 2010. *An anthropology of biomedicine*. Malden: Wiley-Blackwell.
- MacGregor, H. 2006. “The grant is what I eat”: The politics of social security and disability in the post-Apartheid South African state. *Journal of Biosocial Science*, 38(01):43–55.
- MacPhail, C., Pettifor, A. & Rees, H. 2007. Context of risk: HIV/AIDS among young people in Africa and prevention opportunities. *Africa Insight*, 37(3):473–492.
- Madiega, P.A., Jones, G., Prince, R.J. & Geissler, P.W. 2013. “She”s My Sister-In-Law, My Visitor, My Friend’ – Challenges of Staff Identity in Home Follow-Up in an HIV Trial in Western Kenya. *Developing World Bioethics*. 13(1):21–29.
- Malan, M. 2014. Community healthworkers shafted by SA’s policy shambles. [Online]. Available: <http://mg.co.za/article/2014-09-11-community-health-workers-shafted-by-sas-policy-shambles> [2015, August 24].
- Marais, H. 2011. *South Africa Pushed to the Limit: The political economy of change*. Cape Town: Zed Books.

- Matholeni, N. 2012. Judgemental attitudes in pastoral care: Spiritual counselling for women living positively with HIV and AIDS in the Township of Lwandle. Stellenbosch: Stellenbosch University [Online]. Available: scholar.sun.ac.za/handle/10019.1/71620 [2015, August 27].
- Mayosi, B.M., Lawn, J.E., Van Niekerk, A., Bradshaw, D., Abdool Karim, S.S. & Coovadia, H.M. 2012. Health in South Africa: Changes and challenges since 2009. *The Lancet*, 380(9858):2029–2043.
- Mbembe, A. 2004. Aesthetics of Superfluity. *Public Culture*, 16(3):373–405.
- Mgijima, B. & Buthelezi, V. 2006. Mapping museum-community relations in Lwandle. *Journal of Southern African Studies*, 32(4):795–806.
- Micek, M.A., Gimbel-Sherr, K., Baptista, A.J., Matediana, E., Montoya, P., Pfeiffer, J., Melo, A., Gimbel-Sherr, S., et al. 2009. Loss to Follow-Up of Adults in Public HIV Care Systems in Central Mozambique: Identifying Obstacles to Treatment. *Journal of Acquired Immune Deficiency Syndromes*, 52(3):397–405.
- Milford, C., Barsdorf, N. & Kafaar, Z. 2007. What should South African HIV vaccine trials do about social harms? *AIDS Care*, 19(9):1110–1117.
- Millen, J. V, Irwin, A. & Kim, J.Y. 2000. Introduction: What is growing? What is dying? in J. V. Millen., A. Irwin. & J.Y. Kim (eds.). *Dying for growth: Global inequality and the health of the poor*. Canada: Common Courage Press: 3–10.
- Molapo, S.S. 2012. On understandings of HIV/AIDS: Conversations with migrant mineworkers at Monyakeng. Unpublished doctoral dissertation. Johannesburg: University of the Witwatersrand [Online]. Available: <http://mobile.wiredspace.wits.ac.za/bitstream/handle/10539/12018/MAIN%20THESIS.pdf?sequence=2> [2015, August 11].
- Moses, J.W. & Knutsen, T.L. 2007. *Ways of knowing: Competing methodologies in Social and Political Research*. New York: Palgrave Macmillan.
- Moss, P., Boddy, J. & Cameron, C. 2006. Care work, present and future: Introduction, in P. Moss, J. Boddy, & C. Cameron (eds.). *Care Work: Present and future*. London: Routledge: Taylor & Francis Group. 3–17.
- Murray, N. & Witz, L. 2013. Camp Lwandle: Rehabilitating a migrant labour hostel at the seaside. *Social Dynamics*, 39(1):51–74.

- Murray, N. & Witz, L. 2014. Hostels, homes, museum: Memorialising migrant labour pasts in Lwandle, South Africa. Cape Town: University of Cape Town Press.
- Musumari, P.M., Feldman, M.D., Techasrivichien, T., Wouters, E., Ono-kihara, M. & Kihara, M. 2013. “If I have nothing to eat, I get angry and push the pills bottle away from me”: A qualitative study of patient determinants of adherence to antiretroviral therapy in the Democratic Republic of Congo. *AIDS Care*, 25(10):1271–1277.
- Naidu, M. & Darong, G. 2015. When illness is more than just a sick body: Probing how isiZulu-Speaking nurses’ construct illnesses and healing. *The Oriental Anthropologist*, 15(1):91–108.
- Naik, R., Doherty, T., Jackson, D., Tabana, H., Swanevelder, S., Thea, D.M., Feeley, F.G. & Fox, M.P. 2015. Linkage to care following a home-based HIV counselling and testing intervention in rural South Africa. *Journal of the International AIDS Society*, 18(1):19843.
- National Council of Provinces. 2007. NCOP: “Taking Parliament to the people” Western Cape. Cape Town: Parliament of the Republic of South Africa [Online]. Available: <http://www.parliament.gov.za/live/click.php?u=/content/Report+Western+Cape+TPTP.doc&o=Item+1787&v=8ba8da>. [2015, October 13].
- Newton, T., Deetz, S. & Reed, M.I. 2011. Responses to social constructionism and critical realism in organization studies. *Organization Studies*, 32(1):7–26.
- Nguyen, V.-K. 2009. Government-by-exception: Enrolment and experimentality in mass HIV treatment programmes in Africa. *Social Theory and Health*, 7(3):196–217.
- Nguyen, V.-K. 2010. The Republic of therapy: Triage and sovereignty in West Africa’s time of AIDS. Durham: Duke University Press.
- Niehaus, I. 2014. Treatment literacy, therapeutic efficacy, and antiretroviral drugs: Notes from Bushbuckridge, South Africa. *Medical Anthropology*, 33(4):351–366.
- Obadare, E. & Okeke, I.N. 2011. Biomedical loopholes, distrusted state, and the politics of HIV/AIDS “cure” in Nigeria. *African Affairs*, 110(439):191–211.
- Ogden, J., Esim, S. & Grown, C. 2006. Expanding the care continuum for HIV/AIDS: Bringing carers into focus. *Health Policy and Planning*, 21(5):333–342.
- Opollo, J.G. & Gray, J. 2015. Stigma in HIV-infected Health Care Workers in Kenya: A Mixed-method Approach. *Journal of the Association of Nurses in AIDS Care*, 26(5):639-651.

- De Paoli, M.M., Mills, E.A. & Grønningsaeter, A.B. 2012. The ARV roll out and the disability grant: a South African dilemma? *Journal of the International AIDS Society*, 15(1):1–10.
- Patel, L. 2014. Gender and care in the non-profit sector in South Africa: Implications for welfare policy, in V. Reddy, S. Meyer, T. Shefer, & T. Meyiwa (eds.). *Care in Context: Transnational Gender Perspectives*. Cape Town: 246–264.
- Peltzer, K., Friend-du Preez, N., Ramlagan, S., Anderson, J. & Preez, N.F. 2010. Antiretroviral treatment adherence among HIV patients in KwaZulu-Natal, South Africa. *BioMed Central Public Health*, 11(10):1–10.
- Petryna, A. 2002. *Life Exposed: Biological Citizens after Chernobyl*. Princeton: Princeton University Press.
- Phillips, H. 1992. Introduction, in T. Emmett (ed.). *Squatting in the Hottentots Holland Basin: Perspectives on a South African social issue*. Pretoria: Human Sciences Research Council: 1–16.
- Rachlis, B.S., Mills, E.J. & Cole, D.C. 2011. Livelihood security and adherence to antiretroviral therapy in low and middle income settings: a systematic review. *PLoS One*, 6(5):e18948.
- Raghuram, P. 2012. Global care, local configurations - Challenges to conceptualizations of care. *Global Networks*, 12(2):155–174.
- Ramphela, M. 1989. The dynamics of gender politics in the hostels of Cape Town: another legacy of the South African migrant labour system. *Journal of Southern African Studies*. 15(3):393–414.
- Reddy, V., Meyer, S., Shefer, T. & Meyiwa, T. 2014. Towards a critical theory of care, in V. Reddy, S. Meyer, T. Shefer, & T. Meyiwa (eds.). *Care in Context: Transnational Gender Perspectives*. Cape Town: HSRC Press. 1–27. [Online]. Available: <http://www.hsrcpress.ac.za/product.php?productid=2320&freedownload=1> [2015, April 14].
- Reynolds, L. 2014. “Making known” or “counting our children”? Constructing and caring for children in epidemic South Africa. *Medicine Anthropology Theory*, 1(1):114–143.
- Reynolds, L., Cousins, T., Newell, M.L. & Imrie, J. 2013. The social dynamics of consent and refusal in HIV surveillance in rural South Africa. *Social Science and Medicine*, 77(1):118–125.
- Reynolds-Whyte, S., Meinert, L. & Twebaze, J. 2014. Clientship, in S. Reynolds-Whyte (ed.). *Second Chances: Surviving AIDS in Uganda*. Durham: Duke University Press: 56–69.

- Robins, S. 2006. From “Rights” to “Ritual”: AIDS Activism in South Africa. *American Anthropologist*, 108(2):312–323.
- Robins, S. 2009. Foot soldiers of global health: Teaching and preaching AIDS science and modern medicine on the frontline. *Medical Anthropology*, 28(1):81–107.
- Van Rooyen, H., Barnabas, R. V, Baeten, J.M., Phakathi, Z., Joseph, P., Krows, M., Hong, T., Murnane, P.M., et al. 2013. High HIV testing uptake and linkage to care in a novel program of home-based HIV counseling and testing with facilitated referral in KwaZulu-Natal, South Africa. *Journal of Acquired Immune Deficiency Syndromes*, 64(1):e1–8.
- Rottenburg, R. 2009. Social and public experiments and new figurations of science and politics in postcolonial Africa. *Postcolonial Studies*, 12(4):423–440.
- Saethre, E. & Stadler, J. 2013. Malicious whites, greedy women, and virtuous volunteers: negotiating social relations through clinical trial narratives in South Africa. *Medical Anthropology Quarterly*, 27(1):103–20.
- Sawers, L. & Stillwaggon, E. 2010. Understanding the southern African 'anomaly': Poverty, endemic disease, and HIV. *Development and Change*, 41(2):195–224.
- Schneider, H. & Lehmann, U. 2010. Lay health workers and HIV programmes: Implications for health systems. *AIDS Care*, 22(S1):60–67.
- Schneider, H., Hlophe, H. & Van Rensburg, D. 2008. Community health workers and the response to HIV/AIDS in South Africa: Tensions and prospects. *Health Policy and Planning*, 23(3):179–187.
- Seabe, D.S. 2014. Understanding volunteering in South Africa: A mixed methods approach. Stellenbosch: Stellenbosch University [Online]. Available: <https://scholar.sun.ac.za/handle/10019.1/95949> [2015, January 15].
- Sen, A. 1999. *Development as freedom*. New York: Alfred A. Knopf.
- Sen, A. 2005. Human Rights and Capabilities. *Journal of Human Development*, 6(2):151–166.
- Shisana, O., Zungu, N. & Pezi, S. 2009. Poverty and HIV and AIDS, in P. Rohleder, L. Swartz, S.C. Kalichman, & L.C. Simbayi (eds.). *HIV/AIDS in South Africa 25 Years On*. New York: Springer: 89–104.
- Simelela, N.P. & Venter, W.D.F. 2014. A brief history of South Africa’s response to AIDS. *South African Medical Journal*, 104(3):249–251.

- Sips, I., Haeri Mazanderani, A., Schneider, H., Greeff, M., Barten, F. & Moshabela, M. 2014. Community care workers, poor referral networks and consumption of personal resources in rural South Africa. *PLoS One*, 9(4):e95324.
- Sondlo, D. 2012. Exploring business and owner traits of small and medium enterprises that exhibit increased revenues in South African townships: The case of selected townships in Strand. Unpublished Masters thesis. Stellenbosch: University of Stellenbosch [Online]. Available: <http://scholar.sun.ac.za/handle/10019.1/71928> [2015, October 18].
- South African Press Association. 2014. Ses'Khona denies Lwandle opportunism. [Online]. Available: http://www.iol.co.za/news/politics/ses-khona-denies-lwandle-opportunism-1.1723243#.U_OdmPm4VCg [2014, August 19].
- South African Social Security Agency. 2014. Disability grant. South African Social Security Agency [Online]. Available: www.sassa.gov.za/index.php/social-grants/disability-grant [2015, November 8].
- Stadler, J., & Saethre, E. J. (2010). Rumours about blood and reimbursements in a microbicide gel trial. *African Journal of AIDS Research*, 9(4), 345–353.
- Standing, G. 1989. Global feminization through flexible labor: A theme revisited. *World Development*, 27(3):583–602.
- Statistics South Africa. 2014. Quarterly Labour Force Survey. Quarter 2. Statistical release P0211, Pretoria: Republic of South Africa.
- Statistics South Africa. 2015. Mid-year population estimates 2015. Statistical release P0302, Pretoria: Republic of South Africa.
- Strategic Development Information & GIS Department. 2013a. [Online]. Available: https://www.capetown.gov.za/en/stats/Documents/2011%20Census/Wards/2011_Census_CT_Ward_085_Profile.pdf [2015, October, 12].
- Strategic Development Information & GIS Department. 2013b. [Online]. Available: https://www.capetown.gov.za/en/stats/Documents/2011%20Census/Wards/2011_Census_CT_Ward_086_Profile.pdf [2015, October, 12].
- Surender, R., Noble, M., Wright, G. & Ntshongwana, P. 2010. Social Assistance and Dependency in South Africa: An Analysis of Attitudes to Paid Work and Social Grants. *Journal of Social Policy*, 39(2):203-221.

- Takasugi, T. & Lee, A.C.K. 2012. Why do community health workers volunteer? A qualitative study in Kenya. *Public Health*, 126(10):839–845.
- Theron, J. 2009. Indecent employment: What is to be done about labour broking? *South African Labour Bulletin*, 33(2):151–153.
- Tronto, J.C. 2013. *Caring Democracy: Markets, Equality, and Justice*. New York: New York University Press.
- True, G., Alexander, L.B. & Richman, K.A. 2011. Misbehaviors of front-line research personnel and the integrity of community-based research. *Journal of Empirical Research on Human Research Ethics*, 6(2):3–12.
- Tsarenko, Y. & Polonsky, M.J. 2011. “You can spend your life dying or you can spend your life living”: Identity transition in people who are HIV-positive. *Psychology and Health*, 26(4):465–483.
- UNAIDS. 2014. 90-90-90 An ambitious treatment target to help end the AIDS epidemic. Geneva. [Online]. Available: http://www.unaids.org/Sites/Default/Files/Media_Asset/90-90-90_En_0.Pdf. [2015, November 18].
- Western Cape Government. 2015. Tygerberg Hospital: Overview. [Online, Available: https://www.westerncape.gov.za/your_gov/153] [2015, November 15].
- Western Cape Government. 2012. Provincial Strategic Plan on HIV/AIDS, STIs and TB [Online]. Available: https://www.westerncape.gov.za/assets/departments/health/provincial_strategic_plan_on_hiv_aids_stis_tb_2012_-_2016_-_15_june_2012.pdf \n www.westerncape.gov.za [2015, October, 13].
- Whiteside, A. 2002. Poverty and HIV/AIDS in Africa. *Third World Quarterly*, 23(2):313–332.
- WHO. 2015. Guideline on when to start antiretroviral therapy and on pre-exposure prophylaxis for HIV. [Online]. Available: http://apps.who.int/iris/bitstream/10665/186275/1/9789241509565_eng.pdf?ua=1 [2015, October 2].
- Witz, L. 2011. Revisualising township tourism in the Western Cape: the Migrant Labour Museum and the re-construction of Lwandle. *Journal of Contemporary African Studies*, 29(4):371–388.
- Wreford, J. 2005. Negotiating relationships between biomedicine and Sangoma: Fundamental misunderstandings, avoidable mistakes. (138). Cape Town: The Centre for Social Science

Research. [Online]. Available: <http://cssr.uct.ac.za/sites/cssr.uct.ac.za/files/pubs/wp138.pdf> [2014, September 30].

Wreford, J. 2009. Adaptations, Alterations and Shifted Strategies: The Pragmatics of Knowledge Transfer in HIV and AIDS Interventions in South Africa. (248). Cape Town. [Online]. Available: <http://cssr.uct.ac.za/sites/cssr.uct.ac.za/files/pubs/WP248.pdf> [2014, September 30].

Wynne, B. 1988. Unruly Technology: Practical Rules, Impractical Discourses and Public Understanding. *Social Studies of Science*, 18(1):147–167.

Xulu, N. 2012. Changing migrant spaces and livelihoods: Hostels as Community Residential Units. Unpublished doctoral dissertation. Cape Town: University of Cape Town [Online]. Available: <https://open.uct.ac.za/handle/11427/14376> [2012, October 3].

Young, A. 1976. Some implications of medical beliefs and practices for social anthropology. *American Anthropologist*, 78:5–24.

Zulliger, R., Moshabela, M. & Schneider, H. 2014. “She is my teacher and if it was not for her I would be dead”: Exploration of rural South African community health workers’ information, education and communication activities. *AIDS Care*, 26(5):626–632.

Addenda

Addendum A: DTTC Ethical Clearance



04 August 2014

Departmental Ethics Screening Committee (DESC)
Department of Sociology and Social Anthropology
Stellenbosch University

To whom it may concern

Re: Permission for Mr Dillon Wademan to collect and analyse data towards completion of a MA in Sociology in terms of Health Research Ethics Committee approval granted to the Desmond Tutu TB Centre; that is, amendment 4 of the PopART trial approved on 26 February 2014 (HREC Ref: N12/11/074).

This letter serves to confirm that the Desmond Tutu TB Centre has received approval from the Health Research Ethics Committee to conduct social science research in 9 community sites in the Western Cape as part of the HPTN 071 (PopART) trial. Part of this approval includes a variety of data collection procedures to: “describe contextual, social factors in the HPTN 071 (PopART) study communities in relation to a diversity of community members’ experiences of HIV, ART, UTT, and related health and public health variables”. It is our understanding that Mr Wademan’s MA proposal falls within this remit.

Therefore, in terms of the attached data-sharing agreement, we confirm that Mr Wademan has approval to collect and analyse data in terms of his MA proposal (attached). Furthermore, we confirm that we have submitted a note to file to the Health Research Ethics Committee indicating this for their records.

Yours sincerely,

Dr Peter Bock
Co- Principal Investigator

Addendum B: Good Clinical Practice Certificate

Good Clinical Practice Certificate 2014

This is to certify that
DILLON T. WADEMAN

Successfully completed the following *Level 2* course

Good Clinical Practice: Beginners' Course
(Activity No: GCP-Beg/2014)

The above-mentioned practitioner qualifies for
17 CEUs (of which 5 are Ethics CEUs)

Facilitator: Marijke Geldenhuys **Date: 11 & 12 September 2014**




Teaching Clinical Research to All

Accreditation: GCP provider: MT-2014/002; SACRA/GCP/76/2013

Addendum C: Map of Lwandle as Understood by Community Members

The figure below is the culmination of several discussions concerning the layout of Lwandle. I was able to visit some of the areas more frequently than others for one or other reason, be it the size of the area, the lack of CCWs visiting the particular area, or even safety concerns. As such, the following areas are roughly numbered in order of visitations per area:

- (1) Lwandle, (2) Nomzamo (3) Greenfields, (4) Zola (Asande Village), (5) Pholile, (6) Moholweni
- (7) Solly’s Town, (8) Desert, (9) Inkhaneni, (10) Masakanye, (11) Happy Rest, (12) Ithembeni, (13) Siyanzaela, (14) Chris Nissen Park and (15) Broadlands.

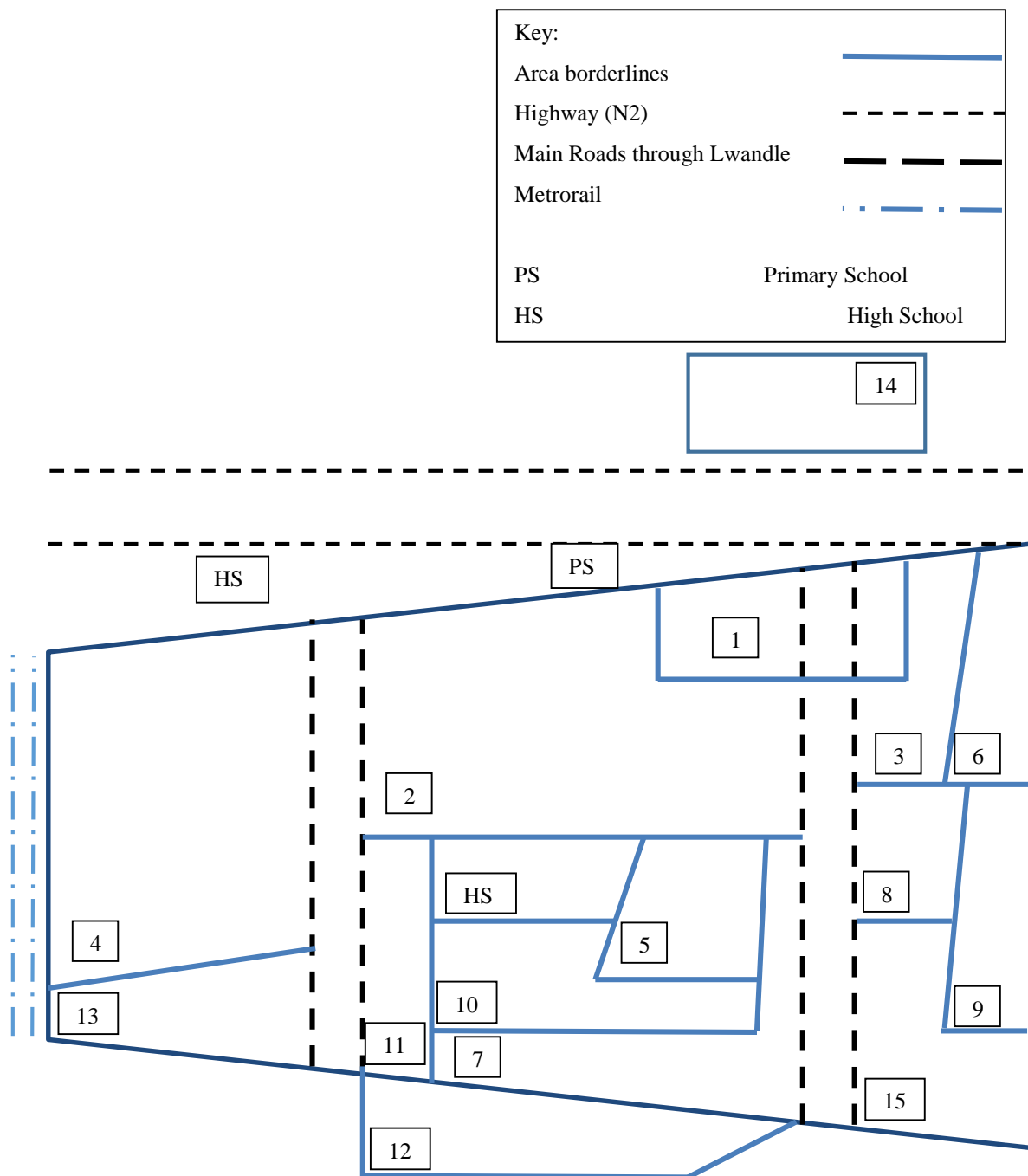


Figure 6.1 Map of Lwandle as understood by my participants

Addendum D: List of Participant Interviews

| Participant Pseudonym | Description | In-text Reference |
|------------------------------|---------------------------------------|--------------------------|
| Cebisa | CHiPs supervisor | CHiPs1 |
| Kuhle | Community member living with HIV/AIDS | Community Member1 |
| Luvellen | Community member living with HIV/AIDS | Community Member4 |
| Ndileka | Community member living with HIV/AIDS | Community Member2 |
| Nesiwe | CCW | CCW2 |
| Ruth | Community member living with HIV/AIDS | PLWH5 |
| Sandile | CHiP | CHiP2 |
| Sara | Community member living with HIV/AIDS | Community Member3 |
| Vuyokazi | CCW | CCW1 |