Of Blood and Belonging:

the practice of antiretroviral treatment among HIV-positive youth in South Africa's Eastern Cape

Beth Vale

Linacre College

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Abstract

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Beth Vale
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HIV-positive adolescents are an increasingly numerous and challenging population in the South African HIV/AIDS epidemic. Their access to, and retention in, ART care has become a pressing public health concern. Comprised of four journal articles, this thesis explores the practice of antiretroviral treatment (ART) among a cohort of HIV-positive adolescents (age 10–19) in South Africa's Eastern Cape. By 'practice', I mean the volatile, situated and relational 'work' that goes into young people's everyday achievement of ART — into consuming daily medication, regularly attending health appointments, and participating in HIV programmes. Through an exploration of the ways in which some HIV-positive adolescents use, appropriate or reject ART care; this thesis contributes to a much-needed evidence-base on the needs and survival strategies of adolescent ART users. Data for this study was gathered through eight months of multi-method ethnographic fieldwork with 23 HIV-positive youth, their families, and local health workers.

The findings elucidate adolescent ART as a complex (and often volatile) form of social incorporation, through which young people negotiate survival, care and moral connection in contemporary South Africa. Enrolling in ART meant being encompassed into a (often hierarchical) set of social relationships, through which adolescents sought belonging, recognition and protection, amid profound insecurity. Through ART and its associated programmes, adolescents and their families attempted to strengthen familial ties, appeal to powerful patrons, petition for care, and access basic resources. Yet these pursuits were deeply ambivalent, as discipline, blame, and resentment often came encased in the terms of care. At the crux of each article is an attempt to understand how adolescents, alongside their families, negotiated both the social stakes and possibilities of ART. Through these discussions, we might better be able to grasp the fragility and complexity of young people's retention in ART.

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Introduction

It is difficult to imagine late modern history without the multifarious presence of HIV/AIDS. Since the early 1980s, over 78 million people worldwide have been infected with HIV (UNAIDS 2014), with the worst of the epidemic in sub-Saharan Africa. This has prompted an unprecedented global effort to guarantee access to antiretroviral therapy (ART) in order to treat HIV among those living with it. As the distribution of ART expands, the population of adolescents on ART is rising. More and more HIV-positive youth are able to access lifelong treatment, while improved access to paediatric ART has seen a growing cohort of HIV-positive children survive into adolescence.

Yet, adolescents are the only population group for whom AIDS-related deaths have risen since 2001 (WHO 2013; UNAIDS 2013), attributed in part to a lack of retention in care and poor adherence to HIV treatment (Denison et al. 2015). This impresses the need to better understand the lives of young ART users, particularly in sub-Saharan Africa, where the vast majority of the world's HIV-positive adolescents live. Identifying obstacles to adolescent ART requires detailed, contextual, and nuanced insight into the continuum of youth HIV care: how adolescents come to know and signify their HIV status, their enrolment in ART, their experiences of persistent health surveillance, as well as the social relationships within which their everyday treatment-taking is embedded (Mattes 2014, p.28).

This thesis investigates the practice of antiretroviral treatment among a cohort of HIV-positive adolescents (age 10–19) living in South Africa's Eastern Cape. By 'practice', I mean the volatile, situated and relational 'work' that goes into young people's

everyday achievement of ART — into consuming daily medication, regularly attending health appointments, and participating in HIV programmes. Data for this study was gathered through eight months of ethnographic fieldwork with 23 HIV-positive youth, their families, and local health workers.

The project of youth ART involves multiple institutions of care. Families, health facilities, non-government programmes and welfare organisations all claim a moral stake in the process with varying levels of collaboration and conflict between them. Through an exploration of the lifeworlds [1] of HIV-positive adolescents, and the institutions in which they are nested, this thesis investigates how adolescent ART has been promoted and coerced, the modes of agency young people exercise through their ART participation or not, and how this interplay reflects adolescent use, miss-use or rejection of regimes of ART care. In doing so, the thesis explores the social stakes and possibilities of youth ART a decade into South Africa's treatment rollout.

The findings elucidate adolescent ART as a complex (and often ambivalent) form of social incorporation, through which young people negotiate survival, care and moral connection in contemporary South Africa. Yet adolescents' ART participation was also frequently attended by blame, accusation and punitive discipline, and was for some symbolically associated with the loss of a parent or the rupture of familial sociality. Hence, ART not only had biomedical effects. It also had social consequences, embedded in adolescents' local moral worlds. ART shaped the ways that adolescents practised and imagined their relatedness, both to relatives and neighbours, as well as to

[1] Originating in the philosophical work of Edmund Husserl, 'lifeworld' refers to life as it is lived by subjects, grounded in their experience of their everyday worlds.

centres of power. It meant being encompassed into a (often hierarchical) set of social relationships, through which young people sought belonging, recognition and protection, despite profound insecurity.

Understanding the social-moral properties of young people's ART is vital if we are to grasp the stakes of their retention and adherence. ART programmes succeed or fail through the everyday practices of those who use and deliver them, amid the specificities of their local contexts. While some anthropological research has been conducted on the institutional discourses and practices surrounding ART adherence in Africa, as well as the ways in which people have appropriated and reinvented them (Beckmann 2012; Colvin et al. 2009; Mattes 2011; Mfecane 2011; Niehaus 2014; Richey 2012; Robins 2006), little attention has been given to how this might be complicated for young people, whose ART care is regulated as part of the broader social organisation of 'youth'.

GENERATION

To pay attention to the lives of young people is to position 'generation' as a tool for social analysis. "Whether we think of intergenerational links within families or across historical periods, generation is about connections and contrasts — and often conflicts — in temporal perspective" (Whyte et al. 2008, p.1). The experiences of the young ART users in this study have a generational particularity. This is shaped by their position as daughters, sons, or grandchildren; by their membership to a category of 'youth'; by their shared bio-status; and by their location in the social history of South Africa and its HIV/AIDS epidemic. This study's generational interests pivot around

three broad concerns. First, I am attentive to HIV-positive youth as part of a 'body politic'. By this I not only mean their experience as citizens, but also their location within a bio-political project. As members of HIV programmes, adolescents in this study are also artefacts of social and political control and participants in bodily regulation. Second, I am concerned with young ART users as family members, whose lives and livelihoods are made through relationships with the generations preceding them. And finally, I am interested in how the experiences of young people in this study might speak to constructions of youth and childhood.

Body Politic

In her most recent book, Henderson (2011) draws on three years of ethnographic research (2003–2006) to describe how AIDS illness was folded into the everyday lives of families in rural KwaZulu-Natal. The ethnography traces repertoires of care within AIDS-affected homes, during a time when ART was not readily available and death was inevitable. Outside the institutional domains of hospitals and clinics, Henderson shows the emotional, material and ritual resources that were brought to bear on AIDS illness, with little assistance from the state. While my ethnographic undertaking is similarly interested in everyday practices of care, and how these are mobilised in the face of HIV illness, it is made different by its temporal location in the post-ART era. I am interested in young people's ART as a process of, and a means to, social incorporation — how youth ART has come to mediate families' everyday pursuits of survival, sociality, and recognition, often at high stakes. In an era of ART availability, HIV care is increasingly crafted at the intersections between public and private institutions, where the boundaries between home and clinic, parent and healthworker, surveillance and care, frequently blur. This thesis therefore serves as an examination of

how ART has shaped a generation, but also how the resources and particularities of generation are brought to bear on ART.

Young people in this study have grown up during a time of immense transition in the country's HIV response. Since 2004, South Africa's rapid scale-up of HIV treatment has sought to shift HIV from a terminal illness to a treatable, lifelong condition. The certainty of death is incrementally being replaced by "the uncertainties of life on HIV treatment" (Whyte et al. 2014, p.269). Youth in this study are among the first generation to benefit from this newfound ART availability. Many of them will spend a large part of their life course under a biotechnological programme. These youth therefore share a relation to HIV and its treatment. Moreover, they do so during the first decade of widespread treatment availability in South Africa. The stories of this cohort therefore offer a unique lens through which to examine continuity and change in the HIV/AIDS epidemic, as well as the shifting meanings attached to life on ART.

In addition to their unique location in the trajectory of South Africa's HIV/AIDS epidemic, the generation of youth in this study also has socio-political significance. Among the first to be born into South Africa's new democracy, their cohort have been dubbed the "Born Frees" and "Mandela's children" (Barbarin & Richter 2013; Richter et al. 2007). This generation of youth have grown up amid immense social and political change, attracting significant research interest (Bray et al. 2010). Their lives have served as a barometer for the progress, possibilities, and stagnation of a 'new' nation. In the post-apartheid period, a growing body of qualitative research has explored what it means for young people to live under socio-economic and political structures that are simultaneously 'old' and 'new' (Bray et al. 2010; De Lannoy 2007; Graham 2011;

Henderson 1999; Ramphele 2002; Swartz et al. 2012). Because of their position on the cusp of new democracy and new therapeutic technologies, the lives of young people in this study offer an opportunity to examine how the past continues to articulate in the present, juxtaposed with fresh hopes for the future.

As the democratic transition has unfolded, young people in this study have witnessed marked shifts in the relationship between the South African state and its citizens. The mass rollout of ART has been located amid an expansive system of welfare provision, for which young people in this study have been key beneficiaries. To support the upbringing of their HIV-positive youth, families in this study have received foster child, childcare and occasionally care dependency grants. The imperative to document recipients of health and welfare has meant that youth are now more visible to the South African state than ever before. To examine adolescents' ART care is also to ask how young people have mobilised their 'new' citizenship status — as 'deserving' state beneficiaries.

By paying attention to body politic, I consider young ART users as citizens and beneficiaries of a 'new' South African state and as objects of its 'new' bio-political interventions. These interests are historically located, born out of an era in which HIV treatment and social welfare are being distributed en mass, and the country's socio-political terrain is shifting along with meanings of citizenship. In reflecting on the historical positioning of young ART users, I am guided by De Boeck and Honwana (2005, p.2), who ask: "how can we situate the lives of youth in the present, grasp the meanings revealed in their shaping of a future, and ground both in an understanding of the past?" These questions are as potent in conceptualising adolescents' socio-historical

positioning as they are for understanding their location within families, where young people are an extension in time of the generations preceding them.

Family

As relations between state and citizen have shifted, so too have domestic relations been in flux. The dissolution of apartheid laws has produced a significant increase in internal migration (Marais 2005, p.8), including in the Eastern Cape, where this study is located. Since the 1990s, many rural parts of the province have seen a substantial outmigration of women and young adults to regional towns and cities, along with a decline in long-distance migrant labour and drastic job losses in the formal sector (Bank 2001, pp.137–138). Agrarian lifestyles have become increasingly untenable, while more and more families have relied on the post-1994 social grants economy (Ainslie 2014, p.6). Women's disproportionate access to social welfare, their participation in self-help groups, as well as their increased access to the labour market has contributed to increasingly feminised residential spaces (Ainslie 2014; Bank 2001) — particularly where children are present. Marriage has also been on a continuous decline, with growing numbers of young women co-habiting and bearing children outside of marriage (Bank 2001; Fray 2015).

Using generation as an analytical lens places young people's ART care amid these ongoing changes in South African society and political economy, which have had significant effects on gendered and generational dynamics within homes and families. For the most part, young people's contemporary ART practice is being negotiated in female-centred, multi-generational homes. More so, these households are increasingly dependent on state welfare and linkages to development NGOs.

To investigate young people in the HIV/AIDS epidemic is to ask how HIV sharpens and complicates intergenerational relationships, not only across historical generations, but also within families. So much of the discourse about HIV is about relationships with sexual partners. Yet relationships with children, and children's children, are often equally fraught and problematic (Whyte et al. 2014, p.164). In many homes, the implications of HIV/AIDS span as many as three generations — including those living, dead, and estranged. The HIV/AIDS epidemic has contributed to a series of generational anomalies: the elderly have buried their young, small children have nursed their parents, and adolescents have headed households. It has also amplified and necessitated intergenerational reciprocity, as grandmothers and grandchildren step in to complete the work of their ailing children or parents.

Adolescent ART is achieved primarily in the home. Homes are physical spaces with domestic routines and arrangements, designated spaces of interaction and privacy, and varying levels of resources to manage care. But they are also ideological spaces with age hierarchies and gender roles, ideas about marriage and procreation, allocated responsibilities, and means of socialising youth. Just as ART can reform meanings of home, so too does 'home', as an ideological and physical space, have bearing on how ART is practised. Antiretroviral treatment is often a relational practice, particularly for adolescents who have grown up with HIV. Relatives often assist in administering medication, while domestic routines and obligations are re-organised in line with a demanding treatment regimen.

Childhood

Finally, to study adolescent ART is to foreground key themes in studies of youth.

INTRODUCTION

Recent literature has pointed to the inherent ambivalence of youth as a category (Comaroff & Comaroff 2006; De Boeck & Honwana 2005). Young people are characterised not only 'at risk', but also 'as risk'. Youth are positioned as victims and perpetrators, as both vulnerable and resilient. The relation between youth and risk, coupled with a bulging global youth population, has spawned a complex aid industry with youth as the new developmental target (Van Dijk et al. 2011, p.2). Questions of risk are particularly acute for HIV-positive youth: while they are made vulnerable by their stigmatised, incurable illness, they also embody a powerful threat as potential transmitters of HIV. As more and more youth live full lives on ART, adolescent ART users embody both an enormous hope and a potential liability.

The question of young people's "ambiguous agency" (Bordonaro & Payne 2012) — infused with both possibility and threat — has been of immense importance in re-defining the discipline of youth studies. ART itself entails an ambivalent form of agency: to consume antiretrovirals is both a routinized confirmation of one's illness, and thus vulnerability, and a powerful strategy to keep it at bay. Taking medication is about claiming control of the virus, but it is also about losing control through dependence on lifelong treatment, and sometimes through uncomfortable and embarrassing side effects (Persson & Newman 2012). Young people's medication-taking may serve as a site of independence and self control, while also being configured through the perceived desires of adult others — including healthworkers, caregivers, social workers, and teachers (Longhofer & Floersch 2010). In this sense, medical technology is simultaneously enabling and constraining, reassuring and threatening, empowering and alienating. Hence, the distinction between "technologies of enablement" and "technologies of surveillance" may not always hold in practice

(Poland et al. 2005, p.176).

The overlaying of impotence and power in discourses of youth on ART is particularly relevant for contemporary South African youth, for whom post-apartheid democracy has promised both everything and nothing. Today's generation of black youth have greater access to education and welfare than their parents, and no longer face legal barriers to social, economic or physical mobility. But while they are frequently encouraged to grasp the fruits of liberation and to 'dream big', this is amidst the lingering and powerful structural constraints of apartheid. Similarly, while democratic modernity aims to empower youth, give them a political voice, and offer prospects for upward mobility, this may be in contradiction to the age-based hierarchies of their families, where respect for elders may dictate obedience and subservience. Indeed, it has been suggested that to understand the lives of young people growing up in post-apartheid South Africa, one must grasp both rapid change and crushing continuity, which make the adolescent experience one of ambivalence and contradiction (Bray & Moses 2011).

This research investigates the practice of youth ART as an expression of complex and multiple forms of agency – where power and subjugation conflate in unexpected ways, and multiple institutions may invoke conflicting discourses in the regulation of youth ART.

THIS STUDY

As a 'DPhil by Publication', this 'thesis' takes the form of four stand-alone papers.

INTRODUCTION

Rather than offering a series of chapters, what I present here is a set of journal articles, each intended for separate publication. The included articles are threaded together by the ways in which they reveal young people's ART participation as a volatile form of social incorporation. Adolescent ART is revealed as both a form of, and a means to, recognition, care, and relatedness. This introduction contextualises these articles as a body of work and in doing so serves as an extended form of editorial. First, I describe how HIV positive youth have been characterised as an emerging challenge for global public health. Following this, I offer a brief history of the HIV/AIDS epidemic in South Africa, paying attention to three questions of generation: 1) I attempt to locate youth in the HIV/AIDS epidemic, both as a cohort deeply affected by HIV/AIDS and as a policy target; 2) I reflect on the implications of HIV/AIDS for intergenerational relationships between families and their care practices; and 3) I explore the historical positioning of a generation that has grown up as recipients of a newly-constituted bio-political project in a newly-democratic state. Following this historical overview, I provide an account of the qualitative literature on the lives and challenges of HIV-positive adolescents in sub-Saharan Africa. The review outlines key themes in the contemporary literature, while also signalling the contribution of this thesis and offering an overview of each of the included articles. I also offer reflections on the selection of the thesis' title. Following this introduction, I dedicate a chapter to describing the ethnographic fieldwork from which this thesis draws. Here, I discuss the research sites, data collection, and analysis methods for this study.

Throughout this thesis, I use the terms 'youth', 'adolescent' and 'young person' interchangeably to refer to research participants within the age bracket of 10–19 years old. Most of these adolescents would fall within the South African government's

definition of 'youth', although this traditionally refers to an older and more expansive age bracket (age 14–35). Given the complexity of adolescence and the heterogeneity of young people's 'transitions' to adulthood, age-based definitions of adolescence are largely arbitrary. For the purposes of this study I have used the World Health Organisation definition of adolescence (age 10–19), which is broad enough to capture both adolescents who inherited HIV from their parents and those who contracted it later in life.

PUBLIC HEALTH RATIONALE

This small ethnographic study forms part of a larger, interdisciplinary research project, titled *Mzantsi Wakho* (Your South Africa). Mzantsi Wakho is a research partnership between the Universities of Oxford and Cape Town, which seeks to investigate ART adherence, and sexual and reproductive health among Eastern Cape adolescents (age 10–19). In collaboration with UNICEF, the South African Departments of Health, Social Development and Education, as well as local NGOs, it aims to inform future policy and programming for HIV-positive youth.

The research project is born out of a mounting public health concern with adolescent HIV. Adolescents have been described as a "fulcrum" at the epicentre of the HIV/AIDS pandemic (UNAIDS 2013). In 2012, an estimated 2.1 million adolescents (age 10–19 years) were living with HIV globally: eighty-five percent of them were in sub-Saharan Africa (UNICEF 2013).

The increased availability of paediatric ART has meant that a growing cohort of HIV-

positive children is reaching adolescence. Globally, there are 3.3 million children living with HIV, who are set to enter adolescence in the coming years (UNAIDS 2013; WHO 2013, p.viii). In addition to those who grow into adolescence having contracted HIV early in their lives, there are also significant numbers of young people becoming newly infected. Adolescents and young adults account for 41 percent of annual new infections worldwide (UNAIDS 2013; WHO 2013). Young women (age 15–24) are especially at risk with 380, 000 new infections annually (UNAIDS 2014). Adolescence is a period when many start to explore their sexuality for the first time. Young people may also be vulnerable to coerced and forced sex, which carries a high risk of HIV infection (Garcia-Moreno et al. 2006; Pettifor et al. 2009).

The pivotal role of adolescents in defining the trajectory of the global HIV/AIDS pandemic has prompted amplified efforts to provide treatment and care tailored to the specific needs of this population (UNICEF 2011). The health and longevity of the global population of HIV-positive adolescents hinges on their treatment success. Consistent ART radically reduces AIDS-related morbidity and mortality (Lowenthal et al. 2012; Pallela et al. 1998), decreases the likelihood of drug resistance (Pillay 2001) and prevents onward transmission (Cohen et al. 2011)[2]. But attaining these clinical benefits depends on strict adherence (at least 80–95%) to an onerous, lifelong and highly stigmatised treatment regimen. As the number of adolescents on ART grows, poor adherence has emerged as a major threat to levels of health, survival, and sexual transmission among this age group (Hudelson & Cluver 2015; Nachega et al. 2010;

[2] Findings of the revolutionary HPTN052 trial, which sampled 1763 sero-discordant couples, provide conclusive evidence that initiating antiretroviral treatment at an earlier stage in disease progression (at a CD4 count between 350–500 cells/mm3) can prevent onward transmission whilst improving the health of people with HIV. HIV-positive participants who initiated HAART early showed a 96% reduction in transmitting to their HIV-negative partner.

Scanlon & Vreeman 2013; Van Dyke et al. 2002). Further, between 2005 and 2012, AIDS-related deaths doubled among adolescents (WHO 2013, p.12).

Young people's success on ART is embedded in their access to, and retention in, care. Yet the limited evidence that exists suggests that adolescents might be less easily retained in ART care than their child or adult counterparts (Auld et al. 2014; McNairy 2011; Nachega et al. 2009). The few existing studies from sub-Saharan Africa show suboptimal ART adherence among youth and poor virological outcomes (Lowenthal et al. 2014; Mavhu et al. 2013; Vreeman et al. 2008; Wiens et al. 2012). Drawing data from nine African countries, one study found that adolescents were half as likely to achieve optimal adherence as adults (Nachega et al. 2009). To add to this, AIDS remains the number one cause of death among adolescents in Africa (WHO 2014).

A growing body of international (specifically American) research has explored adolescent ART adherence in high-income settings (Chandwani et al. 2012; MacDonell et al. 2013; Naar-King et al. 2006). As the global HIV/AIDS epidemic matures, the burden of adolescents with perinatal HIV is shifting onto low and middle-income countries (Hudelson & Cluver 2015, p.805). Although sub-Saharan Africa has the largest global population of adolescents living with HIV, research on adolescent ART is comparatively sparse. This is despite the unique socio-economic circumstances that might complicate ART adherence for young people and high levels of loss due to late ART rollout.

South Africa has the highest population of HIV-positive adolescents worldwide, estimated at 300, 000 (Kasedde & Olson 2012). Almost a quarter of the country's new

infections occur among adolescents and young women (Shisana et al. 2014). To add to this, the delayed rollout of ART has meant that the country is now witnessing its first generation of HIV-infected babies entering adolescence, many of them orphans (Hornschuh et al. 2014; Kimani-Murage et al. 2013; Li et al. 2010; Petersen et al. 2010). By 2020, 150 000 adolescents in South Africa are expected to be in need of ART (Jaspan et al. 2009). As public health policy moves towards earlier ART initiation (National Institute of Health 2015), the number of treatment-eligible adolescents is likely to exceed these estimates. The limited research available from South Africa suggests that youth (age 15–24) who initiate ART have worse treatment outcomes than their adult counterparts, both in terms of virological failure (Evans et al. 2013; Nglazi et al. 2012) and retention in care (Evans et al. 2013). While HIV-positive youth are an increasingly numerous and challenging group in the country's HIV/AIDS epidemic, we are only just starting to learn about this cohort of young people and the ways in which they understand, experience, and engage with ART care.

Two Generations of HIV-positive Adolescents

Public health and academic research has frequently imagined the population of HIV-positive adolescents as two distinguishable epidemiological cohorts. Receiving most attention are those 'vertically-infected' youth, who inherited HIV from their parents and have since survived into adolescence as a consequence of improved ART access. Second are those adolescents who have contracted HIV horizontally (whether sexually or through unsterilized needles). In sub-Saharan Africa, horizontally-infected adolescents (mostly girls) are likely to have been sexually-infected (Idele et al. 2014, pp.145–146).

INTRODUCTION

Adolescents' mode of infection is described as having important implications for their interaction with HIV services. Most vertically-infected adolescents would have fallen ill at an early age and have been co-opted into HIV care. Born at a time when treatment was largely inaccessible, many in South Africa would have lost parents to AIDS and have spent their early years with little or no treatment access. The existence of South Africa's generation of vertically-infected youth is uniquely contingent. Had they been born a short while later, their mothers might have had access to the medications that would have prevented them from being born with HIV. Yet had they been born even a few years earlier, many might not have had access to the drugs that have kept them alive.

Vertically-infected adolescents often will not remember being tested for HIV. Many are diagnosed very young and almost certainly not of their own volition. As a result, vertically-infected adolescents often grow up with limited knowledge of their HIV status, as guardians bestow pieces of information over time (Heeren et al. 2012). Many do not fully understand the nature of their medication. As with any childhood story, these incomplete illness narratives might take on a mythical quality — a mixture of memories, fables, and unexplained terms.

Generally, sexually-infected youth discover their HIV status at a much older age than their vertically-infected counterparts. Today, most newly diagnosed adolescents know they will be able to access ART when they are eligible. Yet these largely asymptomatic youth also enter a system of ART care that has been discursively constituted by the 'resurrection' of patients from "near-death" to "new life" (Robins 2006). For healthworkers, families and ART users alike, there is a struggle to signify ART for

those who initiate early and healthy. The ambiguity of taking medication while 'well' is at the crux of re-imagining HIV as a 'chronic condition'.

Because sexually-infected adolescents generally remain healthy into their twenties, they are often unaware of their HIV status (WHO 2011). The exceptions are pregnant teenagers who might undergo an HIV test as part of routine antenatal screening (MacPhail et al. 2009). In South Africa, these young women are immediately started on HIV treatment to prevent HIV transmission to their babies. Unless they test while pregnant, horizontally-infected adolescents are unlikely to be in immediate need of ART. As a consequence, many do not return for regular health monitoring and are thus largely absent in the health system (Snyder et al. 2014, p.2).

Until recently, it was assumed that vertically-infected babies would not survive more than a few years without ART. But recent reports from sub-Saharan Africa show a substantial number of vertically-infected adolescents presenting at clinics untested and untreated (Ferrand et al. 2009; Shepherd et al. 2015). These "slow progressors" have often survived more than a decade without ART. This has complicated the assumption that those diagnosed as adolescents are certainly horizontally-infected.

Conversely, new research has questioned the presumption of vertical infection among HIV-positive babies. In Mozambique, Class (2014) reported unexpected numbers of HIV-positive babies and children born to sero-negative mothers. Despite this, health practitioners rarely discussed possible modes of horizontal infection in babies (perhaps through blood contact or abuse), and instead adopted a unilateral discourse of 'mother-to-child-transmission'.

Delineating adolescents in terms of their mode of infection is useful for conceptualising the epidemiology of adolescent HIV as well as young people's entry into care. Yet discerning mode of infection is often murky for families and practitioners alike. One of the articles presented for this thesis explores how these frequently-ambivalent classifications are socially imbued as moral categories, and relatedly, as vehicles for blame and shame.

By exploring how mass interventions are received and appropriated in local contexts, in-depth qualitative research makes an important public health contribution. Indeed, public health research is often dominated by quantitative perspectives, which can be enriched, complemented, and explained by qualitative insights. This thesis offers ethnographic input to questions, which, as I have highlighted, are of major public health concern. In doing so, it aims to elucidate the micro-dynamics of power surrounding ART technologies, the creative and precarious ways in which youth ART is negotiated, and the socio-historical specificities that permeate this process. It is to this social history that this introduction now turns. In what follows, I hope to sketch some of the socio-historical forces that have characterised South Africa's generation of youth on ART.

A HISTORY OF SOUTH AFRICA'S HIV/AIDS EPIDEMIC

It is a tragic irony that AIDS began to take root in South Africa just as the country was transitioning into democracy. During the early 1990s when activists and politicians busied themselves with crafting new democratic institutions, very few would have been thinking about the future impact of AIDS (Simelela et al. 2015, p.257). In 1990, when

the country's HIV prevalence was estimated at one percent, Chris Hani issued a warning: "we cannot afford to allow the AIDS epidemic to ruin the realisation of our dreams", he said. "Existing statistics indicate that we are still at the beginning of the AIDS epidemic in our country. Unattended, however, this will result in untold damage and suffering by the end of the century" (Karim & Karim 2002, p.39).

Hani was right. Within a decade, HIV prevalence in South Africa skyrocketed from 1–22 percent (Marais 2007, p.21), yet received little attention from Mandela's government (Leclerc-Madlala 2005). The spread of the HI-virus in South Africa has traced, demarcated, and re-instated existing structural inequalities, such that those living with HIV are mostly poor and black, and amongst them it is mostly women who are affected (Marais 2007). "The AIDS epidemic is interlaced, in other words, with the circuits and terms on which power, opportunity, and entitlements are distributed and desires and needs are pursued" (Marais 2005, p.10). Devastatingly, the young, black South Africans who were most well poised to benefit from newfound freedom would also carry a heavy HIV/AIDS burden, both because of their own susceptibility to infection and the weight of their caregiving responsibilities for sick adults.

In July 1996, highly active antiretroviral therapy was shown to halt the replication of HIV (Steinberg 2008, p.90). Debates circulated about whether poor people could adhere to lifelong HIV treatment, and whether ART programmes could be implemented in resource-limited settings, given a lack of infrastructure, healthworkers and specialists (Steinberg 2008). Despite being made available to middle-class citizens throughout the world, these revolutionary drugs remained inaccessible in the South African public health sector. HIV therefore remained fatal for the vast majority of those who

contracted it, and a new political dispensation was accompanied by a wave of AIDS deaths.

Life and Death before ART

While the demise of apartheid carried the promise of "new life" in the form of opportunities, entitlements and aspirations previously denied to the black majority, it also brought an aggressive "new death" (Posel et al. 2007, p.139). Without hope of accessing treatment, families scrambled to provide palliative care to their sick. Many lost their most economically and biologically-productive generation. Often it was close relatives, especially grandmothers, who assumed care for the orphaned children of their dead. In some South African localities, escalating AIDS deaths were interpreted as a symptom of "cultural damage" (Posel et al. 2007, p.144), stemming from the flouting of sexual taboos, and the troubles of modern life and political transition. Through the allocation of rights and freedoms to women and children, and the erosion of forms of patriarchal 'tradition', democracy marked a point of rupture in social relations between men and women, young and old. AIDS deaths therefore took on a generational significance: first because those who were dying were doing so at the prime of their lives, and second, because AIDS deaths signalled the social disruptions of democratic modernity.

The period of untreatable HIV was marked both by the bodily publicity of AIDS illness and death, and by the concomitant practices of secrecy that sought to shield this from view. Before treatment was available, providing AIDS care would inevitably culminate in the intimate bodily care of a dying relative or patient. Without ART, AIDS illness

disfigures the body conspicuously. The final stages of AIDS were marked on the bodies of sufferers, who were seen to literally decompose while they were still alive.

Some ethnographers (Ashforth 2002; Niehaus 2007; Viljoen 2005) have argued that the association between HIV/AIDS and death is its primary source of stigma. Drawing on ethnographic research in Hammanskraal and Soweto, Ashforth (2002, p.16) and Viljoen (2005, pp.68–87) showed that residents interpreted AIDS as a "waiting room for death" and those living with HIV as "dead before dying". Similarly, Niehaus (2007) found that persons with AIDS were considered "living corpses" by those in Impalahoek. According to Niehaus, the inexorable association between AIDS and death was only exacerbated by public health campaigns, which in the pre-ART era had articulated AIDS as an incurable 'killer'.

Conspicuous AIDS deaths have also positioned children as barometers of the HIV/AIDS epidemic. From the early years of the epidemic, children have been central in the unfolding situations of households affected by HIV. Before the advent of ART, HIV/AIDS was associated with the deaths of small children born to infected parents, and to the escalating numbers of orphans left behind after their deaths. The loss of a baby could be grounds for suspecting the HIV status of the mother, and by implication the father. A child's death might also be re-interpreted years later as the death was pieced together with other indications of a parent's HIV illness.

Because of their role as child-bearers and child-carers, it has most often been women who discover the existence of HIV illness in their families. Frequently, "this 'discovery' has attached to them as blame, since in their discovery they are perceived as creating the disease" (Barolsky 2003, p.38). Whether through their own pregnancy or their

child's sickness, women have often been first to know HIV. Women's knowledge of HIV/AIDS has sometimes been interpreted, by men, "not as knowledge of the empirical, but as a creation of that reality" (Barolsky 2003, p.39). In addition to being positioned as the source of infection, HIV-positive women have experienced guilt and blame for having failed in their 'appropriate' role as carers, responsible for the next generation (Lawless et al. 1996, p.1371).

Families, death and orphanhood

Women's position within families made them especially vulnerable to the burdens and stigmas of HIV. From the early years of the epidemic, it has been within families that HIV/AIDS is most acutely felt: it is within families that those living with HIV must negotiate disclosure and support, that resources are allocated, relationships built and broken, and decisions made about the futures of children. As a pre-existing network of care, the family constitutes one of the most important social resources for buffering the impact of AIDS, particularly for children. But the AIDS epidemic is also a profound test of the integrity and resilience of the family institution. In her reflections on family, during an era of inevitable AIDS death, Henderson (2011, p.21) remarked that AIDS exposed "the tensions and fault-lines of family". She described the family as becoming "increasingly acrimonious and, indeed murderous" because it was linked to death (Henderson 2011).

But Henderson (2011) also explored the family as a primary site for care. In her book, subtitled *A Kinship of Bones*, she told the story of a young woman, dying of AIDS, who thanked her mother for having "touched her bones" while nursing her. Reflecting on this phrasing, Henderson explored how the mother's care might have encompassed,

rather than denied, her daughter's emaciation. It reinforced their interconnection even in death. Some weeks before she died, the young woman was carried on her mother's back through Johannesburg in order to recoup her possessions and gather the documents she would need to obtain state grants for her children. Care therefore constituted a mutual ordering of life in preparation for death.

In the years before ART, providing HIV care to relatives was fundamentally about the negotiation of untimely death. After death, the past continued to have bearing on the present as the living sought to dignify their deceased through rituals and practices of care. Indeed, much of Henderson's ethnography has explored how the misfortunes of alienated and estranged dead are attended to by their living descendants (Henderson 2012; White 2001). The inherited illness of an HIV-infected child is strikingly literal in this respect. Many vertically-infected adolescents in South Africa are grappling with a lifelong illness that is symbolically attached to their deceased parents. These adolescents also occupy the quintessentially vulnerable status of 'AIDS orphan' (Meintjes & Giese 2006a), having lost parents at a time when HIV was inevitably fatal.

In the Eastern Cape, where this study is located, there are estimated to be 187, 391 children who have lost one or more of their parents to AIDS illness (Actuarial Society of South Africa 2008). The tragic image of the AIDS orphan has been mobilised by global policy and intervention discourses to refer to the mass of vulnerable children who, as a consequence of AIDS, have been supposedly stripped of adult care. Research has illustrated that children of AIDS-sick parents carry a heavy caregiving burden, taking on adult responsibilities both during their parents' illness and after their death, with some becoming household heads (Barolsky 2003). These children have been

shown to lack community and institutional support and regularly skip or drop out of school (Cluver et al. 2011; Robson et al. 2006). Early constructions of AIDS orphanhood often reflected a moral panic about the impending social breakdown that was anticipated to follow rising numbers of orphans (Bray 2003). These children were believed to be deprived of functioning homes and families to oversee their proper socialisation (Meintjes & Giese 2006b, p.415). Today, psychosocial distress amongst orphans has given rise to similar levels of panic and widely circulated discourses of vulnerability (Cluver et al. 2007; Wild 2001). As a consequence of academic and policy discourses emphasising orphan vulnerability, donor funding and interventions have often revolved around this group of children.

In order to critique and complicate the literature on South African orphanhood, Meintjes and Giese (2006a) have shown that, in contexts of generalised poverty, the circumstances of poor, orphaned children may not be too far removed from those of non-orphans. Apartheid-enforced restrictions on black mobility, and flows of migrant job-seekers have contributed to a long history of separation between parents and their children, producing many severed and stretched households (Bray 2003; Henderson 2012). Hence, irrespective of their orphan status, South African youth have long been involved in fluid and extended childcare arrangements, where both children and adults are in mobile pursuit of work, education, healthcare or political safety. Whether they have lost parents or not, it has not been uncommon for grandparents to contribute to the livelihoods of their grandchildren, particularly through old-age pensions.

A growing body of research has illustrated the role of multiple caregivers throughout the course of children's lives (Henderson 1999; Meintjies & Hall 2009; Ross 2010).

The contemporary lives of children orphaned by AIDS are perhaps best understood in the context of a longer history, characterised by generational experiences of death and the changeability of social relationships of care. In other words, the demands of HIV/AIDS might only amplify other forms of separation, severance and loss. As such, families might call upon pre-existing repertoires of care to attend to the new exigencies of HIV/AIDS.

The Struggle for HIV Treatment

Thus far, I have explored the social history of HIV/AIDS in South Africa before antiretroviral treatment became publically available. I have given particular attention to the impact of AIDS deaths within families and the home as a site of care. While families absorbed the growing numbers of AIDS orphans, attended to the unfinished work of the dead, and nursed the sick in their homes, communities also responded organically to the emerging crisis. Through orphanages, home-based care programmes, hospices, faith-based organisations, and peer education (Friedman & Mottiar 2005; Rau 2006), they subsidised and shouldered the country's care burden.

Civil society also took action. In 1999, *Medicines Sans Frontières* (MSF), supported by the Treatment Action Campaign (TAC), initiated pilot treatment sites in Khayelitsha (Coetzee et al. 2004) and Lusikisi (Bedelu et al. 2006) to confront the dearth of lifesaving ART. These pilot programmes sought to demonstrate that ART could run successfully despite limited resources. MSF's approach was to teach nurses, lay people and ART users how the medicines worked, fostering 'expert' patients and shifting tasks from doctors to nurses, professionals to community healthworkers. Layworkers were

entrusted with monitoring treatment adherence, administering voluntary testing and counselling, and facilitating support groups.

Despite scientific evidence and the success of pilot ART programmes, the South African government under President Thabo Mbeki (1999–2008) became an epicentre of AIDS 'denialism', resistant to supporting ART programmes and offering support for alternative treatments. These included Virodene, a purported 'African' solution' to AIDS, traditional medicines like 'Ubejane', and alternative diets of African potato, olive oil, garlic and lemons (Robins 2009, p.324). Contesting the causal link between the HI-virus and AIDS, Mbeki sought to dismantle associations between AIDS and 'black promiscuity' and resist African dependency on Western health technologies. Thus, embedded in his challenges of the scientific orthodoxy was an anti-imperialist and anti-racist rhetoric that sought to resist Western hegemony in both defining and solving Africa's problems (Fassin & Schneider 2003).

In addition to rolling out and advocating ART at pilot sites, TAC and MSF also lead a highly organised and globally-connected network of scientists, health professionals and activists in a political struggle for life-saving treatment. AIDS activists leveraged newly-instituted democratic institutions, particularly the courts, in a rights-based campaign for drug access, whilst also crusading against pseudo-science and promoting an approach to AIDS grounded in scientific evidence (Mbali 2013). These activists also exploited multiple and fluid tactical allegiances – collaborating with trade union COSATU in support of the Basic Income Grant, with government to oppose pharmaceutical overpricing, and with international organisations against government-sanctioned AIDS denialism (Friedman & Mottiar 2005). These strategies were

complemented by grassroots mobilisation, which drew on rhetorical and protest strategies employed in the anti-apartheid struggle (Friedman & Mottiar 2005; Mbali 2013). Mobilising the experiences of HIV-positive activists and the success of pilot programmes, the treatment access movement sought to bring HIV into the open, claim the right to treatment, and give people ownership of AIDS science.

Anthropologists across a diversity of African settings have explored the self-help techniques and forms of testimonial through which AIDS activists have mediated access to essential resources, established important social networks, counteracted discrimination, and campaigned for drug access (Nguyen et al. 2007). These ways of assuming an HIV identity have been dubbed "therapeutic citizenship" (Nguyen et al. 2007) and "responsibilised citizenship" (Robins 2005).

As a means to attest to the lives and deaths of those with HIV, the practice of 'witnessing' was firmly established before ART (Nguyen et al. 2007; Whyte et al. 2014). But among those accessing early treatment, 'testimony' was consumed with stories of resurrection through pharmaceuticals. Tales of ART's restorative powers were recited to reassure, to convince, and to astound, during a time when HIV treatment was a novelty. By holding out the promise of recovery, they also served to encourage HIV testing and adherence.

In addition to national-level 'denialism', some AIDS activists have also had to contend with local expressions of distrust, scepticism and antagonism towards biomedical interventions. Some of these are rooted in a history of racial discrimination and biological weaponry in South Africa, from which public health interventions have not

been exempt (Fassin & Schneider 2003). In other instances, these responses are based on alternative understandings about the roots of illness, which do not disaggregate between social and physical explanations of death and disease, and may include witchcraft aetiologies (Ashforth 2002; Epstein 2008; Rödlach 2006). Social researchers (Babb et al. 2007; Mills 2006) have found that many in South Africa practice medical pluralism, using biomedicine alongside complementary and alternative treatments, including African traditional medicine, Pentecostal faith healing or homeopathy.

Sex, Youth and HIV Prevention

While AIDS activists advocated passionately for ART, many also sought to halt the spread of HIV. Thus, alongside campaigns for HIV treatment, the late 1990s also saw the emergence of large-scale HIV prevention programmes. Many were aimed specifically at South African youth. The most prominent of these, *Lovelife*, used mass media to promote sexual responsibility and healthy living among young people. Campaigns included billboards, radio, nationwide events and the recruitment of young peer educators, known as *Groundbreakers*. Lovelife fused safe sex messaging with popular youth culture in an effort to make safe sex 'cool' and bring sex talk into the public sphere.

Focusing on open communication about sexuality, shared responsibility for sex, and informed choice, Lovelife meshed positive sexuality with personal development and motivation. In doing so, it encouraged young people to "set goals, seize opportunities and overcome difficulties" (Lesko 2007), entailing a "refashioning of the self in line with the aspirations of newfound modernity" (Posel 2005). But this set of messages were often contested in their implementation as Groundbreakers came into conflict with

intergenerational silences around sex, cultural limits on youth autonomy, and socio-economic constraints that limited young people's growing optimism and ambition.

Despite these challenges, Lovelife messaging has had wide reach, producing a public discourse on the risks of youth sexuality and promoting the self-empowered sexual citizen. In a recent quantitative survey of 3,123 youth across four South African provinces, one in three participants had participated in Lovelife activities (LoveLife 2012). But despite the infiltration of Lovelife messaging into public discourse, the impact on behaviour has been mixed, with positive effects on condom-use (Pettifor et al. 2007), but little impact on the uptake of testing and treatment services (Taylor 2010). The prominence of youth risk in South African public discourse on AIDS can also be attributed to popular television dramas revolving around the sexual choices of urban, black youth, including *Soul City*, *Soul Buddyz* and *Yizo Yizo*.

In the pre-ART era, two prevalent discourses came to characterise discussions of youth and HIV: the 'crisis' and 'vulnerability' associated with AIDS orphans, as well as the risks (and potential empowerment) of youth sexuality. Indeed, the early academic literature on youth HIV in sub-Saharan Africa was preoccupied with HIV prevention and sexual risk, exploring the attitudes, HIV knowledge and sexual behaviours of adolescents (Woog 2003).

While perinatally-infected youth might be treated as victims of their circumstances or marked as quintessentially vulnerable AIDS orphans, sexually-infected youth risk being blamed for their 'deviant' sexuality. This is especially so if they are pregnant and diagnosed in an antenatal clinic. Indeed, the pervasive discourse surrounding

teenage pregnancy in South Africa has been characterised by moral angst over the untimely sexuality and age-inappropriate behaviour of pregnant girls (Macleod 2001). This discourse becomes particularly pertinent for those adolescents in this study who tested for HIV while pregnant.

Life after ART

A recent calculation estimates that more than 330,000 people lost their lives, and 35,000 HIV-positive babies were born, as a result of delayed ART rollout under the Mbeki-led government (Rohleder & Kalichman 2009). The arduous struggle for accessible, affordable antiretroviral treatment was finally won in 2004 when the state instituted a national, public sector ART rollout programme, currently the largest of its kind in the world. More than three million people are currently on HIV treatment in South Africa (Ramaphosa 2015). The young people in this study are among the first generation to benefit from this scaling up of ART — when the price of ART fell, free drugs were distributed en mass, and a plethora of programmes surfaced to offer treatment and support. While these ART support initiatives are unevenly distributed, and in some areas in short supply, they have nevertheless had an indelible impact on the country's care landscape.

With the advent of ART, the 'work' of HIV care has entered the domestic sphere in new ways. The project of ART reconfigures, and occasionally blurs, the work of home and clinic: just as medical surveillance is folded into the care practices of the home, so too has the purview of the clinic extended to the intimacies of sex, nutrition, and familial relations. In a study of caregiving in Burkina Faso, Hejoaka (2009, p.6) described mothers caring for HIV-positive children as "substitute healthcare workers". Similarly,

health providers in Busza's (2014) Tanzanian study were reported to position themselves as "aunts" or "grandmothers". More so, the frequently-moralising authority of female elders may govern both domains of home and clinic.

The daily intake of strictly-scheduled HIV drugs is precariously inculcated into household routines and care obligations. In studies across sub-Saharan Africa, successful ART among HIV-positive youth has been partly attributed to their ability to integrate medication into their daily lives. Interruptions or changes to daily routine were cited as one of the most significant barriers to adherence (Biadgilign et al. 2009; Bikaako-Kajura et al. 2006; Fetzer et al. 2011; Marukutira 2012; Vreeman et al. 2009; Vreeman et al. 2010). ART has imprinted itself on the home, requiring a re-orienting of routines and care relationships that facilitate pill-taking. But similarly, the social dynamics of home might be imbued into ART, as medication becomes a vehicle to assert obligation, reciprocity, and order.

HIV industry

Antiretroviral treatment is now mediating the survival, health, and wellbeing of millions of people and rendering their lives contingent on the global, local and humanitarian financing mechanisms that keep ART rollout afloat. Following from a history of globally-networked advocacy and prevention campaigns, South Africa's national ART rollout has continued to link global and local actors in unprecedented ways (Richey 2012). In addition to modelling itself on World Health Organisation guidelines for ART delivery, and pursuing global policy standards for community-based and holistic ART delivery, colossal global health programmes also fund the current ART programme in South Africa. These include Presidents Emergency Fund

for AIDS Relief (PEPFAR) and the Global Fund to fight AIDS, Tuberculosis and Malaria (Richey 2012). In addition, the South African government has recently partnered with the Clinton Health Access Initiative and PEPFAR to drastically decrease the price of antiretroviral drugs in state tender agreements (Venter 2013, p.40). These international institutions have had an epistemic influence on local models of ART care, framing the nature of the problem, establishing priorities, and setting standards for monitoring and evaluation (Cassidy & Leach 2009, p.11).

Even more so than in the pre-ART era, the provision of HIV treatment and support has given rise to a complex HIV/AIDS industry with its own occupations and economic logics, as well as a multitude of non-state enterprises and smaller support groups at work. In this economy, HIV identities accumulate moral and economic value. Through them, people become visible to flows of financial and other resources organised by NGOs (Prince 2012). Ethnographic research on ART programmes across Southern, East and West Africa has reflected on the competition for NGO-distributed resources among the "poor and positive" (Beckmann & Bujra 2010; Boesten 2011) and the tactics of making one's needs legible to funding institutions (Nguyen 2010). This literature has also signalled the social stakes involved in vying for donor recognition (Frank & Rödlach 2013). In South Africa, the ability to access HIV-targeted resources is complicated by a context of deepening socio-economic insecurity in which access to well-resourced patrons is hotly contested.

Chronicity

The widespread distribution of ART has been accompanied by a shift in focus from questions of access to the challenges of sustaining a mass treatment programme (Venter

2013). Given that ART requires strict adherence in order to prevent treatment failure and drug resistance (Hardon et al. 2006), health activists have given increasing attention to the challenges of ongoing treatment (Hardon et al. 2006; Mills et al. 2006). In an era of ART, the formation of empowered HIV-positive identities has been used not only to manufacture AIDS activists, but also to generate ART adherence. In many South African ART clinics, the creation of 'responsibilised' therapeutic citizens has allowed for the construction of ART as a set of rights and responsibilities: the right to treatment access corresponds with the responsibility to understand and adhere to it. Accordingly, many ART programmes have called for a "new contract" between health providers and "clients" to foster highly-motivated and knowledgeable HIV-positive patients (Colvin et al. 2009, p.8). This has extended beyond medication-taking to include picking up treatment on time, avoiding alcohol, using condoms, planning pregnancies, enduring medication side effects, and disclosing one's HIV status. 'Salvation' on ART is only possible for those who commit to the prescribed behaviours entailed in this 'positive living'.

For growing numbers of people, life with HIV is constituted by lifelong treatment, an epistemic commitment to AIDS science, and the adoption of prescribed lifestyles. However, barriers to care, persistent HIV/AIDS stigma, and debilitating side effects undermine assertions that HIV is a 'chronic' illness (Moyer & Hardon 2014). Nevertheless, the fact that millions of people are now able to treat HIV through lifelong medication has radically altered the nature of HIV care. In the early years of the HIV/AIDS epidemic, HIV-positive people from all walks of life shared the common vulnerability of certain death. Care for those living with the virus was frequently defined in palliative terms, aimed at alleviating suffering from frail, wasting, and

scarred bodies. In the era of ART availability, HIV care has increasingly been constituted by the mass rollout of state-provided pharmaceuticals, bureaucratic strategies for health surveillance, and the regulation of 'lifestyles'.

The recent arrival, and mass distribution, of ART in South Africa has been concomitant with the unprecedented rollout of other chronic medicines. A substantial proportion of South African ART users would have initiated HIV medication whilst on tuberculosis (TB) treatment, and many will need to be treated for TB in their lifetimes (Cohen & Meintjes 2010). Compounding the burden of HIV and TB is the rising number of patients suffering from non-communicable diseases (NCDs), which now form part of South Africa's "quadruple burden of disease" (Lawn & Kinney 2009). While ART availability transforms HIV into a chronic, rather than a terminal, illness, it also increases overall chronicity. This is not only because HIV-positive patients live longer, but also because they do so at increased risk of additional chronic conditions.

In this context, interactions with medical facilities are less ad hoc and less determined by desperately sick bodies. Instead, the bulk of patients in South Africa's health facilities are regular attendees. Their experience of care is increasingly characterised by the ritualised collection and consumption of pharmaceutical technologies, and lifelong participation in health surveillance. Routinised measurements of bodyweight, blood sugar, immune cells and blood pressure create new ways of imagining and ordering the body. People become members of a health programme, giving way to new forms of sociality and belonging.

ART and Belonging

INTRODUCTION

To access ART is not simply to seek treatment here and there. It entails affiliation to a programme through check-ups, monitoring and refills. In the words of Richey (2012) and Whyte et al. (2014, p.58), the new generation of ART users in sub-Saharan Africa is a generation of "clients". A client, they argue, is not merely a customer the way a patron in a drug store might be. Nor is a client simply a patient. Instead, clients participate in institutions of care with associated expectations and entitlements. Success on ART entails an everyday performance in which users partake in acts of self-surveillance and self-care.

Within the anthropological literature on (predominantly adult) ART users, some authors have sought to distinguish clientship from articulations of therapeutic citizenship. Therapeutic citizenship is frequently understood as a rights-based sociality (Nguyen 2005). People formulate group identities based on their shared biological status, mobilise their treatment narratives to make empowered claims on state and donor resources, and are transformed into 'expert', 'self-reliant' and 'responsibilised' patients. Yet, in rapidly expanding treatment programmes across sub-Saharan Africa, the production of ART adherence has also articulated in less empowered forms of 'getting by' (Mattes 2011; Meinart et al. 2009; Richey 2012). Rather than drawing on communities of solidarity to confront public and private donors, many people have played to their patrons, instrumentally adopting the language of funders. They have participated in tactical competition for donor spoils, negotiating multiple relationships of hierarchy and dependency. This type of "capacity building" has fostered obedient patients over and above political mobilisation or the forging of political alliances (Beckmann & Bujra 2010, p.10). While learning to speak as 'HIV-positive', many also learn to articulate this identity in different moral registers: sometimes as responsible

health citizens, sometimes as needy and suffering (Prince 2012, p.17).

Indeed, there is another meaning of clientship also at play: clientship invokes hierarchical dependence between a patron and a beneficiary, where the former offers the latter scarce resources in exchange for less tangible forms of loyalty and discipline (Whyte et al. 2014). In a recent compilation of case studies from Uganda, Whyte et al. (2014) examine the experiences of the country's first generation of ART users. The authors recall a story in which one of their respondents, Robinah, tellingly described her relationship to her home-based care programme, saying: "I am their person" (Whyte et al. 2014, p.56). In ART programmes, the personal, emotional quality of these "lop-sided friendships" (Pitt Rivers in Wolfe 1963, pp.19–17) is often mediated through a nexus of paradoxically impersonal, bureaucratic procedure.

In their study of ART participation in Tanzania, Beckmann and Bujra (2010) articulate these socialities historically. They argue that, along with the increasing availability of ART, the focus of debate among those living with HIV has shifted from physical survival in the face of a deadly disease to economic survival and reintegration into society. ART prompts people's struggle for work, partners and a 'normal' life, rather than articulating their HIV identities. Indeed, Biehl (2007, p.94) has argued that the "patient-citizenship" of ART users in the developing world frequently articulates within a global "politics of survival", combining struggles for food, housing and social security with a new political economy of pharmaceuticals.

Questions of sociality have been central to anthropological and social science literature on ART in Africa. The labels of 'clientship' and 'citizenship' are now widely and

varyingly used. Their distinctions have at times become murky. Regardless of the labels attached, attempts to understand ART as a social relation nevertheless signal something important about the meaning of life on HIV treatment. To be an ART user involves a sense of belonging to a programme and often an intricate network of personal relationships, expectations and entitlements (Whyte et al. 2014, p.58). Increasingly, HIV-positive people belong to organisations that register their information, offer regular services, and have expectations of their users. Whether as 'therapeutic citizens', 'patient-citizens' or 'clients', ART users enter into "local moral economies", calling on "networks of obligation and reciprocity" to negotiate life on ART (Nguyen 2005, p.126).

In some situations, HIV can be an asset, opening up spaces for recognition and entitlements, and making one legible to the organisations that distribute material resources. But in other situations, HIV can be a source of stigma, a threat to belonging and sociality, and a status best kept hidden. As people negotiate life with HIV, they also "move between these different registers of invisibility and visibility" (Prince 2012, p.17). Those participating in contemporary ART programmes negotiate highly ambivalent social worlds in which openness and solidarity are idealised, while secrecy, fear and discrimination are also everywhere. By maintaining the ambiguity of their HIV status, a person might exercise "defiance or deference, self-preservation or resignation" (Comaroff in Dilger & Luig 2010, p.26).

Politics of Distribution

In South Africa, the mass distribution of antiretroviral drugs has been carried out alongside a grand-scale project of social welfare delivery. Over 18 million people

— that is one in every three South Africans — benefits from a state grant (Bundy 2015, p.1). While the growth of social welfare preceded 1995, the extraordinary expansion of state benefits has been the most striking characteristic of policy and practice since democracy.

The South African state's investment in welfare has served as a response to profound social and economic changes, which gathered steam in the final decades of apartheid. The most important among these was a steady withdrawal from fixed, large-scale, labour intensive production, which amounted to mass unemployment (White 2012, p.339). In combination with reduced marriage rates, the country's labour market changes mark a generational shift, which Hunter (2010, p.5) describes as follows: "from mostly men earning a living and supporting a wife, to many men and women, making a living in multifarious ways".

Although political liberation has legally and politically incorporated black South Africans into the economy, jobs have become scarcer. The radical dissolution of agrarian livelihoods in the former homelands, alongside skyrocketing unemployment, has thwarted both of the "great fantasies" of black family life in South Africa: the extended rural household providing for its members, and the urban nuclear family centred on the male breadwinner (Ferguson 2015, pp.78–79). In the post-apartheid period, inclusion and citizenship through work is a remote possibility, owing to widespread unemployment (White 2012). Notwithstanding the extent of joblessness, the unemployed have received almost no support, neither from the South African state nor private schemes.

INTRODUCTION

Evidence suggests that, since the 1990s, one section of South Africa's unemployed population have suffered particularly, not only because of their lack of employment, but also their systemic disadvantage in accessing jobs (Seekings 2003). The most disadvantaged of the South African populace are also often isolated from society and do not have networks outside of their close communities. This lack of connection has profound cost because personal contacts get people jobs (Seekings 2003, p.7).

Sociologist Jeremy Seekings (2006) has drawn on considerable evidence to suggest that, in recent decades, many of South Africa's unemployed have found jobs, and their employers workers, through informal networks. Drawing on research from the Northern Province, Barber (1998, pp.219–220) has described the South African labour market as comprising of a "protected group of 'insiders' and a considerably worse-off group of 'outsiders', trapped in unemployment or in low-paid, unskilled jobs with high rates of turnover". As a result, those with employed friends and relatives have been better able to access work. "Employment and unemployment tend to cluster in households" (Wittenberg in Seekings 2003, p.14). Connections can also help the rural unemployed find jobs in distant urban areas. Sparber (1993), for example, found that a large proportion of migrant workers from one Ciskei village were employed in two specific dairies in Port Elizabeth and Cape Town. Thus, South Africa's worst-off might be characterised by profound social exclusion, in which poverty and marginality stem from a collapse of the relationship between society and the individual.

In a context of joblessness and HIV/AIDS, pressures on reciprocal relations among kin and neighbours have arguably persisted and intensified (Bähre 2011, p.3). It is through kin and connection that many negotiate survival and opportunity. For those households

that are delinked from the labour market on a more or less permanent basis, members often depend on their welfare-recipients. The distribution of government social grants has the potential to reconfigure domestic and neighbourhood relations (Bähre 2011, p.5). Women, in their position as child-bearers and carers are the primary beneficiaries of this welfare. In many other homes, it is perversely the sick, the orphaned, the disabled, or the elderly who generate income, rather than young adults in the prime of their lives (Bähre 2011, p.12). Some families might rely on their youngest children for material support — those in whose names grants are available (Henderson 2012).

In South Africa, a context of mass unemployment and social exclusion has arguably provoked new kinds of dispositions towards the authority of the state (White 2012). People are seeking less mediated, paternalistic relationships with government patrons — a relationship that is sometimes imagined through welfare. This growing "politics of distribution" (Ferguson 2015) highlights the increasing materiality of the civil link between citizens and state. Insufficient anthropological attention has been given to large-scale redistribution "as a distinct mode of exchange and sociality" (Bähre 2011, p.4).

One of the characteristic features of state-citizen relations in an era of mass health and welfare programmes is the centrality of bureaucratic technology in signifying membership, distributing resources, and enacting surveillance. Birth certificates, death certificates, identity documents, and blood test results form part of the litany of documents required to demonstrate eligibility for social grants. Once registered as grant recipients, people continue to interact with state welfare through technology. A high-tech system of biometric identification and smart-card transactions facilitates a

complex interchange between state and citizens, carried out millions of times every month (Donovan 2013, p.23).

ART users are similarly involved in regularised, technologically-mediated interactions with the state. And as in the social welfare system, membership to an ART programme is indexed through paperwork. Records of treatment history, medical prescriptions, and appointment dates not only register patient entitlements, they also document and attempt to induce compliance.

As beneficiaries of foster child, disability and child support grants, as well as regular users of ART services, young people in this study are uniquely located in state health and welfare programmes. The technologies and bureaucracies of these systems have therefore had important implications for how they imagine their life and livelihoods in contemporary South Africa.

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This brief historical overview has sketched changes in South Africa's HIV/AIDS epidemic and socio-political landscape, as they have unfolded during the lifetimes of young people in this study. The overview has sought to locate youth within this history — as family members, welfare beneficiaries and targets of intervention. In the next section, I will discuss existing qualitative literature that has explored adolescent HIV in sub-Saharan Africa. In line with the discussions so far, I have organised this review as a generational analysis, paying attention to adolescents as sons, daughters, and grandchildren, as a category of 'youth', and as a cohort uniquely located in the history of the region's HIV/AIDS epidemic.

TO BE YOUNG AND HIV-POSITIVE IN SUB-SAHARAN AFRICA: A THEMATIC REVIEW OF THE QUALITATIVE LITERATURE

As HIV treatment has expanded across sub-Saharan Africa, accompanied by a growing cohort of adolescents on ART, qualitative researchers have shown increasing interest in the specific experiences and challenges of this cohort. Although the first of these studies were published just over a decade ago, research remained sporadic until 2012. The past few years have seen an extraordinary surge in qualitative studies exploring the lives, needs, and care of HIV-positive adolescents in the region. Indeed, research output has increased more than three-fold since 2012.

In June 2015, I conducted a systematic search of major electronic databases[3] for qualitative studies concerned with HIV-positive adolescents in sub-Saharan Africa. Reference lists of retrieved articles were scanned for studies that may have been overlooked in the search. To be included in the review, articles needed to explore some aspect of the life and care of HIV-positive adolescents in sub-Saharan Africa. At least some of the study participants had to fall within the WHO definition of adolescence (age 10–19). Evaluations of specific support tools for adolescents were excluded, as were mixed methods studies. The search was further refined to include only English language papers. A total of 65 articles met these inclusion criteria. They are listed chronologically at the end of this review. Just over half of these were Southern African studies, while the remainder drew from East and Central African research. Twenty-four percent of the included studies were based on research from South Africa.

[3] *PsychInfo, Embase, CAB, Global Health, Medline, Google Scholar*.

The qualitative literature on adolescent HIV in the region now has great scope. The process of informing adolescents of their HIV status has received particular attention. Other themes include experiences of stigma, uptake and retention in HIV care, and sexual and reproductive health. Only 11 percent of the included articles have been directly concerned with the experience of adolescents as ART users. Just one of these studies, conducted in 2010, was from South Africa.

I cannot hope to give a comprehensive account of the breadth and depth of this research here. Instead, I am interested in how this literature might be illustrative of the 'generational' experiences of the region's HIV-positive adolescents. In offering a thematic review of the literature, I ask how adolescents' negotiation of life with HIV has been shaped by three generational factors: 1) Their relationships with adult caregivers, 2) constructions of youth and childhood, and 3) their being the first generation to grow up in an era of ART. In each case, I consider not only what existing research reveals about the generational experience of HIV-positive adolescents in sub-Saharan Africa, but also how the articles in this thesis might add to this work. While questions of generation are implicit in the literature, I hope through this review to foreground and sharpen them. Doing so might underscore the unique needs and challenges of the region's HIV-positive adolescents, while also signalling areas for future research.

Intergenerational Care

The vulnerabilities and social implications of HIV/AIDS orphanhood have been well rehearsed in the literature from sub-Saharan Africa (Bray 2003; Bicego et al. 2003;

Cluver & Gardener 2007). So too have the burdens of foster care for caregivers, and grandmothers in particular (Kuo et al. 2014; Schatz & Ogunmefun 2007). Among the region's AIDS-orphaned children are those who have inherited HIV from their now-deceased parents. Yet their experience of growing up with HIV, as well as the challenges of those caring for an HIV-positive child, have been comparatively underexplored. Qualitative research on the region's perinatally-infected youth makes a novel contribution by considering how orphanhood might be complicated for those who inherit HIV from their parents. For many of these adolescents, negotiating life with HIV is bound up with the emotional work of adjusting to parental loss — where the deceased parent has "often left the disease, and little else, as their legacy" (Parker 2009, p.176). Recent research (Hejoaka 2009; Rutakumwa et al. 2015; Sikstrom 2014) has also sought to explore the everyday work of raising children with HIV — how youth HIV testing, treatment and care is negotiated within homes and families.

In Burkina-Faso, Hejoaka (2009) conducted an ethnographic study among mothers caring for HIV-positive children, detailing the intricacies of administering routine pill-taking, and mothers' discomforts in discussing treatment with their children. More recently, Sikstrom's (2014) Malawian ethnography has explored the role of parents and grandparents in the therapeutic trajectories of their HIV-positive children. Her research offers important insight into the gendered and generational dynamics that shape HIV care for children. Because they had not received explicit consent from their husbands, some mothers delayed testing their children for HIV. Grandparents played an important role in mobilising HIV testing and treatment for their grandchildren, drawing on their age-based authority to convince parents of the need for testing.

In Uganda, Rutakumwa et al. (2015) have explored reciprocal care relations between grandparents and their HIV-positive grandchildren. Because of the circumstances in which many grandparents come to care for orphaned children, care is frequently perceived as unidirectional — where the 'needy' child is strictly the recipient and the older person the provider of care (Rutakumwa et al. 2015, p.2131). While adolescents in Rutakumwa et al.'s study depended on grandparents to attend to their basic health needs, grandparents also expected their grandchildren to perform housework and demonstrate obedience. When mutual expectations were not met, this could give rise to intergenerational tensions.

Disclosure and Intergenerational Relationships

In elucidating care for HIV-positive adolescents in the region, qualitative researchers have given disproportionate attention to the dilemmas of informing perinatally infected adolescents of their HIV status. This has largely been explored from the perspective of adult carers, who have often explained the challenges of disclosing to adolescents by calling upon norms of intergenerational communication, and assumptions about the capacities of youth.

While a few studies described the disclosure of an adolescents' HIV status as a once-off event (Pienaar & Visser 2012; Vaz et al. 2010), many more presented disclosure as a messy process, shaped by adult fears over the consequences of this revelation (Bikaako-Kajura et al. 2006; Fetzer et al. 2011; Kidia et al. 2014; Madiba 2012; Mattes 2014). In line with literature from elsewhere, research from sub-Saharan Africa has shown that informing adolescents of their HIV status poses extraordinary obstacles for caregivers (Busza 2011; Petersen et al. 2010): guardians fear emotional damage to the

child (Kajubi et al. 2014; Madiba 2012), ruptures in intergenerational conviviality, and that children's indiscretion about HIV might threaten the reputation of the family (Heeren et al. 2012; Hejoaka 2009; Kidia et al. 2014; Madiba 2012). Consequently, only a minority of children living with HIV in sub-Saharan Africa are reported to have received disclosure of their HIV status (Vaz et al. 2008; Vaz et al. 2010; Vreeman et al. 2010). Caregivers have wrestled over the 'right time' to disclose, occasionally making reference to adolescents' developmental readiness: some perceived adolescents to be 'too young' to grasp the consequences of HIV for their lives and relationships (Kajubi et al. 2014; Kidia et al. 2014; Madiba 2012).

The question of how adolescents discover their HIV status has positioned intergenerational relationships, and indeed relatedness, at the centre of youth HIV studies in the region. For many perinatally-infected youth, the process of coming to know, reconcile and treat their HIV illness bridges three familial generations. The practice of ART might be coproduced by grandmothers and grandchildren, and entail regular, symbolic confrontations with a missing generation.

To tell a perinatally-infected adolescent of their HIV illness is to invoke their parents, which might in turn shore up conversations about sex and death. As sites of sensitivity and taboo, these discussions are reported to have immense inflammatory potential (Kajubi et al. 2014, p.43). Guardians fostering adolescents feared shoring up conversations of their parents' death(s) (Mhlongo 2012, p.157). Given their role in transmitting the virus, biological parents were reluctant to initiate potentially-blaming and hurtful conversations about their own, and their child's HIV status (Kiwanuka et al. 2014; Mandalazi et al. 2014).

Discrete talk about sex and death has served to maintain generational boundaries between youth and adults, where silence is often wrapped up with the protection of adolescents' 'innocence'. Domestic hierarchies and norms of discrete speech have significantly impeded the ability of caregivers to disclose their child's HIV status to them (Kajubi et al. 2014; Mburu et al. 2014; Mhlongo 2012, p.157). In Zimbabwe, Kidia et al. (2014) found that caregivers' anxieties about disclosing adolescents' HIV status made them less effective in facilitating this process than health providers.

In light of its challenges, caregivers have often delayed disclosure or provided incomplete, even inaccurate, information to their children (Kidia et al. 2014; Madiba 2012; Mhlongo 2012). In Kinshasa, Vaz et al. (2010) found that many caregivers provided their children with partial information about their HIV status. These strategies included providing the child some information about their illness, while also refusing to name it.

Drawing on ethnographic research from Tanzania, Mattes (2014) described how the discomforts of disclosing adolescent HIV lead to routine shifting of responsibility between guardians and healthworkers. Among healthworkers, there was a tacit understanding that the responsibility for disclosure lay with adolescents' guardians. After age ten, many healthworkers proceeded as though adolescents had already been disclosed to. Meanwhile, caregivers who felt unprepared for the task of disclosure regularly implied that clinic staff should facilitate this process. As a result of these contradicting strategies of disclosure and concealment, adolescents were reported to "manoeuvre in a field of informational inconsistency" (Mattes 2014, p.28). Many were

left with fragmentary or contradictory information, while others came to the knowledge of their HIV status indirectly through gossip, accident, or inference (Busza 2011; Kidia et al. 2014; Mattes 2014).

ART Adherence and Intergenerational Relationships

As the preceding discussion suggests, there is now a growing body of research exploring how healthworkers and caregivers experience the dilemmas of disclosing HIV to adolescents (Kiwanuka et al. 2014; Madiba & Mokwena 2012; Madiba 2012; Mandalazi et al. 2014; Mutumba et al. 2015; Vreeman et al. 2009; Vreeman et al. 2010). Complementing this work, some researchers have sought children's perspectives on the impact of receiving an HIV diagnosis. Studies from Botswana and Tanzania (Midtbø et al. 2012), the Democratic Republic of Congo (Vaz et al. 2008), Zimbabwe (Kidia et al. 2014), Kenya (Vreeman et al. 2010) and Uganda (Bikaako-Kajura et al. 2006) report that disclosure is generally beneficial for young people who, prior to learning their HIV status, are resentful and confused. Being informed of their HIV status helped adolescents come to terms with their illness and made medication-taking more meaningful (Midtbø et al. 2012; Vaz et al. 2008). Indeed, the qualitative literature from sub-Saharan Africa has shown that both adolescents and caregivers perceive HIV disclosure to be an important facilitator of ART adherence (Bikaako-Kajura et al. 2006; Fetzer et al. 2011; Vreeman et al. 2010).

Implicit in the literature on adolescent ART adherence are two 'generational' concerns: first, that as children enter adolescence they are more prone to resisting medication. And second, that adolescents' adherence is often a product of their relationship with adult caregivers.

In Uganda and Kenya, researchers highlighted growing tensions in caregiver-adolescent relationships as children entered adolescence and became increasingly resistant to taking medication. Resistance was amplified if the purpose of treatment had not been explained to them (Bikaako-Kajura et al. 2006; Vreeman et al. 2009; Vreeman et al. 2010). In these instances, missed medications could serve as a vehicle for young ART users to express their frustration (Bikaako-Kajura et al. 2006; Fetzer et al. 2011; Kunapareddy et al. 2014). For some caregivers, disclosure was a last resort to assuage adolescent defiance or questioning, and promote treatment-taking (Kajubi et al. 2014; Madiba 2012). Studies from the Democratic Republic of Congo and Kenya affirm that caregivers who chose to disclose adolescents' HIV status to them were often motivated by a desire to improve their child's medication-taking (Vaz et al. 2010; Vreeman et al. 2010).

Hence, in line with research from elsewhere, qualitative literature from sub-Saharan Africa has shown that adolescent ART is bound up with the child-caregiver relationship, where taking or refusing ART can be an expression of intergenerational concord or conflict (Denison et al. 2015; Fetzer et al. 2011; Marukutira 2012). While ART adherence could be a product of mutuality and collaboration, it was not necessarily so. Successful ART could also be achieved through forms of hierarchical discipline and compliance. Drawing on qualitative research from Zimbabwe, Mupambireyi et al. (2014) observed that some adolescents who confessed their adherence slippages risked being scolded, blamed or punished by their carers. In studies from Uganda and the Democratic Republic of Congo, some of the most compliant participants proved to be undisclosed younger adolescents. Many of them had been

coerced into good adherence by their caregivers through physical force or bribery (Bikaako-Kajura et al. 2006; Fetzer et al. 2011).

Growing up in a Time of ART

The rapidly growing qualitative literature on adolescent HIV in sub-Saharan Africa has signalled a series of ambiguities in the lives of young people with HIV. These are born out of their position as the region's first generation of adolescent ART users. As ART access has expanded, so too has the discourse of living a 'normal' life with HIV. Numerous studies in this review have explored adolescents' struggles to reconcile their idea of being socially-integrated 'normal' youth with that of being 'different' on the basis of their HIV status (Mattes 2014; Pienaar & Visser 2012). Adolescents worked continuously to resolve the disjuncture between maintaining a sense of normalcy, while also experiencing debilitating drug side effects, social discrimination, and precarious sexual relationships (Mattes 2014; Mhlongo 2012; Pienaar & Visser 2012).

In Parker's (2009) Tanzanian study, perinatally-infected youth struggled to reconcile their low energy and chronic lung complaints with the physical work and play expected of a 'normal child'. Similarly, Petersen et al. (2010) identified the struggle to live a normal life as a source of great distress among HIV-positive adolescents. In Uganda and Zimbabwe, Bernays (2015) found that, despite radical developments in the prognosis of HIV-positive adolescents, their experience of HIV was largely constructed in the language of sickness. Living with HIV was characterised by the recounting of past illness narratives and the recitation of medicalised talk related to ART adherence (Bernays et al. 2015). The challenges that many young people faced in trying to articulate the relative buoyancy of their health, were considered indicative of the

uncertainties of adolescents' future at this moment in the HIV/AIDS epidemic (Bernays et al. 2015).

Negotiating Stigma and Care

These ambiguities translated into young people's experiences of ART and social support services. Antiretroviral treatment was reported to aid adolescents in managing distress and stigma, yet consuming daily ART could also be a reminder of one's illness (Thupayagale-Tshweneagae 2010). In Dube and Ross' (2012) study, adolescents at Nkosi's Haven appreciated the centre as a place of care, nurturing and educational opportunity. But there was also discrimination and social exclusion associated with living at the home, which limited young people's ability to freely integrate with their peers. Consequently, Dube and Ross described Nkosi's Haven as a "double-edged sword" for resident adolescents.

Similarly, Fournier (2014) and Mupambireyi (2014) observed that residing in a group home or belonging to a support group offered some HIV-positive adolescents care and a sense of belonging. But many also worried about stigma and the threat of accidental or deductive disclosure. In Mupambireyi's study, some adolescents invested substantial effort into being deemed 'normal' by their HIV-negative peers, occasionally by avoiding HIV-related activities. Those who continued to attend support group had to grapple with inconsistencies in practices of telling and concealing: while support groups often required open disclosure, this contradicted with family instructions to conceal HIV status (Mupambireyi et al. 2014; Wrang 2012).

Adolescents' disclosure of their HIV status was shown to elicit both stigma and care and could take different (and at times contradictory) forms in private, public and intimate settings. Some studies from sub-Saharan Africa suggest that adolescents who disclose their HIV status to others are better able to access financial and emotional support (Bikaako-Kajura et al. 2006; Denison et al. 2015; Kidia et al. 2014; Kunapareddy et al. 2014; Li 2008; Madiba 2012; Midtbø et al. 2012; Siu et al. 2012; Vreeman et al. 2010). But this disclosure can also prompt stigma at home, at school, and among neighbours (Li 2008; Siu et al. 2012; Walsh 2015; Wolf et al. 2014).

Managing HIV stigma was also reported to compound the burden of care for adolescents' guardians. In Burkina-Faso, Hejoaka (2009) described a tension between the secrecy surrounding the virus and the openness required for providing care and accessing social support. Mothers, many of whom lived in fear of disclosing their child's HIV, instead developed a host of concealment strategies. These served to hide their children's treatment as well as the nature of their disease. At the same time, some mothers tactically disclosed to relatives in order to gain social support.

In theory, ART rollout and the consequent transformation of HIV from a terminal to a chronic illness should have radically decreased stigma and encouraged the normalisation of HIV. Yet, research from sub-Saharan Africa has described secrecy as a way of life for many HIV-positive adolescents and their families (Jena 2014; Kunapareddy et al. 2014; Marinkovich 2014). Studies have illustrated how the structures of families' everyday lives are ordered to limit exposure of adolescents' HIV status. This has involved the cautious control of information sharing, as well as tactics to take, store, and dispose of medicines in secret. As already discussed, guardians

attempts to preserve secrecy have often involved concealing their child's HIV status from them. Where HIV status had been disclosed to adolescents, caregivers often dissuaded or forbade their children from revealing their HIV illness outside their immediate families (Busza et al. 2014; Daniel 2014; Jena 2014; Kajubi et al. 2014, p.41; Madiba 2012; Mhlongo 2012, p.167).

Some studies suggested that, whether they were instructed to or not, children mimicked adult responses in their practices of secrecy (Daniel 2014; Kajubi et al. 2014), exercising partial disclosure or deceiving others. In a Ugandan study (Marinkovich 2014), adolescents were shown to employ diverse and tentative strategies to disclose their HIV status. These included joking in order to "test the waters" and emotionally prepare the other person for their disclosure.

Youth

Qualitative research from sub-Saharan Africa suggests that HIV care for adolescents is often imbued with ascriptions of what it means to be young. Decisions to disclose HIV to adolescents, as well as strategies for managing young people's treatment taking, have often pivoted on ideas about childhood and the social placement of children in relation to caregivers.

Similarly concerned with adolescence as a developmental phase, a small body of qualitative literature has sought to explore the nascent sexuality of perinatally-infected youth in sub-Saharan Africa. Perinatally-infected adolescents have inherited a sexually-transmitted virus, despite most of them never having had sex themselves. Many of these adolescents are reported to be slow to reach puberty, to weigh less, and also to be

shorter than their peers. Bodily development was a major concern for some perinatally-infected adolescents in Cote d' Ivoire (Dago-Akribi & Adjoua 2004). Those who had not yet achieved puberty were barred from undergoing traditional ceremonies. Others were concerned with how their HIV status would affect their ability to marry and have children. In a study of perinatally-infected adolescents in Tanzania, Busza (2014) found that many were uneasy with sexual relationships, which they considered dangerous and inappropriate given their HIV status.

However, research from South Africa (Li, 2008) and Uganda (Loos et al. 2013) illustrates that some perinatally-infected adolescents want sexual lives. In Loos et al.'s (2013) study, perinatally-infected participants saw sex as a way of becoming a "social somebody". Sex helped them to cope with HIV and achieve emotional and financial independence. Similarly, Mwalabu (2014) showed that, for some perinatally-infected young women in Malawi, sex served as a precarious tactic to access scarce emotional, material and social care. These resources were essential to young women's ability to carve out a sense of identity and belonging.

Although perinatally-infected youth have many sexual anxieties and aspirations, many of them have struggled to communicate with health providers and guardians about their sexuality (Belton 2014; Mwalabu 2014). Adult carers reportedly experience similar discomfort. In Busza's (2013) and Parker's (2009) studies, adolescents' anxieties about sex were re-enforced by caregivers' and healthworkers' reluctance to acknowledge adolescent sexuality. In Uganda, some guardians appeared to tie their own social identities to a form of respectability politics that required their children to be asexual (Belton 2014). Failing to control youth sexuality was to fail as a guardian.

Consequently, caregivers were unlikely to facilitate adolescents' uptake of HIV or sexual health services. Similarly, Varga's (2008b, p.796) research in South Africa showed that nurses often occupied positions of social respect, with many seen as "arbiters of social mores and appropriate comportment". This power differential between nurses and their young, unmarried, female patients reportedly manifested in providers stigmatising the sexuality of pregnant teenagers.

Amid this literature on the sexual and reproductive health of HIV-positive adolescents is a small body of research investigating the participation of pregnant teenagers in prevention of parent-to-child transmission (PPTCT) programmes. In South Africa and Tanzania, researchers sought to understand why young, HIV-positive mothers deviated from PPTCT prescriptions (Muheriwa et al. 2013; Varga & Brookes 2008a). These studies showed that many adolescents valued familial advice over clinical expertise. Young, unmarried women were compelled to show deference to senior female relatives who had years of child-rearing experience (Muheriwa et al. 2013; Varga & Brookes 2008b).

Agency

In line with a growing field of child-centred anthropology (James & Prout 1990), some studies of adolescent HIV in sub-Saharan Africa have sought to explicitly affirm young people's agency as social actors (Bernays et al. 2015; Kajubi et al. 2014; Mattes 2014; Midtbø et al. 2012). These authors have illustrated that, despite their position as ART-dependents and generational subordinates, young people express their agency by using the possibilities and gaps available to them, and by appropriating institutional practices for their own ends.

This approach to agency is a significant, and recent, development in youth HIV research. Almost a decade ago, Persson and Newman (2006) published a critical discourse analysis of 'first-world' academic research on youth HIV. They demonstrated that HIV-positive youth (particularly those perinatally-infected) were often depicted as inexorably vulnerable and dependent — incapacitated by the stressors of parental loss and chronic illness. Other times, HIV-positive adolescents were portrayed as inadequately equipped to manage their sexuality and therefore in desperate need of adult intervention. While living with a stigmatised, lifelong and sexually-transmitted virus is highly challenging for young people, who need adequate support, the preoccupation with HIV-positive youth as 'problems in need of intervention' has often negated their competencies and inventiveness.

Increasingly, and particularly in sub-Saharan Africa, authors have sought to recognise young people's agency as a relational, precarious practice made through intergenerational and institutional relationships. Some authors have spoken explicitly about the nested and interdependent spheres of influence that support or hinder adolescent ART. These include the domains of the individual adolescent, the caregiver-adolescent relationship, the household, the community, and the health care system (Vreeman et al. 2009). Others have described how adolescents' HIV experience emerges through a symbiotic relationship between children, carers, and healthcare workers, while also being shaped by broader discourse (Bernays et al. 2015).

Contribution

Over the course of my DPhil, qualitative research on adolescent HIV in sub-Saharan Africa has flourished. This interest is timely and important as the needs and challenges

of HIV-positive adolescents become a more pressing public health priority. The articles in this thesis form part of this very new, but rapidly growing research field. As a contribution to an increasingly broad and rich literature, my aims are modest. Each of the four articles aims to further existing work, posing new questions and dilemmas, while also adding contextual depth and local specificity. Below, I provide an overview of the thesis papers, suggesting how they might contribute to preceding research.

Article1: Mobilising AID(S)?

The first article, titled *Mobilising AID(S),* explores how some HIV-positive adolescents have negotiated both the burdens and potential resources of HIV, as they work to make a life on ART. It shows how some perinatally-infected youth mobilise their HIV and orphan status to tap into the resources and networks of a burgeoning AIDS industry, sometimes at significant social stakes. These discussions are historically located during a time in which the category of HIV-orphanhood carries significant clout, both in the social grants economy and in the NGO industry. Indeed, South Africa's expansive social welfare system, in which HIV and youth are awarded particular benefits, is the largest in the region. This has had important implications for youth in this study, adding local specificity to the article's contribution.

Furthering existing literature on the region's first generation of adolescent ART users, the article locates young people's experience of ART at the intersection between multiple institutions of care. Following preceding work, it shows that the moral worlds of HIV care institutions can sometimes conflict with those of family and neighbourhood. As other authors illustrate, this is often most acute in the negotiation

of care amid persistent stigma. The article illustrates how some HIV-positive youth incur resentment and recrimination in the process of accessing care.

Mobilising AID(S) makes a novel contribution by suggesting that it is not simply in presenting themselves as HIV-positive that young people are stigmatised. Instead, the receipt of seemingly-privileged care can itself provoke resentment, in a context in which resources for care are scarce. The ability of HIV-positive adolescents to access HIV-targeted resources provoked conflict within, and between, families. Some also felt vulnerable to resentment from neighbours. This was attributable both to a context of generalised poverty and the uncomfortable confluence between desirable care and a stigmatised illness.

While considering the positioning of HIV-positive adolescents in the country's contemporary HIV/AIDS response, as well as their generational location within families, this article is also interested in adolescents' membership to a category of 'youth'. It was because of the resources that circulated around 'vulnerable youth' that some adolescents in this study were able to mobilise these designations in pursuit of social and economic resources. It was also partly because of their youth that this resource access had the potential to produce generational tensions.

Article 2: Redeeming Lost Mothers

While the first article positions HIV-positive youth at the interface between multiple institutions of care, the second is firmly situated in adolescents' households. It is interested in how the practices of adolescent ART become infused with those of home-making, and are used as a means to strengthen social ties. The article shares concerns

with much of the literature on HIV disclosure by exploring how adult guardians have sought to promote and signify HIV treatment for perinatally-infected adolescents. As with disclosing HIV status, these stories have often required invocations of deceased or absent parents. Like making meaning out of HIV, signifying a life on ART required that guardians draw narrative links between the past and the present, telling stories that bridged multiple generations, including those living and dead.

The article explores narrations of ART in the homes of perinatally-infected adolescents whose biological mothers were either dead or absent. Titled, *Redeeming Lost Mothers*, it makes a novel contribution by showing how missing parents were often demonised by adolescents' remaining guardians. More so, blame was disproportionately attributed to mothers. By contrasting the purportedly reckless behaviour of missing mothers, with the discipline and obedience entailed in ART, some guardians sought to imbue adolescents' pill-taking as a practice of intergenerational mutuality and social repair. The article therefore contributes to preceding research that locates adolescent ART adherence as a product of intergenerational care. Uniquely, *Redeeming Lost Mothers* suggests that it is not only knowledge of HIV status that might promote adolescents' ART adherence. The types of HIV narratives that are told are also important.

Guardians play a crucial role both in signifying ART for young people and in helping them come to terms with parental loss. The novelty of the article's contribution is in showing how these two projects might be reciprocally (and perhaps uncomfortably) intertwined.

Article 3: Bureaucracies of Blood and Belonging

The third article, *Bureaucracies of Blood*, locates adolescent ART practice in an era of mass HIV treatment and grand-scale social welfare. Both systems have been bureaucratically mediated. As such, the HIV-positive adolescents that benefit from them have learned and appropriated these bureaucratic technologies into their everyday lives.

Bureaucracies of Blood shows that adolescent ART is not simply a matter of medication. It also entails membership to an ART programme: participation in health surveillance, attendance at regular appointments, and the interpretation of blood tests. While belonging to homes and families, adolescents also belong to ART programmes. Each of these institutions entails dependencies, entitlements, and obligations. Negotiating these institutional cultures requires tactics and competencies that make life on ART possible. Although the wider social literature on adult ART users has given ample attention to their position as biopolitical subjects, this remains underexplored for HIV-positive youth. Given that 'agency' has been a primary concern in youth studies, exploring the socialities of youth in ART programmes could offer important insights.

Because the youth studies literature has so often focused on categories of youth marked by exclusion, victimisation or poverty, assertions of agency have often served more as a political statement than a research finding (Bordonaro & Payne 2012). There has been an "epic effort" by social science authors to grant a "level of power, resistance and political influence to those who are commonly considered to be devoid of any" (Bordonaro & Payne 2012, p.367). Social science literature has often tied agency to 'positive' moral goals in which agents move towards self-empowerment and

autonomous responsibility. Because this literature has been largely disparaging of dependent, hierarchical relationships with care providers, the attractiveness and nuances of these relationships remain underexplored. *Bureaucracies of Blood* complicates existing work on the agency of HIV-positive youth by investigating relations of hierarchical affiliation and subordination, as well as the forms of subtle power that might be embedded in them. It shows how adolescents' submission to bureaucratic discipline has also entailed care, recognition and tactics.

Finally, while the literature on youth HIV in sub-Saharan Africa has highlighted the centrality of bodies in young people's lives, less attention has been given to how this might be impacted by ART. The era of ART availability has introduced new ways of living and imagining the body — through indices. Lifelong treatment of HIV has been accompanied by a seemingly objective set of measures for determining sero-status, monitoring weight, and tracking the progression of the virus in the blood. These tests and procedures, as well as the semiotic symbols they produce, take on social significance for ART users, who use them to reflect on their lives, bodies and relationships (Meinart et al. 2009). This is central to discussions in *Bureaucracies of Blood.*

Article 4: Negotiations of Blame and Care

The final article of this thesis, *Negotiations of Blame*, explores how some HIV-positive mothers and daughters have contended with seemingly inescapable recrimination in the process of accessing ART. The article adds to existing literature, which has highlighted the ambiguities of care for HIV-positive youth, who often incur stigma in clinics, orphanages and support groups. It makes a novel contribution by exploring how

anxieties about adolescents' mode of infection can shape the distribution of stigma, particularly between HIV-positive mothers and their HIV-positive children.

Negotiations of Blame also furthers research on the tactical practices through which families have sought to negotiate the stigma of adolescent HIV. In line with previous work, it shows that managing stigma is often a joint project, shared between adolescents and their guardians. More so, bodies were central to the negotiation of stigma: adolescents' bodies could conceal or reveal confidences. This feature of bodies was mobilised in adolescents' attempts to redistribute blame. Despite the advent of ART, and the promise of 'invisible' HIV, this article suggests that life with HIV has by no means lost its bodily-ness. Not only do some adolescents display visible HIV symptoms, bodies also continue to be read as social and moral diagnostics.

While sexuality was not a primary concern for any of the articles in this thesis, *Negotiations of Blame* relates to previous research on sexual and reproductive health among HIV-positive adolescents. It does so by exploring the experiences of four adolescents who initiated ART as part of antenatal care. As suggested by the preceding literature, the preservation of adult respectability and youth deference was central to the achievement of care for these young women. This article builds on previous work by elucidating how care, respectability and blame intertwine in young women's negotiations of life on ART.

REFLECTIONS ON TITLE

Each of the articles included in this thesis presents an independent argument. Yet, as a

body of work, they also begin to sketch what HIV treatment might mean for South Africa's first generation of adolescent ART users. The concepts of 'blood' and 'belonging' help to weave a conceptual thread through the articles, connecting salient themes. In doing so, they provide a conceptual lens for the thesis, which lends itself to a broad view of its contribution.

Linking concepts of 'blood' and 'belonging' is evocative of the bridge between the biological and the social. The articles in this thesis are about how ART, a biotechnology, takes on social meaning in the lives of HIV-positive adolescents. Each article reflects on the social stakes, social possibilities and social consequences of ART.

Blood

HIV is a blood-born virus. In this respect, any story about HIV is in some way a story about blood. 'Blood' signifies viral transmission and 'pollution'. The economy of HIV/AIDS stigma has often pivoted around how transmission is imagined. South African research suggests that it is most often women who have been posited as vectors of disease, blamed for their 'out-of-control' sexuality, and imagined as threats to men and babies. The second and fourth articles of this thesis include explorations of the linkages between gendered blame and HIV transmission.

It is through readings of the blood that we discover HIV status, even when the illness is not visible on the body's exterior. In an era of ART, the bodies of those living with HIV might be better able to mask the virus in their blood. In this respect, blood is about secrets and the ways in which they are concealed or exposed. Indeed, one of my central aims in *Negotiations of Blame* (paper four) is to explore how some young women have

used their bodies' exterior to disguise the secrets of their blood, and their blood line.

As more and more people are able to live asymptomatically with HIV, the virus's progress is charted through routine blood tests, which reveal the body's immunological health. These tests are used to assess how well ART users are adhering, and responding, to their treatment. Thus, in the context of ART, blood is also about legibility and discipline. It therefore evokes themes related to the regulation and surveillance of bodies. The surveillance of adolescent ART-taking, including through blood tests, is a central theme in the third paper of this thesis, *Bureaucracies of Blood*.

Among adolescents in this study, readings of the blood did not only serve for health monitoring. Printed lab results also formed part of a complex bio-bureaucracy, through which ART users demonstrated their entitlements to HIV support services, medical treatments, and social grants. Blood could therefore serve as a form of currency through which those living with HIV negotiated survival and connection under tenuous circumstances. In this respect, 'blood' ties in conceptually with the literature on biopolitics, which explores how biological categories are mobilised to make claims on material resources. These themes are of primary concern in the first paper of the thesis, titled *Mobilising AID(S).*

The concept of 'blood' not only has meaning in HIV institutions and health facilities. It also serves as a symbol for connection within families, evoking relations among 'blood relatives'. For most adolescents in this study, families were central to the negotiation of life with HIV. Mothers, grandmothers and aunts helped signify, narrate and promote HIV treatment. Many collected medication on adolescents' behalf,

facilitated linkages to NGO care networks, and administered social grants. In this respect, being an adolescent ART user was often about affirming, mending and mobilising 'blood-ties'.

Particularly for those adolescents who inherited HIV from their parents, life on ART also appealed to a 'bloodline' that bridged generations. To take ART was to treat an illness received from their parents' generations and thereby address the ills of their bloodline. The protection of bloodline is about the preservation of social order, social standing, and social reproduction. In relation to these ends, youth offer a sense of hope, just as HIV/AIDS represents a grave threat.

Belonging

The articles in this thesis explore ART as a process of social incorporation (or belonging). Belonging to ART programmes, support groups, or NGO care networks was determined by membership to a blood-based category — 'HIV-positive'. Adolescents' experiences of ART were also embedded in other forms of 'blood-based belonging', namely lineage and family.

Belonging is about attachment. Each of the articles in this thesis speaks in some way to adolescents' pursuit of attachment under fragile conditions. Crippling poverty, parental loss, stretched and severed households, as well as ubiquitous stigma, contributed to profound social and economic insecurity for youth in this study. Indeed, the articles in this thesis identify numerous threats to adolescents' sense of belonging, including blame, resentment and the sometimes-cold indifference of bureaucratic health facilities.

Under these circumstances, the drive for care and connection had immense urgency. The pursuit of attachment —to families, private patrons or state providers — could be a matter of life or death. Rather than seeking self-reliance or empowered autonomy, adolescents in this study seemed to be in pursuit of belonging.

To 'belong' is not to participate as an individual. Rather, it is to be connected to others — as a mother, child, client, support group member, or patient. To belong to ART programmes was not simply to take medication. Instead, it entailed a set of obligations and entitlements, ways of organising and narrating one's life, as well as tactics for relating to care providers.

By using 'blood' and 'belonging' as conceptual hooks, the reader might begin to see the articles as a story (however patchy and incomplete) of the challenges, possibilities, and contexts of adolescent ART in South Africa.

Table 2: Qualitative Literature on the Experience, Needs and Care of HIV-positive Adolescents in Sub-Saharan Africa

Year	Author	Title	Place	Participants and Methods
2004	Dago-Akribi, H. and Adjoua, M.	Psychosexual development among HIV-positive adolescents in Abidjan Cote d'Ivoire, *Reproductive Health Matters* 12(23), 19-28.	Cote d'Ivoire	Eighteen HIV-positive adolescents (age 13-17) Individual therapy sessions, group discussions, family support sessions
2006	Bikaako-Kajura, W. Luyirika, E. Purcell, E. Downing, J. Kaharuza, F. Mermin, J. Malamba, S. Bunnell, R.	Disclosure of HIV status and adherence to daily drug regimens among HIV infected children in Uganda', *AIDS Behaviour* 10(1), 85-93	Uganda	42 HIV-positive adolescents, 42 primary caregivers In-depth interviews
2008	R. Li	*Growing up on HAART: the experiences and needs of HIV-positive adolescents in care and treatment in the Western Cape*	South Africa, Cape Town	26 HIV-positive adolescents,

		Province of South Africa, Thesis, University of Cape Town.		Focus groups
	Varga, C. and Brookes, H.	Factors influencing teen mothers' enrolment and participation in prevention of mother-to-child HIV transmission services in Limpopo province, South Africa, *Qualitative Health Research*, 18(6), 786–802.	South Africa, Limpopo	Adolescent mothers (age 15-19) Focus groups Case study, community-based questionnaire
	Varga, C. and Bookes, H.	Preventing mother-to-child HIV transmission among South African adolescents, *Journal of Adolescent Research*, 23(2), 172–205.	South Africa, Limpopo	Key informant workshop with 15 participants (PMTCT clinic staff, lay counsellors, teen mothers, adolescents using sexual and reproductive health services)
	Vaz, L., Cornell, A., Dulyxt, J., Rennie, S., Omba, S., Kiltele, F., the AD Research Group and Behets, F.	The process of HIV status disclosure to HIV-positive youth in Kinshasa, Democratic Republic of Congo, *AIDS Care* 20(7), 842-852.	DRC	19 HIV-positive youth (age 10-21) 21 caregivers Semi-structured interviews
2009	Biadgilign, S., Deribew, A., Amberbir, A., Deribe, K.	Barriers and facilitators to antiretroviral medication adherence among HIV paediatric patients in Ethiopia: a qualitative study, *Journal of Social Aspects of HIV/AIDS* 6(4), 148 – 153.	Ethiopia	12 caregivers of HIV-positive children and 14 key informants (healthcare workers) In-depth interviews
	Hejoaka, F.	Care and secrecy: being a mother of children living with HIV in Burkina Faso. *Social Science & Medicine Journal*, 69(6), 869-876.	Burkina Faso	Ethnography and semi-structured interviews with 20 women mothering HIV-positive children as well as 15 children infected with HIV (age 8-18)
	Parker, C.A.	*The lived experience of HIV-positive Tanzanian orphans*, PhD Thesis, Walden University.	Tanzania	Twelve HIV-positive, orphaned children (age 9–12) Extended interviews
	Vreeman, R., Nyandiko, W., Ayaya, S., Walumbe, E., Marrero, D., Inui, T.	Factors sustaining paediatric adherence to antiretroviral therapy in Western Kenya, *Qualitative Health Research* 9(12), 1716 – 1729.	Kenya	Parents and guardians of HIV-positive children (14 years and below) 10 focus groups 35 individual interviews
	Li, R.J., Jaspan, H.B. O'Brien, V. Rabie, H. Cotton, M.F. and Nattrass, N.	Positive futures: a qualitative study on the needs of adolescents on antiretroviral therapy in South Africa. *AIDS Care* 22(6), 751-758.	South Africa, Cape Town	26 HIV-positive adolescents (median age 12.5 years) Four focus groups
2010	Petersen, I. Bhana, A. Myeza, N. Alicea, S. John, S. Holst, H. McKay, M. Mellins, C.	Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: a qualitative investigation, *AIDS Care* 22(8), 970-978.	South Africa, KZN	25 adolescents (age 14–16) and 15 caregivers In-depth interviews
	Thupayagale-Tshweneagae, G.	Behaviours used by HIV-positive adolescents to prevent stigmatisation in Botswana, International, *Nursing Review* 57(2), 260-264.	Botswana	18 adolescents (age 13-19) Four focus groups
	Vaz, L., Eng, E.Maman, S., Tshikandu, T., Behets, F.	Telling children they have HIV: lessons learned from findings of a qualitative study in Sub-Saharan Africa, *AIDS Patient Care and STDs*, 24(4), 247-256.	Kinshasa, DRC	Eight children and adolescents (age 8–17) and their primary caregivers In-depth interviews

	Vreeman, RC., Nyandiko, W., Ayaya, S., Walumbe, E., Marrero, D., Inui, T.	The perceived impact of disclosure of paediatric HIV status on paediatric antiretroviral therapy adherence, child well-being, and social relationships in a resource-limited setting, *AIDS Patient Care and STDs* 24(10), 639-649.	Kenya	Parents and guardians of HIV-positive children (age 0–14) Interviews and focus groups
	Yeap, A., Hamilton, R., Charalambous, S., Dwadwa, T., Churchyard, G., Geissler, P., Grant, A.	Factors influencing uptake of HIV care and treatment among children in South Africa – a qualitative study of caregivers and clinic staff, *AIDS Care* 22(9), 1101-1107.	South Africa, Gauteng	21 caregivers and 21 clinic staff Interviews In-depth interviews
2011	Busza, J.	Meeting the reproductive health needs of youth living with HIV in Tanzania: a qualitative study exploring the experiences and perceptions of young 97 home based care clients, their caregivers and care providers. *Pathfinder International, Research and Evaluation working pape*r.	Tanzania	27 HIV-positive youth (age 15-24), 10 caregivers and 12 home-based care providers In-depth interviews
	Fetzer, B. et al.	Barriers to and facilitators of adherence to paediatric antiretroviral therapy in a sub-Saharan setting: insights from a qualitative study', *AIDS Patient Care and STDs* 25(10), 611-621.	sub-Saharan Africa	20 sets of disclosed and non-disclosed children (age 8–17) along with caregivers In-depth interviews
2012	Dube, N. and Ross, E.	Sanctuary or double-edged sword? Challenges confronting adolescents living at Nkosi's Haven in Johannesburg, South Africa, *Journal of Social Aspects of HIV/AIDS* 9(4), 200-209.	South Africa, Gauteng	15 HIV-positive adolescents (age 15-19) Semi-structured interviews
	Heeren, G. A. Jemmott, J. B., III Sidloyi, L. Ngwane, Z. Tyler, J. C.	Disclosure of HIV diagnosis to HIV-infected children in South Africa: focus groups for intervention development, *Vulnerable children and Youth Studies* 7(1), 47-54.	South Africa, Eastern Cape	51 caregivers 21 healthworkers 5 adolescents Focus groups
	Hodgson, I., Ross, J. Haamujompa, C., Gitau-Mburu, D.	Living as an adolescent with HIV in Zambia, *AIDS Care* 24(10), 1204-1210.	Zambia	111 HIV-positive adolescents (age 10–19) and 59 key informants, including health care workers and parents/guardians. Semi-structured interviews and focus group discussions
	Madiba, S., Mokwena, K.	Caregivers' barriers to disclosing the HIV diagnosis to infected children on antiretroviral therapy in a resource-limited district in South Africa: a grounded theory study, *AIDS Research and Treatment*, 2012, Article ID 402403	South Africa, Gauteng	Caregivers of children (age 6–13) years who were receiving ART Four focus groups
	Madiba, S.	Disclosing HIV to infected children in South Africa in the Era of HAART: a grounded theory study on the process, reasons and outcomes of disclosure. *World Journal of AIDS*, 2, 319-329.	South Africa, Limpopo	27 caregivers of children (age 6 – 13) who were receiving ART Four focus groups
	Marukutira, T.	*Factors Influencing Adherence to Antiretroviral therapy in Adolescents at Botswana-Baylor Children's Clinical Centre of Excellence- a*	Botswana	Eight adolescents (age14 – 19) on ART In-depth interviews

		Qualitative Study, Msc in Public Health dissertation, University of South Africa.		
	Mhlongo, M.N.	*Normality, Resilience and Agency: The Experiences of Young People living with HIV within the Socio-Cultural Context of KwaZulu-Natal (South Africa).* PhD Thesis, University of Huddersfield.	South Africa, KZN	HIV-positive adolescents (13-18 years), carers of young people and community members. In-depth interviews Focus groups
	V. Midtbø , V. Shirima, M. Skovdal, M. Daniel	How disclosure and antiretroviral therapy help HIV-infected adolescents in sub-Saharan Africa cope with stigma, *African Journal of AIDS Research* 11(3), 261-271.	Botswana Tanzania	16 adolescents (age 12-20) and three healthcare workers were enrolled in Botswana. 12 adolescents (age 12-14) and two healthcare workers were enrolled in Tanzania. Individual and group interviews Participant observation
	Pienaar, L. Visser, M. J.	An exploration of the experiences of adolescents living with HIV, *South African Family Practice* 54(3), 229-236.	South Africa, Cape Town	Six HIV-positive adolescents (age 13-17) Narrative interviews
	G. Siu, S. Bakeera-Kitaka, C. Kennedy, A. Dhabangi, A. Kambugu	HIV serostatus disclosure and lived experiences of adolescents at the Transition Clinic of Infectious Diseases Clinic in Kampala, Uganda: a qualitative study, *AIDS Care* 24(5), 606-611	Uganda	20 HIV-infected youth (age 15–23) Interviews and two focus groups
	Wachira, J. Middlestadt, S. E. Vreeman, R. Braitstein, P.	Factors underlying taking a child to HIV care: implications for reducing loss to follow-up among HIV-infected and -exposed children, *SAHARA* 9(1), 20-9	Kenya	Caregivers of HIV-positive children (HIV-positive and HIV-exposed) In-depth interviews
	Wrang, N.	*Stigma and Challenges Faced by HIV-Positive Adolescents*, Bachelor Thesis, Department of Sociology, Lund University	Botswana	Staff caring for HIV-positive adolescents Key informant interviews and observation
2013	Busza, J., Besana, G.V., Mapunda, P. and Oliveras, E.	I have grown up controlling myself a lot. Fear and misconceptions about sex among adolescents vertically-infected with HIV in Tanzania, *Reproductive Health Matters*, 21, 41, 87–96.	Tanzania	14 HIV-positive adolescents (age 15-19), 10 primary caregivers, and 12 home-based care providers In-depth interviews
	J. Loos, C. Nostlinger, I. Murungi, D. Adipo, B. Amimo, S. Bakeera-Kitaka, D. Oluoch, P. Wobudeya, H. Vandenhoudt, A. Buve	Having sex, becoming somebody: a qualitative study assessing (sexual) identity development of adolescents living with HIV/AIDS, *Vulnerable Children and Youth Studies* 8(2), 149-160	Uganda	119 HIV-positive adolescents (aged 10–19), 54 of their caregivers, and 55 service providers 28 focus groups
	Muheriwa, S. R. Chimwaza, A. Maluwa, A. O. Nyasulu, B. M. Pindani, M.	Beliefs and practices of young women on utilization of prevention of mother to child transmission of HIV services in Malawi, *Health* 5, 1172-1179	Malawi	12 HIV-positive young mothers (age 15-24) Interviews
	Nestadt, D. F. Alicea, S. Petersen, I. John, S. Myeza, N. P.	HIV+ and HIV- youth living in group homes in South Africa need more psychosocial support, *Vulnerable*	South Africa, KZN	20 adolescents (age 10-16), including those HIV-negative and HIV-positive

	Nicholas, S. W. Cohen, L. G. Holst, H. Bhana, A. McKay, M. M. Abrams, E. J. Mellins, C. A.	*Children and Youth Studies* 8(3), 195-205		In-depth interviews
	Parker, L. Maman, S. Pettifor, A. Chalachala, J. L. Edmonds, A. Golin, C. E. Moracco, K. Behets, F.	Barriers to provider-delivered sexual behaviour counselling for youth living with HIV/AIDS in the Democratic Republic of the Congo, *Journal of HIV/AIDS and Social Services* 12(3-4), 294-313	DRC	14 interviews with health providers, caring for young people living with HIV (age 15-24)
2014	Belton, S.	*Exploring the Psychosocial Barriers to Children's HIV Services in Western Uganda: A Case Study of Social Representations*, PHD Thesis, Department of Social Psychology, London School of Economics.	Uganda	15 health care workers (HCWs) 45 adult carers of HIV-positive children, 82 children (age 12-18) Individual interviews Focus groups Draw-and-write exercises Participant observation in clinic settings
	Busza, J., Besana, G., Mapunda, P., Oliveras, E.	Meeting the needs of adolescents living with HIV through home based care: lessons learned from Tanzania, *Children and Youth Services Review* 45, 143-149	Tanzania	14 adolescents (age 15–24) living with HIV, 10 primary caregivers, and 12 providers In-depth interviews
	Class, D.	Effects of HIV prevention messages on treatment-seeking and adherence for HIV-infected children in Maputo, Mozambique: a qualitative study, *Children and Youth Services Review* 45, 64-73	Mozambique	26 caretakers—primarily mothers—of children (age 3–12) on ART as well as their clinicians (7 physicians and 2 dedicated nurses) In-depth interviews
	Fournier, B. Bridge, A. Pritchard, K., Alibhai, A. Konde-Lule, J.	Hear our voices: a photovoice project with children who are orphaned and living with HIV in a Ugandan group home, *Children and Youth Services Review* 45, 53-63.	Uganda	HIV-positive, orphaned adolescents between 12 and 18 years Photovoice to enhance storytelling
	Hornschuh, S. Laher, F. Makongoza, M. Tshabalala, C. Kuijper, L. D. J. Dietrich, J.	Experiences of HIV-positive adolescents and young adults in care in Soweto, South Africa, *Journal of HIV/AIDS and Social Services* 13(4), 420-435.	South Africa, Gauteng	18 young people (age 15–25) living with HIV Focus groups
	Jena, P.	*Exploring the Lived Experiences of Adolescents Living with Vertically acquired HIV*, Masters Thesis, University of South Africa	South Africa, Port Elizabeth (Eastern Cape)	HIC-positive adolescents (age 16-17) Interviews
	Kidia, K. K. Mupambireyi, Z. Cluver, L. Ndhlovu, C. E. Borok, M. Ferrand, R. A.	HIV status disclosure to perinatally-infected adolescents in Zimbabwe: a qualitative study of adolescent and healthcare worker perspectives, *PLOS One* 9(1).	Zimbabwe	In-depth interviews with adolescents (age 16-20) Focus groups with 15 healthworkers
	Kiwanuka, J., Mulogo, E., Haberer, J.	Caregiver perceptions and motivations for disclosing or concealing the diagnosis of HIV infection to children receiving HIV care in Mbarara, Uganda: a qualitative study, *PLoS One* 9(3).	Uganda	Primary caregivers of 40 HIV-positive, undisclosed children (ages 5–15 years) In-depth interviews
	Kunaparedy, C., Nyandiko, W., Inui,	A qualitative assessment of barriers to antiretroviral therapy among adolescents	Kenya	Adolescents (age 10-16) on ART

	T., Ayaya, S., Marrero, D., Vreeman, R.	in Western Kenya, *Journal of HIV/AIDS and Social Services* 13(4), 383–401.		Focus groups and individual interviews
	Mandalazi, P. Bandawe, C. Umar, E.	HIV disclosure: parental dilemma in informing HIV infected children about their HIV status in Malawi, *Malawi Medical Journal* 26(4), 101-104.	Malawi	In-depth interviews with parents
	Mattes, D.	'Life is not a rehearsal, it's a performance: an ethnographic enquiry into the subjectivities of children and adolescents living with antiretroviral treatment in north-eastern Tanzania', *Children and Youth Services Review* 45, 28-37.	Tanzania	13 adolescents (age 9-19) on ART 15 months ethnographic fieldwork
	Marinkovich, Z.	*Growing up with HIV in Kisumu, Kenya: Participatory Action Research with Young People Living with HIV* (2014). PhD Thesis, University of San Francisco. http://repository.usfca.edu/diss/101	Kenya	40 HIV-positive adolescents (13-17 years) Individual interviews, focus groups, observation, journals, and meeting notes.
	Mburu, G., Hodgson, I., Kalibala, S.	Adolescent HIV disclosure in Zambia: barriers, facilitators and outcomes, *Journal of International AIDS Society* 10(17).	Zambia	HIV-positive adolescents (age 10-19), their parents and healthcare providers Interviews Focus groups
	Mburu et al.	Responding to adolescents living with HIV in Zambia: a social–ecological approach, Children and *Youth Services Review* 45, 9-17	Zambia	58 Adolescents (age10–19) living with HIV and14 health care providers and 21 parents. In-depth Interviews Focus groups
	Mupambireyi, Z., Bernays, S., Bwakura-Dangarembizi, Cowan, F.	'I don't feel shy because I will be among others who are just like me' The role of support groups for children perinatally infected with HIV in Zimbabwe, *Children and Youth Services Review* 45, 116-113.	Zimbabwe	HIV-infected adolescents (11-13 years) In-depth interviews and focus group discussions
	Schenk, K.	If you built it, will they come? A qualitative investigation into community barriers accessing paediatric HIV services in Kenya, *Children and Youth Services Review* 45, 18-27.	Kenya	Focus groups with parents and caregivers of HIV-positive children (up to 15 years). Interviews with managers and ministry of health officials
	Sikstrom, L.	"Without the grandparents, life is difficult": Social hierarchy and therapeutic trajectories for children living with HIV in rural Northern Malawi, *Children and Youth Services Review* 45, 47-54.	Malawi	Two years of ethnographic fieldwork with HIV-positive children (up to 14 years) in Malawi
	Vujovic, M., Struthers, H., Meyersfeld, S., Dlamini, K., Mabizela, N.	Addressing the sexual and reproductive health needs of young adolescents living with HIV in South Africa, *Children and Youth Services Review* 45, 122-128.	South Africa, Gauteng and Limpopo	HIV-positive adolescents (10-14 years) Focus groups

			Urban township and rural village	
	H. Wolf, B. Harpen-Felsher, E. Bukusi, K. Agot, C. Cohen, C. Auerswald	'The person suffering from HIV will not be accepted': a qualitative study exploring the reasons for loss to follow-up among HIV-positive youth in Kisumu, Kenya, *BMC Public Health* 14, 1154.	Kenya	Focus groups with community healthworkers Interviews with HIV-positive youth (age 15-21)
2015	Bernays, Sarah 1; Seeley, Janet 2; Rhodes, Tim 1; Mupambireyi, Zivai 3	What am I 'living' with? Growing up with HIV in Uganda and Zimbabwe, *Sociology of Health and Illness* 37(2), 270-283.	Zimbabwe Uganda	HIV-positive adolescents (age 11-13), their caregivers and healthcare workers 104 baseline in-depth interviews 60 follow-up interviews with children after 16 months In Zimbabwe, 12 adolescents kept audio diaries. Twenty of the children from the baseline sample participated in three focus groups (FGDs) in Uganda and Zimbabwe at the end of the data collection period.
	Daniel, M.	Keeping the secret: how HIV-positive children in Iringa, Tanzania, respond to the need for silence and secrecy, *Journal of Child and Adolescent Mental Health* 27(1), 11-23.	Tanzania	13 HIV-positive adolescents (age10-15) and clinic staff In-depth interviews
	Denison, J., Banda, H., Dennis, A., Packer, C., Nyambe, N., Stalter, R., Mwansa, J., Katamoyo, P., McCarraher, D.	"The sky is the limit": adhering to antiretroviral therapy and HIV self-management from the perspectives of adolescents living with HIV and their adult caregivers, *Journal of the International AIDS Society* 18(1): 19358.	Zambia	32 adolescents living with (age 15-18) In-depth interviews
	Hill, L., Maman, S., Groves, A., Moodley, D.	Social support among HIV-positive and HIV-negative adolescents in Umlazi, South Africa: changes in family and partner relationships during pregnancy and the postpartum period, *BMC Pregnancy Childbirth* 15: 117.	KZN, South Africa	15 HIV-positive and HIV-negative adolescent women (age 14-17), either pregnant on recently pregnant In-depth semi-structured interviews
	Mutumba, M., Musiime, V., Tsai, A., Byaruhanga, J., Kiweewa, F., Bauermeister, J. and Snow, R.	Disclosure of HIV status to perinatally-infected adolescents in urban Uganda: A qualitative study on timing, process, and outcomes, *Journal of the Association of Nurses in AIDS Care*, 26(4), 472-484.	Uganda	HIV-positive adolescents (age 13-19) Semi-structured interviews
	Mwalabu, Gertrude Grey Tiwonge	*Telling Their Story: Perspectives of Young Women, Their Caregivers and Service Providers Regarding the Experiences of Growing Up with Perinatally-Acquired HIV in Malawi*, PhD thesis, University of Nottingham	Malawi	14 female, HIV-positive adolescents (15-19 years), a nominated caregiver and a service provider. In-depth interviews

Rutakumwa, R., Zalwango, F., Richards, E., Seeley, J.	Exploring the care relationship between grandparents/older carers and children infected with HIV in South-Western Uganda: Implications for care for both the children and their older carers, International, *Journal of Environmental Research in Public Health* 12(2), 2120-2134.	Uganda	40 children (age 13-17) and their older caregivers (age 50 and above) In-depth interviews
Walsh, S.	'You shall be in the future someone that is very powerful', the experiences of students with HIV/AIDS in rural, post-conflict Uganda, Education/Development and International Cooperation, Masters Thesis, Department of Social Sciences and Philosophy, University of Jyvaskyla.	Uganda	16 HIV-positive adolescents, as well as parents teachers and healthcare workers Interviews

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Methodology

Each of the articles in this thesis includes a tailored description of the research setting, participants, and methods for this study. I do not wish to repeat too much of this here. But given restrictions on the length of journal articles, this chapter presents a greater depth and breadth of ethnographic description than the individual papers allow. In what follows, I reflect more extensively on the research sites, the strengths and limitations of the recruitment process, the development of the study's research methods, and the approach to analysis. This discussion serves to further contextualise the included articles and adds to the "thick description" (Geertz 1973) characteristic of the ethnographic method.

In elucidating the methods of this study, I also centre key ethical considerations. *Mzantsi Wakho*'s extensive ethics protocol was approved by the Interdisciplinary Research Ethics Committee at the University of Oxford, the Centre for Social Science Research Ethics Committee at the University of Cape Town, and the Eastern Cape Department of Health. This protocol, as well as the relevant approval letters, are included in the appendices of this thesis.

Ethics were a constant consideration for this study. Ethical concerns included questions of stigma, secrecy and disclosure; the role of adult gatekeepers in accessing respondents; finding unthreatening spaces to engage youth in their everyday lives; the politics of race, language, class, gender and age in the field; as well as the ambiguities of friendship, expectation, dependency and mutuality in ethnographic research.

Journal articles often do not allow sufficient space to reflect on the ethical lessons and dilemmas of research. Precedence is given to demonstrating that one has met standard ethical guidelines. Rarely is one able to extrapolate the minefield of predicaments that arise in the thick of fieldwork, well after the research has been reviewed. By including reflections on the most salient ethical predicaments for this study, I hope to offer a less sanitised and more reflexive account of the fieldwork.

I was concerned beyond "procedural ethics" with the negotiation of "ethics in practice" (Guillemin & Gillam 2004, p.263). By this I mean the situational, unplanned, and ethically important moments that arose in the field, often in subtle ways. This approach to ethics centres the everyday research encounters and inter-subjectivities that are entailed in 'being ethical'. Within these interpersonal interactions lie the possibilities for respecting the autonomy, dignity, and privacy of participants, as well as the risks of failing to do so.

"Ethics in practice" might be considered a way of thinking through research in which there is a central role for researcher reflexivity (Guillemin & Gillam 2004, p.273). This demands that the researcher regularly take stock of their own actions, as well as their role in the research process, subjecting these to the same critical interrogation as they would their data (Mason in Guillemin & Gillam 2004, p.274). Indeed, reflexivity required that I regularly examine both the type of knowledge produced through the research, as well as how said knowledge was being generated. In my attempts to inculcate ethical thinking into my research practice, I also sought to reflect on my social positioning, my use of power, and the complexities of my research relationships. Clifford Geertz (1973, p.9) believed that "anthropological writing was "really our own

constructions of other people's constructions of what they and their compatriots are up to". For the reader to gauge the credibility of the author's interpretations, the context in which they were made must be thoroughly described. In the discussions that follow, I have tried to remain alert not only to the fieldwork setting, but also my own location within the research process, as well as the methodological and ethical implications of this.

RESEARCH SETTING AND RECRUITMENT

The Eastern Cape

The Eastern Cape is one of South Africa's most impoverished areas. A significant proportion of the province's population live in former 'homelands' of the Ciskei and Transkei. Created by the apartheid government in the second half of the twentieth century, 'homelands' served as resettlement sites to which large proportions of the black population were deported. Thousands of urban black residents were forcibly removed to the reserves, where access to cities was deliberately restricted. These reserves became increasingly 'self-governing' and eventually nominally independent. Their exclusively black residents were initially subject to indirect rule through white magistrates and traditional authorities and were, throughout the history of the reserves, denied the rights attached to South African citizenship (Evans 2014).

There is a well-documented history of resistance to the creation of the Eastern Cape 'homelands' (Beinart 2012, p.5; Mbeki 1964). The institution of 'homeland' 'Betterment' schemes, in particular, provoked fierce opposition. Designed by the

apartheid government to control land-use, 'Betterment' schemes resulted in many 'homeland' residents being dispossessed of arable grazing land (Mbeki 1964, p.95).

Often described as 'dumping grounds' for the black populace, Eastern Cape 'homelands' were characterised as among the most oppressed and impoverished zones of apartheid South Africa (Beinart 2012, p.6). Relying almost exclusively on resources generated by the central apartheid state, local economies in the reserves remained underdeveloped. Yet, amidst palpable poverty and state repression, people were also committed to their rural homes, customs and identities (Beinart 2012). Moreover, there were limits and contestations to state and capitalist control.

Decentralised industrial development in parts of the Eastern Cape reserves meant that in places like Dimbaza and Butterworth, a resident working class emerged (Pohland-McCormick & Minkley 2015). But many more in the 'homelands' migrated for jobs. These migrants left to work on mines, for white farm owners, or in urban industries, often for months at a time. It is reported that, from at least the 1920s, migrant wages were the primary source of rural cash in the Eastern Cape (Sagner 2000, p.541). The generation of cash became increasingly important as more people were landless and stockless (Sagner 2000, p.541). Through migrancy, 'homelands' functioned as labour reservoirs for the white-ruled state. Yet migrant men were not only wage labourers for a capitalist system. They were also proprietors of patriarchal homesteads, whose identities were often wrapped up with maintaining a rural home in partnership with women and other men (Moodie & Ndatshe 1994).

METHODOLOGY

With its long history of colonial and apartheid labour migration, the Eastern Cape continues to suffer more out-migration than any other South African province as residents go in search of better livelihoods elsewhere (Makiwane & Chimera-Dan 2010; Statistics South Africa 2014a). Most migrants are young men of working age, although the number of female migrants has risen significantly (Makiwane & Chimera-Dan 2010, p.21). In 2005, Cape Town alone received an estimated 48, 000 new residents annually, most of them from the rural Eastern Cape (Bank & Minkley 2005, p.3). There is also substantial internal migration from the more impoverished Eastern parts of the province to the West (Makiwane & Chimera-Dan 2010, p.15).

The majority (52.7%) of the Eastern Cape population is female and nearly 21 percent are youth between the ages of 10 and 19 (Statistics South Africa 2014a). Official statistics suggest that, following the first democratic election, poverty has deepened in the province (Statistics South Africa 2014b, p.32), despite the buffer of expanded social grant provision. This is particularly true of rural areas, where the vast majority of the province's 6.7 million people live (Statistics South Africa 2014a).

Shifts in political economy have adversely impacted the surety of migrant labour, and consequently destabilised rural household economies (Ainslie 2014, p.3). Most of the state-subsidised factories in decentralised industrial zones have closed (Bank & Minkley 2005, p.1). In many parts of the rural Eastern Cape, local economies are now based primarily on welfare payments, diminishing urban remittances, and the survivalist employment of natural (including agrarian) resources (Ainslie 2005, p.133).

Over the course of my fieldwork, the province's health services were under immense scrutiny, spurred by the formation of 'The Eastern Cape Health Crisis Coalition'. Activists drew attention to desperate staff shortages and weak primary healthcare. As testimonials were gathered across the province, residents' everyday experiences of health service access were increasingly foregrounded. Patients reported waiting in long queues, travelling far distances to clinics, and arriving to poorly stocked pharmacies. Nurses complained of being overworked and unsupported. These narratives resonated with much of my own data. But I also encountered remarkable stories of families who diligently adhered to chronic medication despite being far removed from healthcare institutions; of village healthworkers who visited patients on foot to consistently monitor their health; and of doctors and nurses who continued to deliver quality care amid immense challenges. In other words, I witnessed the fragile accomplishment of health under significant constraints. This study is about young people's everyday achievement of antiretroviral treatment (ART) — the precarious practice of belonging to ART programmes, consuming daily medication, and struggling for survival and recognition.

Rural Fieldwork

Removed from South Africa's largest cities, the Eastern Cape remains a comparatively under-researched location in the South African healthcare literature. Fieldwork for this study was undertaken in two research sites: one rural and the other peri-urban. [4]

[4] My description of these sites (below) is not as thoroughly cited as I would like, since specific references would likely reveal the fieldwork locations. I have chosen to give anonymity precedence in instances where this is a risk. Sources that are referenced make mention of a number of different localities, therefore obscuring the specific research sites for this study.

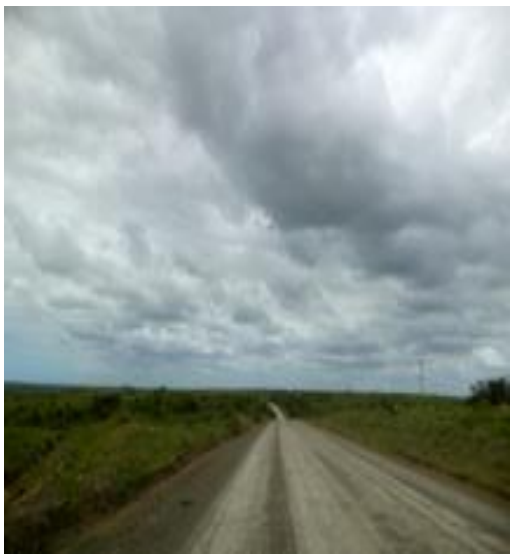


Figure 1: En route to an Mtembu village

The first four months of fieldwork were spent in a rural municipality that I call *Mtembu.*[5] Located in one of the former 'homelands', Mtembu is comprised of 118 rural villages and one small town, where the petrol station, banks, supermarkets, and nearby hospital are located. For every three villages, there is one rural clinic. Most of the villages are less than two hours drive to the nearest city, but access to transport is scarce and expensive. Hitchhiking is an essential mode of transport for many residents, but drivers often demand remuneration. In 2012, the municipality's HIV prevalence (12.6%) was just above the national average (ECSECC 2012).

Government grants are the primary source of income in most Mtembu households. Beneficiaries of old age pensions, disability, and child support grants are most common. Welfare payouts are supplemented by remittances, wages and small-scale agriculture. Reliable, longer-term employment is in diminishing supply and many have to invest in extended social networks that stretch across urban-rural divides.

For some time, there had been a decline in the number of men involved in long distance migrant labour, although many still worked away from home in the region's towns or cities (Ainslie 2014, p.5). Since the 1950s, these areas have seen a dramatic decline in agricultural activity, particularly in field cultivation, which had all but disappeared by

[5] I use italics, in the first instance, to introduce the pseudonym, but henceforth this name will not be italicized.

Figure 2: An Mtembu clinic

the 1970s (Ainslie 2014, p.5). Many Mtembu homesteads lacked arable land: most cultivation occurred in people's small home gardens.

Deepening poverty has had a differential impact on the area's rural households, widening the extent of socio-economic difference between homesteads, and increasing social tensions between those worse and better off (Ainslie 2014, p.6). An injection of social welfare transfers has occasionally given rise to small businesses. Some families, who had been miners and peasants for generations, have in more recent years seen their young adults appointed to civil service jobs. As Steinberg (2015, p.21) has remarked about Lusikisiki, "Most people in the villages have seen somebody get ahead". At least since the mid-1980s, and particularly after the democratic transition, younger women in the Mtembu area, especially those better educated, have seen increased economic independence (Ainslie 2014, p.7). They have found work as teachers, nurses and government employees — positions with significant social clout.

While living and working in Mtembu villages, I met Mildred Thabeng. Mildred had resided in the village for more than a year and had strong relationships with local youth and their families. From August 2013, she worked as my research assistant, playing an invaluable role in the design of the study, the fieldwork, and the preliminary analysis

Mildred was a twenty-year-old social work student, volunteering for a local non-government organisation (NGO) that I will call *Kholo.* I turn now to the work and history of this organisation.

Kholo

Amid widespread AIDS death, Kholo was an oasis of HIV treatment, at a time when ART was not publically available. From the early 2000s, the organisation started buying ART privately and supplying it to those in need. Initially, one of the Kholo layworkers, who I will call Yvette, housed and provided care to five AIDS-sick patients in her home. As patient numbers grew, Kholo established an in-patient treatment centre. Yvette remembered this as an experimental time in which groups of doctors and village carers would gather to discuss the best course of treatment for their patients (interview, Mtembu, 2 September 2013). No one was sure, for example, whether those suffering from tuberculosis (TB) should be treated for TB before starting ART, or the reverse. Treatment was a process of trial and error with deadly stakes.

In these early years, news of HIV/AIDS in Mtembu was regularly received with mistrust (interview with Yvette, Mtembu, 2 September 2013). Yvette recalled early accusations that Kholo staff were tampering with syringes, which some villagers said explained the numbers of people testing HIV-positive at clinics. The association between village healthworkers and white Kholo doctors occasionally resulted in the former being labelled "informers". Under apartheid, the term 'informer' referred to those who had betrayed the liberation struggle and 'sold out' to the security police. But just as white Kholo staff had once been considered complicit with AIDS illness in Mtembu, they

would later be attached with the revelation of HIV drugs.

Recalling life at the treatment centre, Kholo staff described rooms of mostly-female patients, who would braid each other's hair while singing Christian songs about "coming home, never to die again" (interview with Kholo doctor, 9 August 2013). Local villagers and Kholo staff regularly recalled the centre as a place of resurrection, in which miracle drugs had lifted patients from their deathbeds. In 2004, Kholo received funding from the 'Presidents Emergency Plan for AIDS Relief' (PEPFAR) to deliver ART across Mtembu, and its treatment programme was rapidly expanded. Across numerous Mtembu villages, the organisation became associated with salvation through medicine and many referenced their white doctor with an evangelical idiom.

The racialised history of ART provision in Mtembu cannot be adequately explored here, nor is it a concern for the included articles. It would nevertheless be remiss of me not to mention it, since it is likely to have played an important role in how villagers received me as a white researcher. My own whiteness and my known association with Kholo meant that I was often thought to be a medical doctor. Many families interpreted their relationship with me as a potential asset. Their association with a well-networked outsider was perceived to aid their pursuit of essential resources and services.

While I worried that my visible outsider status might attract unwanted interrogation to participants, rural families often remarked on the 'privilege' and social cache of receiving a white, educated visitor in their home. Although white visitors were a source of excitement in Mtembu villages, they were also not entirely uncommon. White outsiders and NGO workers had been involved in a range of health, research, and NGO

work in the area. My presence was therefore not interpreted as a threat for deductive HIV disclosure. Nevertheless, a few adolescents suggested that being seen with affluent (particularly white) outsiders could attract unwanted resentment or jealousy from neighbours. This was due to the extent of poverty in the neighbourhood, and the apparently privileged care received by 'well-connected' villagers.

Following widespread state rollout of ART, Kholo no longer runs a treatment programme. Its ART patients have been transferred to public clinics and hospitals. Today, Kholo's chief health service is to support state-provided ART through a village healthworker programme. It also runs quarterly weekend workshops for its HIV-positive adolescent members, many of whom they had initiated onto ART years prior.

Gender and Society

Kholo had imprinted itself on the social landscape of a few Mtembu villages with important implications for distributions of power and resources. New inequalities took root as villagers acquired more or less access to the goods, services, and networks of the NGO. Kholo's presence had produced contestations over caregiving as parents and Kholo NGO workers sometimes quarrelled over the care of children. Given Kholo's role in providing and lobbying for basic services, they also occasionally conflicted with the local municipality.

Kholo's work had drawn foreign funding and overseas volunteers. In the village where its head office is located, it had also attracted a small community of permanent, white NGO staff. But for the most part, it was local women who participated in, and benefitted

from, Kholo's health and income generation projects. Kholo was also largely staffed by local women, who served as managers, administrators, counsellors, educators and village healthworkers.

A description of the first village healthworker meeting I attended (23 August 2013) is illustrative of the organisation's gendered social consequences. The meeting was attended by approximately fifty village healthworkers from as many as forty Mtembu villages. All were women, dressed smartly. Most wore black and white and donned pantyhose. This erudite, authoritative and conservative attire mimicked nurses' dress. Since the apartheid years, nurses have occupied prestigious professional status among many of the country's black communities. This history is well documented by Shula Marks (1994).

The meeting began with sung worship, interspersed with isiXhosa praise poetry. Next, Kholo's doctor reported back on test scores from a recent village healthworker examination, which had tested them on the new treatment guidelines. The top three students were announced and applauded. In the fashion of Treatment Action Campaign gatherings across the country, the meeting also included adapted struggle songs. These carried messages about "condomizing" and adhering to antiretrovirals. During one such song, which included a gesture of putting a condom on a penis, an inebriated man came from the street and into the community hall, where the meeting was being held. He began fiddling with the zip on his pants, but was aggressively chased out by the women who also laughed hysterically at his actions. "Maybe he wanted to show us his penis", one of them commented to me, chuckling. Other male wanderers were similarly chased away as the meeting proceeded. I was told that one of them would steal things from my

handbag and I should “be careful”.

Working for Kholo meant that these women had access to paid work, which was scarce in Mtembu villages. Their position as village healthworkers also accrued respectability in its association with education, church rhetoric, and in this case, smart attire. Yet, these were also spaces in which women unsettled established boundaries of ‘respect’, talking explicitly about sex across generations and pushing men out. While testing gendered and generational norms, these remained fiercely moralising, and generally conservative, communities. Viewing themselves as moral arbiters, women expelled men precisely because they were considered ‘drunks’, ‘thieves’ or ‘sexually corrupted’. As in many Mtembu homes, this was a space in which men were largely absent, but in which respectability and conservative values remained paramount.

Older women also acted as moral purveyors in the lives of many young girls in Mtembu villages. Yvette once relayed to me how older women had, for decades, conducted ritual virginity tests on adolescent girls in the area. I was told the practice persisted in two nearby villages, but had otherwise disappeared. Historically, young women in Mtembu had been discouraged from penetrative sex, since losing their virginity would depreciate their value as potential brides. The boy “must not go to the cows”, they were told. Reference to cows marked the vagina as the site of potential bride wealth (interview with Yvette, Mtembu, 2 September 2013).

Today, marriage rates in Mtembu have drastically declined, penetrative sex is the norm, and adult men are scarcely present. Yet older women, in clinics, NGOs and homes, continue to act as moral arbiters, particularly over young women. This is important

context for two articles in this thesis — *Redeeming Lost Mothers* (article two) and *Negotiations of Blame* (article four) — which explore the perpetuation of gerontocratic authority and misogynist blame in matrifocal homes.

Kholo's Adolescent Programme

Kholo was one of the first organisations in the province to provide ART to HIV-positive children, most of whom had contracted HIV at birth, and had since lost their parents to AIDS illness. As these children have grown into adolescence, the organisation has followed their progress. Today, Kholo offers psychosocial support to a scattered cohort of adolescent ART users through quarterly weekend workshops as well intermittent home visits from village healthworkers. Initially weekend workshops served to facilitate medical check-ups for a growing number of adolescents from dispersed villages. Kholo staff had also used these weekends to sensitively inform adolescents of their HIV status, usually alongside their caregivers.

Following the closure of Kholo's ART programme, adolescent workshops have had larger treatment literacy and counselling components. Kholo lay counsellors said they wanted to foster "responsibility" in their adolescent "clients", teaching them how to "behave", "have discipline", "take their treatment", refuse alcohol, and "be clean and tidy". During weekend workshops, this self-responsibility was paradoxically fostered through intense adult supervision and an ethos of hierarchical respect.

Recruiting Rural Participants

In August 2013, Mildred and I set out to recruit adolescent research participants (age 10–19) in collaboration with Kholo village healthworkers. The villages from which we recruited were chosen on the basis of their proximity to where we were living. Adolescents needed to be between the ages of 10 and 19[6] and on ART. Participants were purposively sampled in order to get variety in age and gender. We also sought to include members of three key subgroups: those who were more likely to have contracted HIV sexually, those who were reportedly unaware of their HIV status, and those who were said to be struggling on HIV treatment. Village healthworkers informed prospective adolescent participants, as well as their families, of our study. For those interested, a meeting was arranged with Mildred, myself, and a village healthworker, in which we introduced the research and discussed consent.

Written, informed consent was sought both from guardians and adolescents themselves, occasionally over a number of meetings so as to allow families the chance to deliberate. I use the broad term 'guardian(s)' to refer to adolescents' primary adult caregivers, whether these were biological parents, grandparents, aunts, uncles or foster carers. Even in those cases in which adolescents were of legal consenting age (above 18 years), we felt it important to seek the assent of their adult guardians. These authority structures were deeply important to young people, regardless of how old they were. In order to ensure that adolescents' home lives were respected and protected, even after the research

[6] I remind the reader that age-based designations of adolescence are largely arbitrary. Although I use the definition of adolescence (10–19) provided by the World Health Organisation, many of the young people in this study are perhaps better understood as 'youth'. Two of the young men had already been initiated into traditional 'manhood' and three of the young women had children of their own. As such, I often use the terms 'adolescent' and 'youth' interchangeably, because for the purposes of this study, their distinctions are murky.

period was over, we sought to be cognisant of the relationships and hierarchies that operated there. Indeed, we soon learnt that all household members needed to understand and be comfortable with our presence in order for our relationships with families to be successful and for us to be allowed access to intimate home spaces. Making other young people in the house feel recognised was also valuable to ensuring that our research did not create familial tensions.

The process of recruiting participants had significant ethical implications. As I have already suggested, these related to the ways in which we conceived and negotiated consent. But they also included considerations about the confidentiality of prospective participants. I discuss these questions in more depth later in this chapter.

Because of the disproportionate number of perinatally-infected youth in Kholo's programme, we also visited health facilities in search of participants who might have contracted HIV sexually. Premised on the assumption that those sexually-infected adolescents who had initiated ART were most likely to have presented in antenatal care, we perused the antenatal registers of local clinics and hospitals. We found almost no HIV-positive adolescents on their rolls. The few adolescents that had undergone short-term ART to prevent HIV transmission to their babies were often deemed 'too healthy' to start treatment themselves. One such adolescent was recruited to the study to reflect on her previous experience of ART while pregnant.

With the help of four village healthworkers and one local nurse, we recruited thirteen rural households for in-depth ethnographic research. Households spanned five different villages. Because two of our participants were siblings, this equated to fourteen

adolescent participants for our rural fieldwork. Apart from one young woman recruited through a local clinic (mentioned above), all rural participants were identified through Kholo's village healthworker programme. Yet their engagement with the organisation varied immensely. While some adolescents regularly attended Kholo workshops and had built strong relationships with their staff, others had never attended a weekend with Kholo and had limited, irregular interactions with village healthworkers.

Peri-urban Fieldwork

In January 2014, Mildred and I began peri-urban fieldwork in the peripheral informal settlements of a small city that I will call *Ridgetown*. Located outside the former 'homelands', in an adjacent municipality, Ridgetown was about ninety minutes drive from the Mtembu area.

Figure 3: Ridgetown informal settlement

Photo credit: Tomáš Hájek and Jana Jersáková

A large proportion of residents in Ridgetown's peripheral townships are former farmworkers and their descendants. Farm workers started migrating to the city as early as the 1940s, when mechanisation and land rationalisation resulted in many farms losing labour. While jobs in Ridgetown were scarce, life in the country offered even fewer prospects. In the final decades of the twentieth century, the number of farming families seeking a livelihood in Ridgetown continued to rise.

Since 1994, the city has had a steady influx of economic migrants from the former 'homelands' and white farms, adding to the already well-established Xhosa community. Over the past twenty years, Ridgetown's informal settlement has continued to see exponential growth. Including its peripheral townships, the city's population is estimated at 125, 000. The majority (52.5%) of the population in the local municipality are female and 17.9% are between the ages of 10 and 19 (Statistics South Africa 2011). Ridgetown residents remain critically impeded by joblessness. In 2010, the local municipality estimated that more than 50 percent of the city's 'economically active' population (age 15–64) was unemployed. More recently, local press and social movements have publicised a 70 percent unemployment rate. As Mildred once said, Ridgetown families "hustled" to survive and accrued respect for doing so. "If they don't have food, they know whose uncle or auntie to go to. They know their corners" (field notes, Ridgetown 16 April 2014). More and more Ridgetown residents have come to depend on social grants. In the most recent national community survey (2007), approximately 23 percent of the population was estimated to be receiving some form of state grant. This percentage is likely to have increased significantly since.

HIV treatment was first rolled out publically in Ridgetown in 2004. Initially, starting ART involved a long work-up period and "proof of treatment readiness" in a system that was highly punitive. In order to be considered eligible for ART, patients had had to demonstrate that they had a treatment supporter at home, were willing to refrain from alcohol, and had learnt the AIDS science. According to Dr Meyer (pseudonym), who had been involved in the city's ART delivery from the outset, this disciplinary attitude continues to characterise much of the city's HIV care, although guidelines for treatment initiation are now less stringent (interview, Ridgetown, 20 January 2014). Doctors at the

Ridgetown palliative care unit told me that, while their wards had once been filled with patients unable to access treatment, today they tended mostly to those failing on ART (field notes, Ridgetown, 26 February 2014).

Perinatally-infected adolescents in Ridgetown were likely to have started treatment in the town hospital. Since then, most have been down referred to community clinics, where they now collect their regular ART refills and go for check-ups. The integration of ART with other primary healthcare services has resulted in more decentralised and, in Dr Meyer's experience, less personalised care (interview, Ridgetown, 20 January 2014). It is now less common for healthworkers to know and follow an adolescent ART patient through care.

Care Project

As in rural Mtembu, we discovered a pioneering organisation in Ridgetown that is likely to have been among the first in the country to start an adolescent HIV support group. The organisation, which I call *Care Project*, has historically provided end-of-life care. For much of its history, it cared for dying cancer patients living in the white areas of Ridgetown central. As the HIV/AIDS epidemic took hold, more and more of its patients were black residents dying of AIDS. The first of these AIDS sick patients was Thami's cousin. After the death of her cousin, and months of providing palliative care, Thami would take a job as a home-based carer for Care Project. In these early years, HIV care was about alleviating the suffering of bedridden patients. Although Care Project would visit AIDS sick children, NGO carers were accustomed to communicating exclusively with adult guardians. Thami recalled that many of the children visited by Care Project

had lost mothers to AIDS (interview, Ridgetown, 7 February 2014). Often, they had not been informed of the reasons for their mothers' death or the nature of their own illness.

In 2003, in recognition of the needs of this cohort, Thami initiated a support group for children living with HIV. Many of them would later initiate ART. At the time of our fieldwork, many of these children were entering their adolescent years. According to Thami, their entry into adolescence had been accompanied by increased struggles with treatment adherence and mounting questions about the nature of their illness (interview, Ridgetown, 7 February 2014). In the weeks preceding fieldwork, Thami had attended two funerals for adolescents who had inherited HIV at birth. Both had failed on ART after years on ART.

Over the course of our Ridgetown fieldwork, Mildred and I attended weekly Care Project support groups, where we observed proceedings and sometimes conducted role-play activities with participants. We were told that support group meetings were designed to cover bereavement, treatment literacy, hygiene, self-esteem, puberty and sexuality. Like Kholo, Care Project had also facilitated HIV disclosure to many of its adolescents, but had more recently encouraged caregivers to lead this process. Both Kholo and Care Project mediated adolescents' access to doctors, social grant documentation, NGO resources and government officials.

Peri-urban Recruitment

As was the case with rural fieldwork, peri-urban participants were purposively sampled for variation in younger and older, as well as male and female adolescents. In addition

to those enrolled in NGO support groups, we also sought to include adolescents who were receiving care exclusively through the state, and made special attempt to recruit adolescents who were likely to have contracted HIV sexually. Adolescents had to be between the ages of 10 and 19 and have initiated ART.

Five peri-urban participants were recruited through the Care Project support group. The research was introduced at a weekly meeting. Those interested in the study received isiXhosa pamphlets to take home. They were later followed up over the phone and finally with a home visit. In collaboration with the subdistrict Department of Health, as well as nurses and data capturers at Ridgetown local clinics, we recruited an additional four adolescents through the public health system. Because of the over-representation of younger, perinatally-infected participants in the Care Project support group, clinic-based recruitment targeted older adolescents, including those who initiated ART while pregnant. Nurses, data capturers and treatment supporters served as gatekeepers to prospective participants and their families.

In December 2014, Mildred and I conducted in-depth interviews with two HIV-positive adolescent girls. Both were living on the outskirts of one of the province's major cities and had been recruited as part of the Mzantsi Wakho quantitative survey. The aim of the interviews was to explore how these young women deduced and interpreted different modes of adolescent HIV infection: whether parent-to-child or sexual transmission. This was emerging as a significant theme in the preliminary analysis and demanded further exploration.

Both interviews offered unprompted supporting data about the symbolic rendering of deceased mothers in the lives of perinatally-infected adolescents. As such, these two interviews are included in the analysis for the second article of this thesis, titled *Redeeming Lost Mothers*. Because they did not form part of the primary ethnographic cohort for this study, I do not include these participants in my description of the adolescent sample (below).

The research sites chosen for this study allowed for an in-depth investigation of how state clinics, homes, and non-governmental care programmes interfaced in the delivery of youth ART care. However, the choice of research sites also circumvented a key institution in the lives of young people — the school. Given this, I may have missed significant ways in which schools shaped youth identity and development with important implications for ART. Sidelining schools might also have underplayed the role of peer relationships in young people's ART-taking, skewing the analysis towards caregiver-adolescent or health facility interactions.

As is the case elsewhere in the country, public health clinics in the Eastern Cape are staffed primarily by female nurses who also serve predominantly female patients. HIV/AIDS organisations, too, are populated largely by women. As I later illustrate, families in this research cohort were largely female-headed. In those households in which there were adult male members, these men often spent much time away from home, working in neighbouring towns and cities. For these reasons, I had very little interaction with adult men over the course of my fieldwork. My understanding of men's involvement (or lack thereof) in these households and neighbourhoods is therefore premised almost exclusively on the perspectives of women and children.

ETHICAL CONSIDERATIONS IN RECRUITMENT

Consent

Throughout the recruitment process, Mildred and I sought to present the research to prospective participants in a way that was non-threatening, ethical and honest. These introductions aimed to thoroughly inform families about the study, while also creating room for questions, contestations, and refusal. Indeed, this is understood as the crux of informed, voluntary consent. The question of consent is a disputed terrain in youth studies, since young people are often situated within complex institutional, political, and familial power structures.

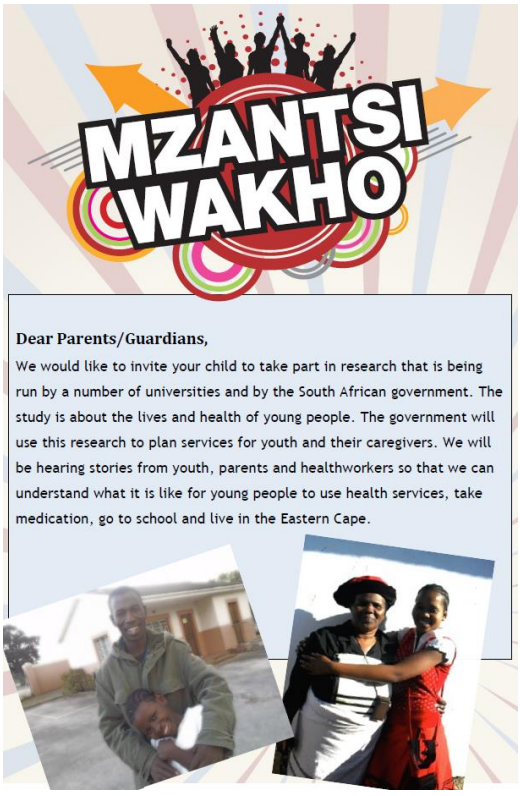


Figure 4: Excerpt from a guardian consent form (English version)

Mildred and I sought to make consent as free and voluntary as possible. However, the circumstances under which adolescent participants consented need consideration. Although the purpose and nature of the study was explained to prospective participants numerous times, the low level of literacy in many households meant that respondents ultimately signed the consent forms premised on trust. While the literacy levels in Ridgetown were better than in rural Mtembu, younger family members often assisted grandparents in reading through the consent forms.

In Mtembu, the presence of a Kholo village healthworker at the moment of eliciting consent may have put pressure on families to agree to the study. My insistence that refusing to participate would have no ramifications for the help they were getting from Kholo might not have been enough to alleviate this pressure, given that village healthworkers were present and watching over them. Further, adolescents' ability to refuse participation may have been limited by the number of adult authorities in the room, which included village healthworkers, researchers, and caregivers. Often, Mildred and I sought to get adolescents alone to discuss their research participation privately. Nevertheless, many of these young people would have been accustomed to obeying and respecting their elders.

In Ridgetown, our experience of recruitment was slightly different. Although Care Project and local clinics helped provide the contact details of interested families, we were largely on our own in facilitating the initial meeting. Meetings with Care Project–associated families were often easier to negotiate than those recruited through clinics: families trusted us by virtue of our association with the organisation. Although the families we contacted through clinic records were far more receptive to the research than we anticipated, in one case, we had to carefully explain our partnership with the local department of health in order to alleviate the grandmother's understandable fears that their clinic records were being made public.

In this study, informed consent was not a once-off process. Access and consent were negotiated and renegotiated on an ongoing basis, both with participants and their adult gatekeepers, and for the range of research activities that young people were involved in. There was continual re-enforcement that participation was voluntary and could be

withdrawn at any time without repercussions. Perhaps most importantly, Mildred and I ensured that any sign of discomfort (whether verbal or not) be treated as non-consent. To illustrate this, I reflect on the few instances in our study in which adolescents, or their families, appeared to decline participation.

'Drop-outs'

During the final months of rural fieldwork, Mildred and I were struggling to find time to see one of our adolescent participants, Tito (pseudonym). When we called to check whether Tito was home from school, his grandmother told us two or three times that the family were too busy for us to visit. Theirs was a sensitive family story, with Tito's mother having passed away within the previous year and the grandmother caring for five young toddlers. Two of these were Tito's younger siblings, who the grandmother reported had not yet been tested for HIV. She was afraid of what would happen to all these children after she died and believed they were all "sick" (interview, Mtembu, 10 September 2013). Tito's grandmother had not yet disclosed to Tito the reason for his mother's death or his own HIV-status. The third time we called, we sensed her reluctance, and reminded her that participation in the study was voluntary and could be retracted at any time. She took our offer to withdraw from the study. Soon after, we took a thank you gift and certificate of participation to the family.

In Ridgetown, one family seemed to implicitly refuse participation in the study, despite having taken interest initially. After presenting the research at their home, the family became difficult to reach and did not send us any text messages. Following a few attempts to reach them, we took this as an indication that they had declined participation.

For the purposes of this research, it was important to distinguish what forms of 'non-participation' should be read as lack of consent, and what forms of 'non-participation' could be more accurately described as a re-direction or re-appropriation of the research for participants' own ends. I return to questions of power and (non-)participation later in this chapter.

Participation-associated Stigma?

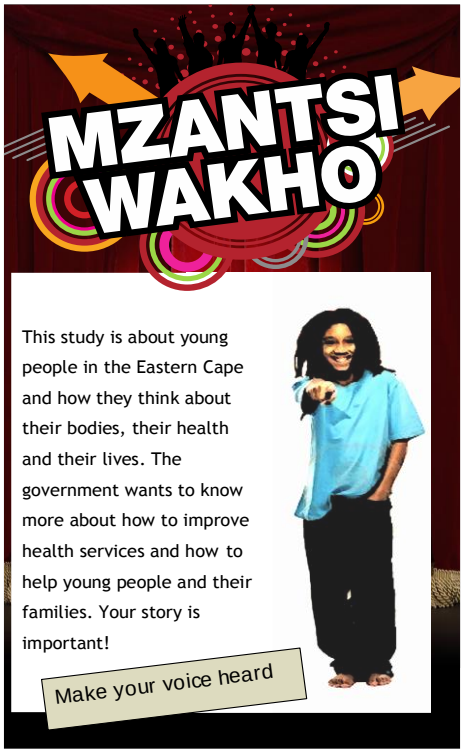


Figure 5: Front cover of adolescent recruitment pamphlet (English version)

Throughout the recruitment process, Mildred and I were at pains to ensure that our presence in the homes of prospective participants did not amount to unintentional disclosure of their HIV status, or attract attention for which they were not prepared. Never did we arrive at a family's house without them having already agreed to our visit. Here, NGO workers, nurses, data capturers, and community carers served as key liaisons. We also called families beforehand to ensure the timing of our visit was appropriate.

The research project was presented as a study about the lives and health of young people in the Eastern Cape. We explained that we were particularly interested in the ways that young people experienced health services, how they understood their medication, and how they perceived their bodies. This explanation of the research sought to prepare prospective participants for the possibility that they would be discussing serious and

intimate matters with us. But we were also deliberate in making no explicit mention of HIV. HIV was also not mentioned on any of the information sheets, consent forms, or recruitment pamphlets for the study. This decision was taken for a number of important reasons:

1) By avoiding explicit reference to HIV, we sought to lower the risks of participants suffering unwanted, involuntary disclosure, simply by carrying or possessing recruitment material.

2) Even in settings where adolescents were known to be HIV-positive, and formed part of a pre-existing group of HIV-positive youth, we wanted them to be in control of how much they were willing to openly discuss with us and when.

3) By keeping the recruitment materials reasonably vague, we sought to respect practices of discrete speech within some households. This allowed us to present, and conduct, the study in families that did not have a precedent of speaking openly about adolescents' HIV status.

4) Finally, this strategy for presenting the research enabled adolescents who were not aware of their HIV status, or not accustomed to openly discussing it, to speak in broad terms about their medication, and their experiences of health and illness.

Choosing not to make explicit mention of HIV in the recruitment materials meant that certain knowledge was kept tacit, thus entailing a form of deception. Standard ethics models would disparage deception in research, unless (as in this case) openness might

pose important risks to participants.[7]

Even with these precautions, Mildred and I were deliberately discreet in carrying research materials. Neither our clothes nor the vehicles we drove revealed us as researchers. Importantly, we asked families how they would prefer us to work with them: if there were spaces or places that they would rather we did not enter; friends or family they believed we should/should not meet; aspects of their lives they would like to share with us (whether church, clinic, school etc.); as well as hours of the day when they were unavailable.

Research Cohort

Twenty-three HIV-positive adolescents (age10–19) and their families make up the core research cohort for this study. Fourteen of these adolescents were living in rural villages of Mtembu, while the remaining nine lived in the peripheral informal settlements of Ridgetown. The cohort included an almost equal distribution of male and female participants. Just over half of these participants were above the age of fifteen, while the remainder were younger adolescents. Nineteen of the adolescent participants were presumed to have inherited HIV from their parents, while four were assumed to have contracted the virus sexually. Assumptions about mode of infection were premised on the treatment narratives told by young people, their guardians, and their healthworkers, and often supported by assessments of adolescents' physical symptoms. The ambiguity of these epidemiological categories is explored further in the fourth article of this thesis,

[7] For a fuller discussion of ethics and deception in anthropological research, see Carolyn Fleuhr-Lobban's (2013) chapter: 'Transparency and deception in anthropological ethics'.

Negotiations of Blame.

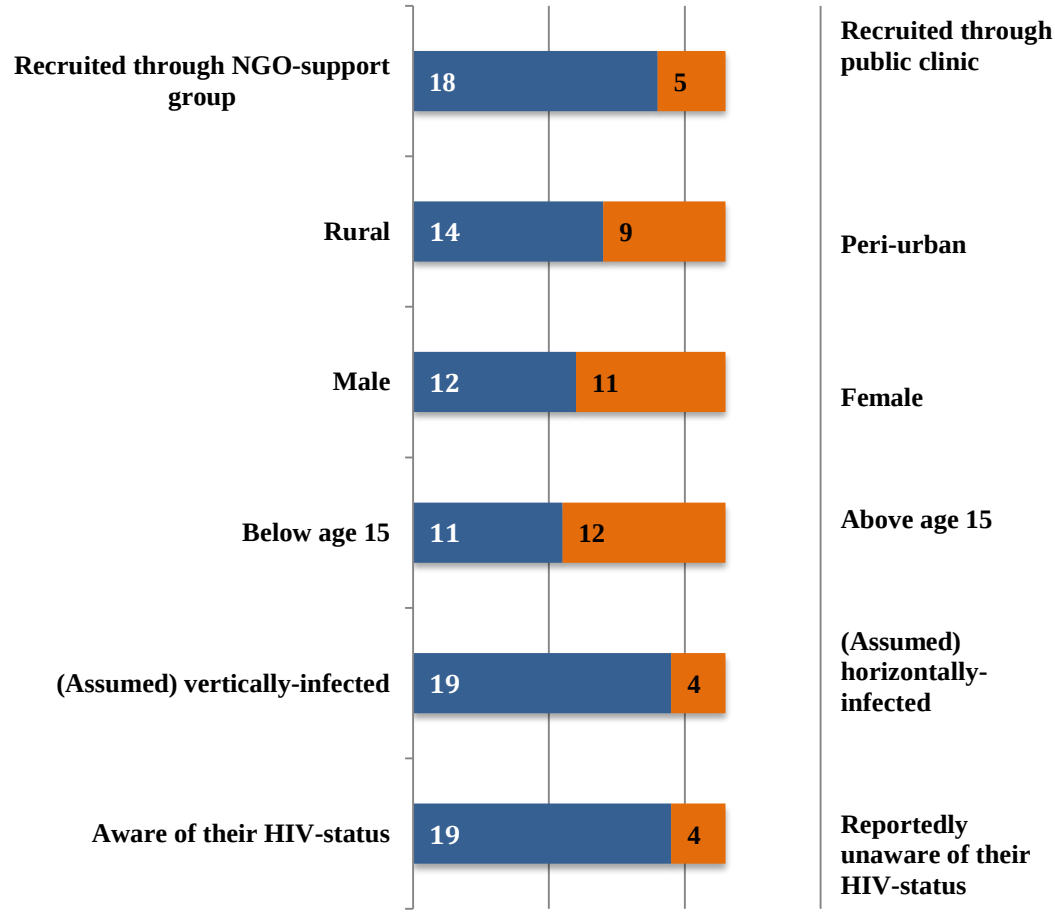


Figure 6: Description of adolescent research cohort (23 participants)

For most adolescents in this study, the achievement of ART entailed a complex alignment of families, NGO-affiliated layworkers, and state clinics. Only five adolescents were not members of support groups and thus negotiated ART care exclusively through the state system.

At the time of fieldwork, one rural participant had been classified as a ‘defaulter’, due to his persistent struggles with ART adherence. Another had removed herself entirely from ART care and would thus be considered ‘lost to follow up’. Some rural participants reported taking treatment ‘breaks’ in the past because their clinics had run out of medicines. One adolescent said there had been a week in which she was unable to collect her pills.

In Ridgetown, a young girl in our study reported having stopped her medication for long periods due to insufficient food. A second peri-urban participant was selectively not taking one of his three ART pills to escape its side effects. And a third Ridgetown participant frequently ran away from home, leaving her medication behind. Indeed all adolescent participants in our study reported occasionally missing medication, and faced a range of circumstantial challenges to HIV treatment. These included not wanting to take medication outside the home, fears of unintended disclosure to friends or sexual partners, forgetting, oversleeping, or not having food to eat before pill-taking.

Only four of the twenty-three adolescent participants in this study were reported, by their guardians, to be unaware of their HIV status. Of these, two turned out to know their HIV status, but did not discuss this knowledge at home.

All adolescents in our study were attending school, although three had dropped out by the end of our fieldwork. At least half of the adolescent participants in this study were taking an especially long time to complete their schooling. This was attributable to a combination of poor schooling, long periods of sick leave, and severe learning difficulties. Guardians and healthcare workers spoke regularly of learning difficulties

among HIV-positive adolescents, particularly among those vertically-infected.

Households

Eleven of the adolescents in our study had lost mothers to AIDS illness. Thirteen had fathers who were either deceased or unknown to them. Consequently, many adolescent participants were living without either one of their biological parents. Most of these lived in households headed by grandparents, but a few stayed with aunts or uncles. Families reconfigured themselves around the extra needs for support and care, necessitated by AIDS illness and death. In Ridgetown, some orphaned adolescents had moved a number of times from one caregiver to the next or had been recently taken into a new family. Nine adolescent participants lived with a biological parent. In all of these cases, the parent was also on ART.

Among rural households in this study, social grants were the primary source of income. These included child support grants, foster child grants, pensions and disability grants. In some homes, state welfare was supplemented by intermittent income from relatives working in towns, cities, or nearby farms. Some rural families were involved in small-scale agriculture: two had vegetable gardens, while a further two kept livestock.

In Ridgetown there was greater access to paid work than in the rural areas, although this was largely insecure, temporary employment. Some guardians worked as casual labourers on nearby farms, others on municipal projects, and others still as domestic workers. Social grants remained an important source of income for these peri-urban households.

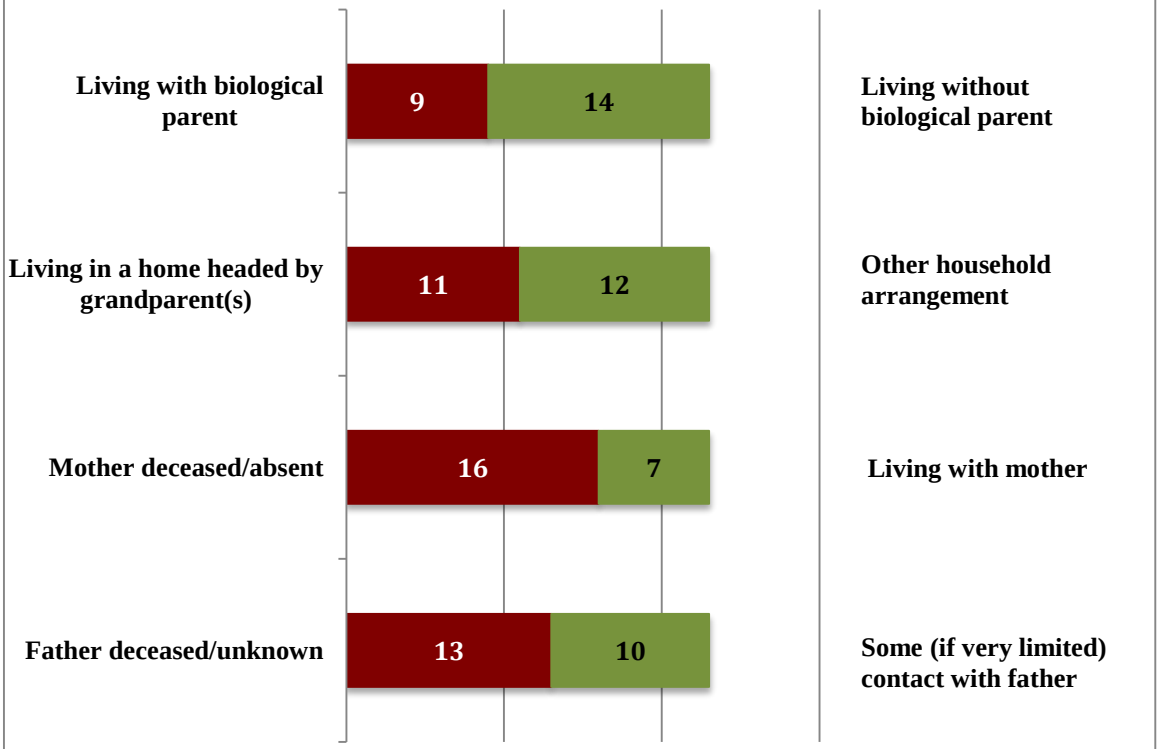


Figure 7: Description of adolescents' home lives (23 participants)

Adolescents in our study woke early, even on weekends. This was often demanded by their early medication time. In rural areas, many adolescents were expected to prepare water for the family to bathe. Most of the young people in our study walked to school with friends or family, although some took taxis. In the afternoons, peri-urban adolescents were much busier than their rural counterparts. After school, they visited the library, played sport, attended music practice, and were out in the streets with their friends. It was much harder to find time to see them. A few of the older, rural adolescents visited taverns on the weekends or spent time drinking with their peers. Others had orchestrated their lives so as not to be seen too much in public, which they believed would only incite gossip.

Sample Limitations

The NGO programmes through which we recruited catered primarily for perinatally-infected youth. It was improbable that sexually-infected adolescents would fall ill with AIDS. As a consequence, they were both less likely to access and less likely to stay in HIV care. The small numbers of sexually-infected adolescents in this study sample are attributable, in part, to their underrepresentation in ART support programmes, both state and non-state.

This was a small cohort of HIV-positive youth, recruited from specific geographic settings and accessing HIV care in unique ways (many with additional NGO support). Their experiences cannot speak to the full population of South African youth on ART. The vast majority of adolescent participants were enrolled in additional NGO care. As a consequence of their level of institutional engagement, these young people may have been uniquely adept at negotiating HIV treatment and care. They were also likely to have been receiving better care than most.

Given my interest in young people's ART participation, this study excluded adolescents who had never tested for HIV, those who tested HIV-positive but had not returned to care, and those not yet eligible for treatment. All adolescent participants had been initiated onto ART at some point in their lives. While some had been on ART for almost a decade, others had initiated as recently as the last year. As already mentioned, one participant had taken a course of ART to prevent HIV transmission to her baby and had since completed her treatment. Because her virus remained suppressed, she was not herself eligible for lifelong ART.

Even among those who had initiated ART, the recruitment strategy for this study is likely to have produced a biased sample. I had limited access to adolescents who had long been lost to the clinic system or opted out of care services. Nevertheless, interacting with adolescents over an eight month period allowed me to work with those whose engagement with care services fluctuated.

Despite these limitations, this study constitutes the largest and lengthiest qualitative study of youth ART in South Africa. Using multiple methods over time, it offers rich and contextually sensitive accounts of how young people have experienced and interpreted antiretroviral treatment and the institutions that have sought to regulate it. By involving professional and lay healthworkers, as well as adult guardians in the study, I have sought to locate adolescents' ART practice as a relational process, negotiated within complex institutions of care.

POSITIONALITY

I have already alluded to some of the ways in which my position as a 'white'[8] researcher may have had consequences for this research. I was conducting fieldwork in villages and townships whose predominantly black inhabitants had been deliberately, yet arbitrarily, dispossessed by the legacy of apartheid. The HIV/AIDS epidemic, which I sought to study, had both revealed and further entrenched these systemic racial inequities. Indeed the epidemic is largely born by black South Africans.

[8] In the sense that it is meaningful for understanding my social positioning with respect to this research, I have referred to myself as white. Throughout my life I have received all the privileges of South African 'whiteness', and would have been received as 'white' by both participants and others in the research field. I am not, however, biologically white and thus do not fully identify with whiteness. For this reason, I have used the term in quotation marks.

My ‘whiteness’ was further complicated by the fact that I was an English-speaking, middle-class female. More so, and as I have already suggested, participating families often associated me with the healthworker or NGO that had initially introduced us. These various, and quickly apparent, aspects of my social positioning had consequences for how I was received in the research field.

Despite the Eastern Cape being my home province, my whiteness signalled my outsider status in the particular neighbourhoods in which I was working. In a few cases, younger (and particularly rural) adolescents seemed to find my whiteness intimidating. One adolescent explained that she was “scared of white people”, although this initial apprehension appeared to quickly subside.

In the vast majority of cases, my whiteness was attached with immediate authority and undue reverence. My race meant that my expertise were presupposed and my requests more readily obliged. I moved in and out of clinic consultation rooms with ease. Indeed, some participants in our study tried to leverage my apparent authority, asking that I skip clinic queues on their behalf or make special requests of nurses and doctors.

In addition to granting me immediate authority and assumed expertise, my whiteness also signalled to some that I was a person of means and connections. In one rural village, for example, a group of children once requested money from me. When I explained why I could not oblige, they responded, “but you are *umlungu* [a white person]” (field notes, Mtembu, 24 September). Both participants themselves, and others in the research field, regularly requested my assistance, whether in the form of food, money, transport or referrals. As an employee on the research project, and by virtue of her association with

me, Mildred received similar requests. Later in this chapter, I reflect on how we grappled with these expectations.

In terms of building rapport with participants, being a white outsider had both advantages and disadvantages. I had to work concertedly to create comfortable and non-threatening research engagements, sensitively building relationships over time, and as a result, being increasingly invited into the intimate spaces of people's everyday lives. While being a white stranger demanded rapport-building, there were also instances in which my position as an outsider engendered trust. The anonymity of speaking to a stranger may have made it easier for some to divulge personal information.

While Mildred spoke isiXhosa, she was originally from Pretoria. This meant that she often straddled the boundaries between 'insider' and 'outsider'. Although she knew the language and understood many local references, she was also (more often than not) sufficiently removed from local families to be deemed an unbiased, trustworthy listener. This was not the case in two Mtembu villages, where Mildred was occasionally associated with the Kholo social worker with whom she lived. In the village in which we lived, Mildred had long-standing friendships with a few participating adolescents and their families, which could both aid and limit what they were willing to share with her.

Partly because of her race and language abilities, research participants would have received Mildred differently than they did me. These differences in how each of us was received prompted important moments of reflection throughout the fieldwork. Where participants spoke good English, and translation was not necessary, Mildred and I occasionally met with them separately, comparing the different and nuanced ways in

which the same participant might present her/himself.

Participants' responses to us were also likely to have been gendered, shaped by what they believed they could or should share with female researchers. Male participants, in particular, may have been guarded about what they disclosed, and occasionally adopted flirtatious styles of engagement with us.

CONCEPTUAL FRAMEWORK

While the articles in this thesis are not intended to test or elucidate a particular theory of human action, their methods and analysis are informed by concepts and approaches drawn from institutional ethnography (Grahame & Smith 2013; Mykhalovskiy & McCoy 2002; Smith 2005). Institutional ethnography is a method developed by Canadian sociologist Dorothy Smith as a means of investigating the linkages between activities of everyday life and relations of social organisation (Devault & McCoy 2001). As a method of study, institutional ethnography begins with the actualities of everyday life and then seeks to understand how these activities hook up with various social and cultural institutions.

For Smith, an institution is not a bounded organisational space, but a vast nexus of coordinated work processes, agencies, discourses, and courses of action (Mykhalovskiy & McCoy 2002), which produce and circulate "ruling relations", and are organised around specific social functions like healthcare. Institutional ethnography explores how everyday lives interface with these intersecting institutional relations— how day-to-day activity is socially organised.

Institutional ethnographers examine relations of ruling through "texts". Texts are defined broadly as documents or representations that can be reproduced, disseminated or transferred by different users. Text need not be literal, but can also refer to the embodiment of meaning in behaviours, spaces, organisations or utterances. In the form of ideologies and practices, texts transport power across sites and between people, not unlike Foucault's concept of 'discourse' (discussed in Wright 2003).

But it is not the discourse of text, nor the subject who makes use of text, that is the starting point for investigation in institutional ethnography. Rather, the inquiry begins with the relations into which the text enters – i.e. how small-scale relations are mediated by texts, thereby linking everyday action to larger institutions and nexes of power. Thus, institutional ethnographers are interested in what text makes happen and how it is used in daily life to coordinate social activities. Rather than simply asking what social forces are operating here, institutional ethnographers give attention to how they operate. The focus on the 'how' centres attention on the use and mobilisation of institutional text. The entry-point for investigation is the embodied, experiential encounter with technologies and texts of social organisation.

For the purposes of this research project, social and institutional texts are not only activated in everyday observable activity, but also inside the minds of adolescents, in their interpretations, self-perception and identity work.

It is important to recognise that I did not have unmediated access to the thoughts and perceptions of research participants. Studying intimate and internal aspects of people's everyday lives carries inherent limitations. One's analysis is inevitably restricted to

participants' representations, recollections and performances of their inner worlds. To interpret the social world through 'texts' is to acknowledge that actions and utterances have a representational aspect. As participants presented their narratives to me, they were also inevitably negotiating power and attempting to have certain knowledge or meanings ratified.

Power is a particularly important analytic focus in institutional ethnography, illuminating how ruling relations are transported through institutions, discourses, knowledge and experience (Wright 2003). Institutional ethnographers analyse power as something that circulates. Power is never localised in a place or person or appropriated as a commodity. Instead, people are always in the process of simultaneously undergoing and exercising power. Thus, individuals are not simply targets of power, but also vehicles of its articulation, or in Smith's terms, "activation". Institutional ethnography examines the mobilisation of institutional texts from the perspective of the targets of ruling, while also acknowledging that they are not mere objects, but subjects in the nexus of power. The fact that institutions take the form of socially-mediated texts suggests that different readings and interpretations of such text are possible.

Institutional ethnography is typically organised around the idea of "work", which is generously defined as, "what people do that requires some effort, that they mean to do, and that involves some acquired competence" (Smith 1987, p.165). This definition could include both paid organisational work and everyday life work, including the work of taking ART and participating in support programmes. Although research on ART care has frequently revolved around medication adherence, in order to determine people's level of compliance, understand why they do not comply, and assist them in becoming

more adherent, less attention has been paid to what people are actually doing when they try to carry out medication regimens – the emotional, time and self 'work' involved. As the articles in this thesis show, enrolling and remaining in ART programmes can be attended by blame, resentment or policing. The constant negotiation of these 'social stakes', as I call them, means that ART, as a process of social incorporation and not just pill-taking, entails precarious work.

METHODS

While the methodological choices for this study were structured, substantiated and deliberate, they were also intuitive, irregular and continuously adapted throughout the research period. Research design was not a discrete stage concluded in the initial conceptualisation of the study. Instead, it was an ongoing process, demanding constant review and adaptation in the face of contextual, ethical and practical demands (Lewis & Ritchie 2003). Data for this study was collected over an eight month period using ethnographic methods in combination with a variety of formal and informal semi-structured interviews. Participants included adolescents, guardians, as well as professional and lay healthworkers.

Adult Participants and Institutional Observation

In almost every case, we began our research interaction with adolescents and their families by interviewing guardian(s). While this indicated our respect for household

Figure 8: Mildred in a community garden with one of the mothers in our study

authority structures, and built trust with adult carers, it is also likely to have influenced how adolescents later responded to us. During the time that adolescents were at school, Mildred and I met with their families separately to facilitate semi-structured in-depth interviews. These conversations traced the life histories of the adolescent in question through the eyes of their caregiver. They also explored key caregiving challenges related to the adolescents' everyday ART-taking and extrapolated care practices within the home.

To further investigate the institutional texts and authorities informing adolescent ART-taking, we also conducted semi-structured interviews with healthworkers and community caregivers. Over the course of our eight months fieldwork, we interviewed four village healthworkers, two support group leaders, a social worker, four lay counsellors, five nurses, and two doctors. Along with inputs from guardians, these interviews sought to investigate the ways in which key adults in young participants' lives interpreted and enacted ART care. Our interactions with adult participants not only offered insight into young people's interpersonal contexts. They also enabled an exploration of the hierarchies of intuitional, familial and cultural authority in which adolescent ART was nested.

Interviews with guardians and healthworkers were complemented by observations in clinics, hospitals, support groups, and to some extent young people's homes. These

provided detailed accounts of the institutional settings informing youth ART. Over the course of fieldwork, we visited four Mtembu and two Ridgetown clinics regularly and accompanied adolescents and their families on clinic and hospital appointments. At health facilities, we engaged regularly with nurses, counsellors, and pharmacy assistants and had informal conversations with six professional healthworkers.

Because Ridgetown health facilities were easily accessible and in closer proximity to one another, Mildred and I were able to spend more time observing in nurses' consultation rooms than had been possible during our rural fieldwork. Conducting general clinic observations, without our research participants present, limited the risk of us only being associated with HIV-related cases. Although nurses, clinic managers and department of health officials had agreed to us observing clinic consultations, the patients who entered the 'research scene' had not. Upon entering the consultation room, each patient was introduced to us and our research. Nevertheless, their ability to consent was limited and the realities of this are difficult to mitigate. In reporting our observations, we have sought to protect the anonymity and confidentiality of these patients as far as this is possible.

Interactions with Adolescent Participants

While an understanding of institutional settings was important, at the crux of this research project was an interest in the ways that young people interpreted, used and appropriated institutional practice through their ART participation. We observed and engaged with adolescents in their homes, over meals, while performing chores, in clinic waiting rooms, on the streets, and in parks. During rural fieldwork, we were able to spend

significant time in homes and villages. In Ridgetown, many young people did not feel comfortable having us in their neighbourhoods. This was largely due to safety and confidentiality concerns. As a result, we often took Ridgetown participants to the local gardens or sports centre, which unfortunately lent itself to more structured and manufactured interactions.

In addition to immersing ourselves in aspects of adolescents' daily lives and observing their interactions with care institutions, Mildred and I also employed more structured data collection tools. Many adolescents struggled to stay focused in standard interviews and were visibly uncomfortable when asked too many direct questions. As a consequence, interview questions were often worked into a series of games.

Sometimes adolescents retrieved interview questions by popping balloons. On other occasions, they were asked to reflect on a series of pre-selected images depicting adolescents at home, in health settings or with friends. Sometimes we integrated conversations into ball games, drawing activities and role-play. These methods were developed and adapted intuitively in field and varied depending on the preferences and capabilities of the adolescent.

In using creative interview techniques, we sought to create a non-threatening environment for adolescents, encourage their participation, and retain their attention. Using a variety of methods, both traditional and innovative helped guard against the bias of using a single method. It also served to cross-check data, allowed us to determine the efficacy of different methods, and helped strike a balance between non-invasive participation and guided interaction (Punch 2002).

Conversations with youth centred on their experience as ART users, but also sought to contextualise this amid their everyday lives and concerns. Often we asked adolescents to talk through an average day in their lives, reflecting on their routines and domestic relationships. Once we arrived at medication time, we prompted adolescents to talk us through their experience of pill-taking: what they did before and after, who was present, their thoughts throughout pill consumption, as well as the size and taste of their medication. To grasp adolescents' experience of different institutions of care, we asked about relationships with relatives, nurses, and support group leaders. Adolescents described procedures for collecting pills as well as their experience of blood tests. As we got to know adolescents, and immersed ourselves in their everyday lives, we were able to converse with them about their day-to-day social concerns. We also talked through what they could remember of their life histories, their parents, and their 'coming-to-know' their HIV status. Our research engagements with adolescents over time, in combination with inputs from their caregivers, healthworkers and peers, provided a complex case study for each adolescent participant.

All research activities were carried out in both isiXhosa and English with Mildred facilitating in-situ translations when necessary. Where possible, interviews with guardians were audio recorded. Quick, informal interviews with nurses in a professional setting were often better suited to note-taking. For the most part, interactions and semi-structured interviews with adolescents were captured in field notes, as the formal, recorded interview was often ill suited to their participation.

Ethical Quandaries of Fieldwork

Ethics in the Interview

We sought to ask questions that were sufficiently sensitive and open ended to allow participants some control over the extent and nature of their disclosures. Nevertheless, researching intimate and deeply personal aspects of participants' lives meant that some shared stories with us that were painful to recount. These included narratives of death, illness, and past abuse. In addition to offering referrals where appropriate,[9] Mildred and I also grappled with how to sensitively manage emotional distress in the context of our research engagements.

These types of intuitive, practical judgements constitute the day-to-day interpersonal ethics that make up the bulk of ethical research practice. When a participant is tearful or upset, what does one say and in what tone of voice? Does one turn off the tape recorder or leave it running? Does one abandon the interview plan or try and return to it? What consolation can be offered? How does one interact with participants in a human, non-exploitative way while also being mindful of one's position as a researcher? (Guillemin & Gillam 2004, p.264) Like those who have extrapolated an "ethics of care" for social research (Edwards & Mauthner 2012; Sevenhuijsen 1998), we tried to think of ethics as caring and careful judgements based on practical knowledge and attention to the details of time and place.

Distress was dealt with on a case-by-case basis, attuned to the timing and context of participants' upset. With some adolescents, it meant breaking the conversation with a

[9] I deal with this more thoroughly in the section titled 'Protecting Participants from Harm'.

game or directing the discussion differently. Others wanted to talk through their reflections with us. On occasions when adult guardians became upset, our responses included stopping the conversation for a while, creating a space of silence, holding their hand, or making a calming cup of tea. Most importantly, we allowed participants to determine how, or if, the conversation continued.

Confidentiality

In order to protect participant confidentiality, it was essential that we did not disclose anything adolescents had told us to their caregivers or vice versa. This often required removing adolescents from their homes in order to spend time alone, or distracting adolescents outside the home while we made time to speak privately with caregivers. In one case, we were asked to conceal the research from a participant's sister, pretending to simply be her 'friends'.

During our rural fieldwork, Kholo staff often asked after their adolescents. Although our relationships with Kholo staff were important, we refused to share anything adolescents had disclosed to us. This became murkier when we were handling adolescents' health or family crises. Members of Kholo would approach us with a case that demanded urgent attention. In our discussions of how to manage it, we had an ethical obligation to protect adolescents from harm.[10] But in doing so, we also risked breaching adolescent confidentiality. Deciding what information demanded disclosure to external parties was a delicate process, which we often negotiated in collaboration with adolescents and their families.

[10] I deal with this more fully in the following section, 'Protecting Participants from Harm'.

Since fieldwork took place either in small villages or compact peri-urban settings, confidentiality was a significant site of struggle. Association with the research risked drawing unwanted attention to participants. This was complicated by the fact that many of our participants knew one another and would speak to each other both about us, and other members of the research cohort. Thankfully, many participants in our study were already disclosed to one another as a consequence of their engagement with NGO support groups. This limited the risk of inadvertent disclosure should they have seen us with another participant. Nevertheless, Mildred and I tried to spend time with both HIV-positive and HIV-negative youth in numerous settings, with the aim of limiting our association with HIV.

Despite how we might have tried to protect it, in reality, the very notion of confidentiality was a charade in homes and neighbourhoods like these. Adolescents experienced unwanted HIV disclosure in clinics, in their association with NGO workers, and through the documents they carried. Gossip also circulated fast. One mother in an Mtembu village said of her son, "He is not disclosed but there's no one who doesn't know his status" (9 August 2013). This was a common situation for adolescents in our study. What seemed at stake was not whether their status was tacitly known, but our ability to nevertheless protect their dignity, discretion and privacy.

Protecting Participants from Harm

Our research cohort was comprised primarily of adolescents on life-preserving, chronic medication. In not taking their treatment, some adolescents placed themselves at

significant risk of harm. When adolescents discussed circumstantial reasons for missing their medication (like forgetting, oversleeping, or being unable to collect their pills), we prompted reflections on how they might contend with these obstacles in future. But, as this thesis illustrates, ART adherence is often much more complicated than the circumstantial. Adolescents' ART was embedded in social relationships and obligations and entailed significant stakes.

During fieldwork, it emerged that two adolescents in our study had serious and long-term problems adhering to their treatment. Another was thought to have suffered recent sexual abuse.[11] Because most of our adolescent participants were registered to HIV support groups, they often had an already-established, and unique, set of care networks from which to draw in such times of crisis. In all three cases described, these networks were soon set in motion. Mildred and I supported existing referral systems where we could, accompanying and transporting participants to local clinics, hospitals and social service departments, and making phone calls where necessary. With the consent of adolescent participants, we occasionally liaised with their community healthworkers and adult guardians about their health status.

The wider Mzantsi Wakho research team, as well as local NGOs with whom we had partnered, were invaluable resources in helping us reflect on questions of harm to participants. We consulted regularly about how to protect and care for adolescents in our study, even if this was often in generalised, hypothetical terms. Mildred and I wrestled with the nature of our involvement in adolescents' lives and sought to make careful, contextual choices about how, if, and when to intervene. Most importantly, we sought

[11] Details of how we responded to these sensitive cases are included in the appendices of this thesis.

to ensure that the support we provided did not damage pre-existing relationships of care and could be sustained beyond our fieldwork. Decisions about how to support adolescents were always made in collaboration with the adolescents (and often the families) themselves.

Managing Expectations

Throughout fieldwork, I was concerned about how to ethically compensate participants for their time, knowledge and emotional investment in the research. This concern was amplified by the extent of joblessness, food insecurity, health problems and psychosocial burdens among research participants.

Predicaments of participant compensation have often been related to those of voluntary consent. Here, researchers have been concerned with the boundaries between payment, incentives and subtle coercion, and how these affect both the fieldwork itself and the study findings (Colvin 2014). Ethical quandaries have pivoted on ensuring that research is neither exploitative nor coercive.

From our initial meetings with families, Mildred and I were clear that we could not offer monetary compensation for participation nor did we have the capacity to provide regular food parcels. Nevertheless, adolescents, families and healthworkers made numerous material requests throughout our time in the field. In rural areas, the fact that we had a means of transport made us a particular resource. Negotiating participants' expectations was a grave ethical struggle. Our approach was to be consistent with respect to monetary gifts or loans, but to make situational decisions with regards to other assistance.

Given that we often took adolescents away from chores, that families often included us in their household meals, and that participants invested time and emotional energy in the research, we felt it important to reciprocate in some way. Reciprocation included building mutuality by sharing about ourselves, giving in improvised and non-monetary ways, as well as offering spaces for fun, learning and sharing through the data collection process. We also offered transport to health facilities and social services, brought food to share with participants, and sometimes assisted with referrals. These forms of reciprocation were important. Nevertheless, a primary ethical concern for this study, and the broader research project, is to generate research that contributes meaningfully to understandings of youth ART and therefore informs our responses to it.

As the first article in this thesis, titled *Mobilising AID(S)*, will illustrate, some families in this study were well versed in mobilising their HIV narratives for material resources. Building personal connections with NGO workers, well-resourced outsiders or state patrons were key to their survival tactics. Given this, it was unsurprising that families asked what material benefits would come from their research participation. I sought to be alert to the "reciprocal instrumentalities" (Posel & Ross 2014, p.20) of these research encounters. Not only did I have to reflect seriously on the ethics of my own research extraction, but research participants also had instrumental interests of their own.

Art-based Participatory Workshops

Observation and structured interviews were further complemented by participatory workshops with a total of 33 HIV-positive youth. These workshops were run in collaboration with others on the research team and used arts-based research

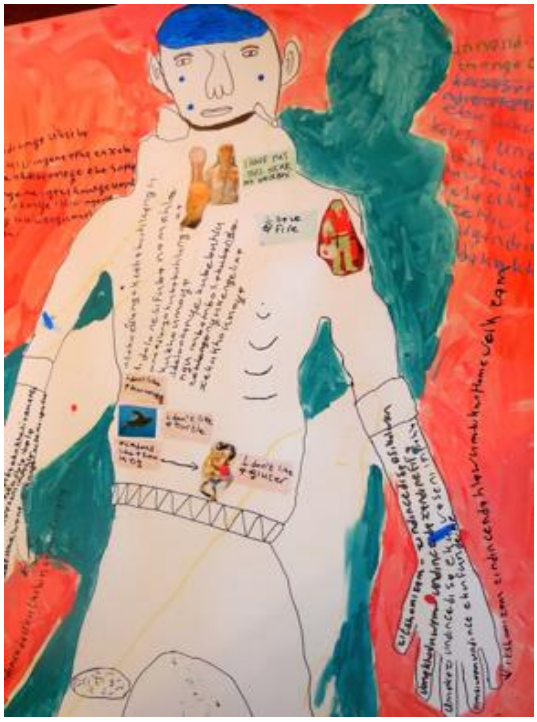


Figure 9: Example of an adolescent bodymap

methodologies to elicit adolescent experiences of health, illness and treatment. The primary research tool was bodymapping.

Bodymaps (MacGregor 2009; Vasquez 2004) are life-sized body outlines, filled with visual representations of experiences, feelings and interactions as they relate to the body and the social world. Bodymaps have been used as a therapeutic tool among HIV-positive women in Khayelitsha to convey experiences of living with HIV and taking ART. During the "Mapping Our Lives" workshops, women engaged with medical knowledge, which included anatomical diagrams of organs and representations of the virus. But participants were also encouraged to create spaces for the social: to "think of the body as a museum of life" (MacGregor 2009, p.88). Undoubtedly, bodymaps do not provide a transparent window into participants' inner worlds. They do, however, offer a different mode of representation.

Adolescents in this study were prompted to map their illness and treatment histories on life-sized outlines of their bodies. During each workshop, researchers took notes about adolescents' responses and interpretations of their drawings. Often, adolescents' illiteracy required us to write on their behalf. Hence, as with other forms of data collection, bodymaps entailed a performance to an audience and were often coproduced by the adolescent and the researchers.

Figure 10: One of the bodymapping workshops with participants' faces obscured for anonymity

Ethics and Bodymapping

Consent

Adolescents and their guardians provided additional written consent for adolescents to participate in bodymapping weekends. We explained to families that young participants would be discussing and drawing their experiences of health, illness, and treatment alongside other youth on medication. After creating their bodymaps, adolescent participants completed a release form, telling us how they would prefer their artwork to be used and stored. These were translated into isiXhosa.

As with our longitudinal ethnographic work, negotiating consent for bodymapping workshops was not a one-off process. Again, we sought to pay attention to implicit forms of non-consent, whether from adolescents themselves or their adult guardians. In one instance, a fifteen-year-old rural participant, who we had been working with for some

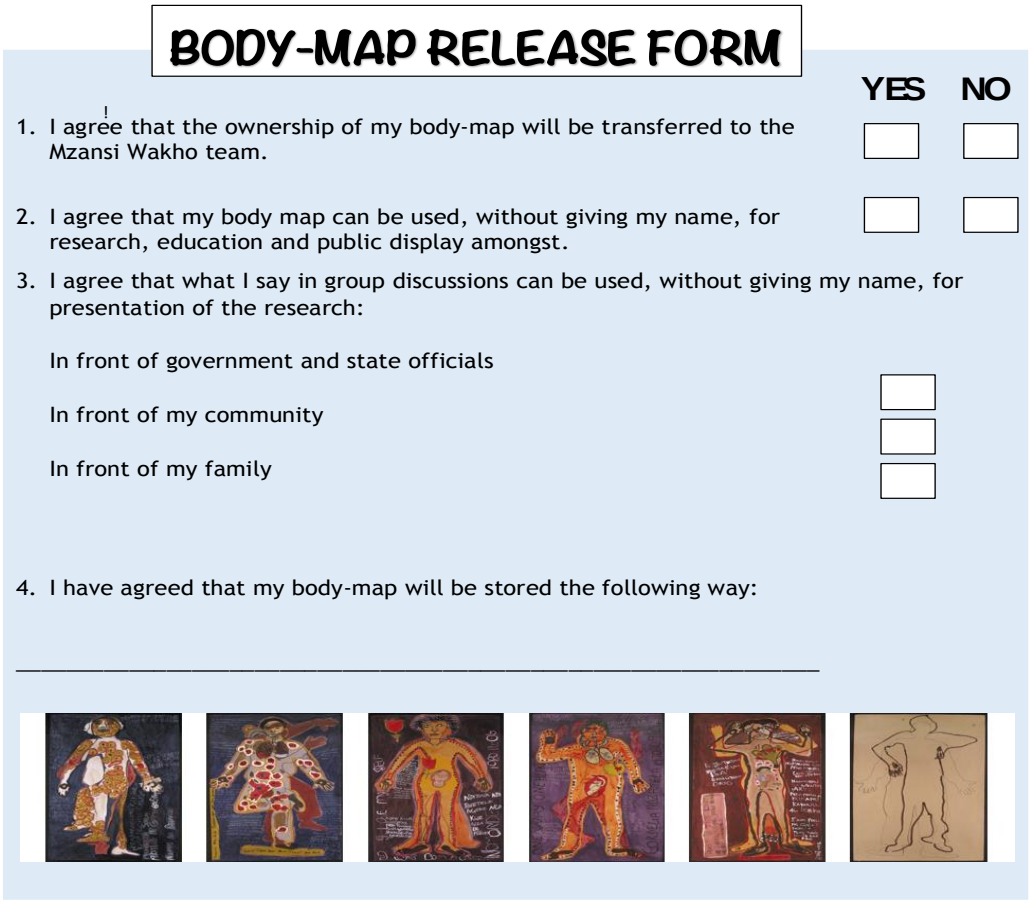
time, showed reluctance to attend one of our weekend bodymapping camps. We will call him Thando. We explained to Thando and his family that attendance at the weekend workshop was entirely voluntary and that we would continue visiting Thando regardless of his attendance. Thando had never slept away from home and was famously shy. His family believed he would greatly benefit from the weekend and had bought him new shoes to attend. Thando's grandmother had only recently started speaking with him about his HIV status, which she believed he had been previously unaware of. She may have hoped the weekend's activities would aid Thando's ability to reconcile himself with his HIV.

While his family were eager for him to attend the weekend away, Thando himself was reluctant. Perhaps it was the fear of being around so many other adolescents or being away from home. But we had also been very open about the weekend's research purposes and our intentions to use bodymapping to explore experiences of health and illness. Given how little experience Thando had in speaking about these parts of his life, and the recent emergence of these conversations in his family, he may have found the prospect particularly daunting. Thando did not attend the bodymapping weekend, but continued to participate individually in other research activities.

Confidentiality

In an endeavour to create a less threatening research environment, we facilitated two separate bodymapping workshops. The first group of workshop attendees was comprised of adolescents who were aware of their own HIV status, had disclosed this information to one another, and had prior experience discussing HIV together in their support groups.

The second group included adolescents who were either unaware of their HIV status or were not vocal about it. We also added to this group, adolescents who were not themselves HIV-positive, but were caring for a family member on chronic medication.


BODY-MAP RELEASE FORM

YES NO

1. I agree that the ownership of my body-map will be transferred to the Mzansi Wakho team. ☐ ☐
2. I agree that my body map can be used, without giving my name, for research, education and public display amongst. ☐ ☐
3. I agree that what I say in group discussions can be used, without giving my name, for presentation of the research:

   In front of government and state officials ☐

   In front of my community ☐

   In front of my family ☐

4. I have agreed that my body-map will be stored the following way:

_____

Figure 11: Bodymapping release form

These additional participants were recruited through snowball sampling as adolescents told us of friends or siblings caring for guardians on treatment. In the context of this second workshop series, researchers described bodymapping as an opportunity to reflect on what it was like to "take medication or care for others on medication". Speaking in broad terms gave adolescents the freedom to depict their stories within the limitations of what they knew or were willing to disclose.

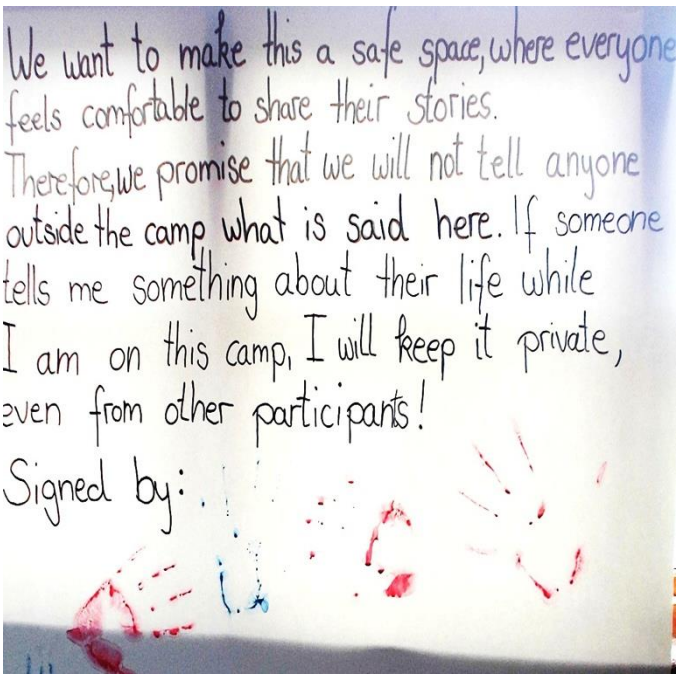


Figure 12: Confidentiality pledge signed with handprints

Each bodymapping workshop began with a 'Broken Telephone' activity, which sought to illustrate how information travels, twists, and can be involuntarily disclosed. The activity emphasised the value of confidentiality, as well as the potential risks of disclosing personal information about oneself or others in a group setting. In addition to these preliminary discussions about gossip and confidentiality, participants signed a confidentiality pledge (as in Figure 12), which emphasised the importance of privacy, although it could not guarantee it.

In addition to bodymapping, participatory workshops also included other art-based activities. On some occasions, adolescents drew pictures of their 'Dream Clinic' (as in Figure 13), depicting their ideal clinic experience. In other instances, adolescents role-played their medical consultations. These role-plays included portrayals of undergoing blood tests (see Figure 15), as well as performances of adolescents' ideal clinic interactions. On two occasions, role-plays were facilitated during Care Project support group meetings.

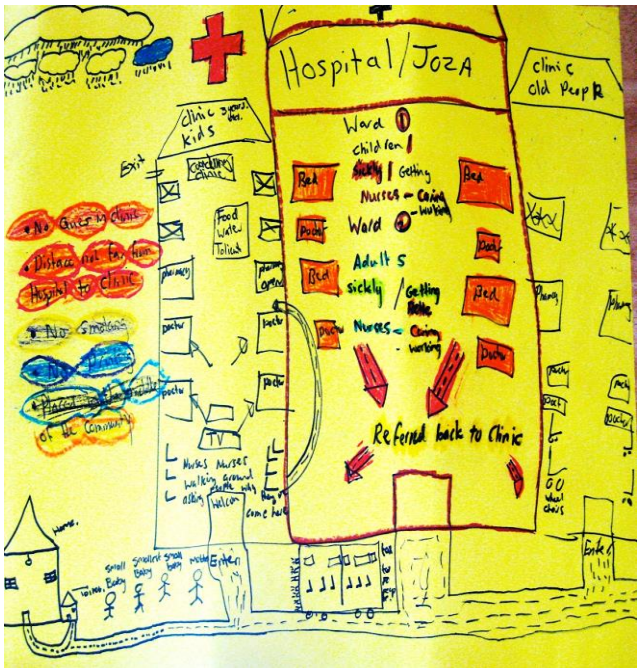


Figure 13: Example of adolescent 'Dream Clinic'

The rich narratives elicited in these art-based workshops do not feature in this thesis, but will certainly serve as primary data for future co-authored publications. For the purposes of this chapter, I have used bodymaps to illustrate adolescents' broad experiences of life on ART. The discussions that follow serves to situate the included articles within a wider description of adolescents' embodied lifeworlds.

Figure 14: Beth and Mildred start the role-plays at a participatory workshop

Figure 15: Adolescent participants illustrate how blood is extracted at the clinic

ADOLESCENTS LIVING WITH ART

Figure 16: Bodymap celebrating "pills" that "help me" and make me '"feel good".

As ART access has expanded, the meaning of life with HIV has increasingly shifted to that of a life on pills. That young people in the study so often explained their HIV status through a narrative of pill-taking is testament to this.

The consumption of ART is onerous, disciplined work. For most adolescents in our study, it meant taking three to four pills at precise, 12-hourly intervals. As a result of inconsistent treatment and support, some adolescent participants were on second-line ART regimens, after having either built up resistance to their first line drugs or switched due to unpleasant side effects.

Figure 17: Adolescent bodymap: "I wish I could gain weight. I don't like how I look"

Four adolescent participants, three of whom had initiated ART in the past year, were lucky to be taking fixed-dose combination (FDC). This pharmaceutical technology combines a first-line ART regimen into a single daily pill and is currently being rolled out to select groups of patients in South African health clinics.

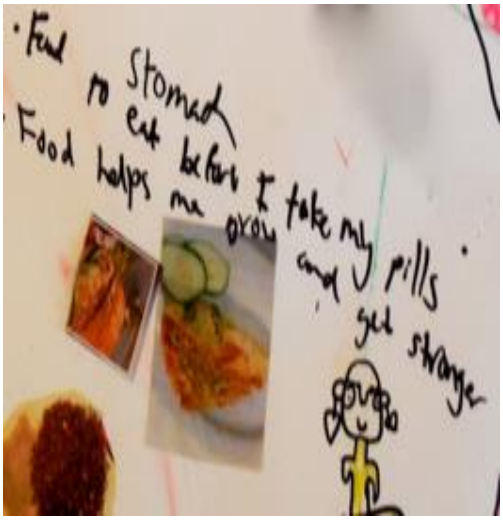


Figure 18: Adolescent bodymap: "Stomach - food to eat before I take my pills. Food helps me to grow and get stronger".

Figure 19: Adolescent bodymap: "My mother told me if you drink the pills they don't like alcohol. I don't like alcohol because it's gonna make you sick".

These priority groups include pregnant women, new ART initiates, and patients with a suppressed viral load. Generally, recipients need to be over the age of eighteen to receive FDC. Because most of our adolescent participants were below this age they did not qualify.

Each day, young people's lived experience of time needed to be brought in alignment with the standardised clock time required by the treatment regimen. In order to ease the swallowing of pills, eliminate their foul taste, and prevent dizziness, many young ART users in this study also required food before, and water during, pill taking. Food recurred often in adolescents' depictions of a healthy body on treatment (see Figure 18). While food is not a central theme in any of the included articles, I have foregrounded ART as part of a wider politics of survival, which was not only determined by pharmaceutical access.

At times, adolescents represented their bodies as being ordered and restored through ART (as in Figure 16). Their disciplined bodies celebrated the efficacy of treatment, did

not smoke, and did not consume alcohol (see Figures 16 and 19). But alongside this were representations of bodies that gave way to uncontrolled illness and treatment side effects (as in Figure 20). The most disturbing of these was lipodystrophy, which had affected a younger boy and an older adolescent girl in the study. Despite diligent adherence to ART, those who had lived with HIV from a young age often experienced chronic difficulties with their lungs, ears or eyes. Many more were very thin and had suffered stunted growth (see Figure 17). Nine of our adolescent participants reported having had TB or another severe opportunistic infection at some point in their lives (see Figure 22). Two were on TB treatment at the time of our research.

Some of the adolescents in our study, particularly those who had tested for HIV while pregnant, were visibly healthier. These were archetypes of the 'unworried well', having never been sick with an AIDS-related illness. For them, the ambiguity was not in taking daily medication that never seemed to fully heal you, but in imbibing pills even though one felt physically healthy.

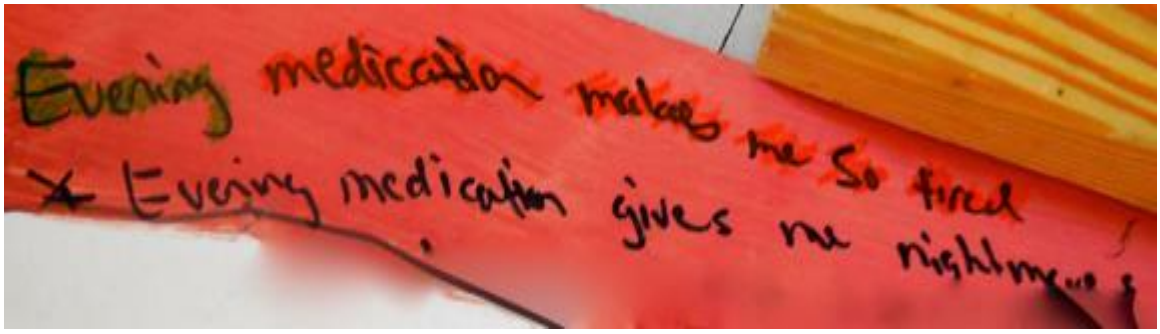


Figure 20: Adolescent bodymap: "Evening medication makes me so tired. Evening medication gives me nightmares"

Adolescents' bodymaps revealed ART as an inescapably social experience (as in Figure 21). It was achieved in collaboration with others. While adolescents made choices, exercised discipline, and cared for themselves, they also talked about their lives in terms of other people. Even in large, anonymous settings, amidst impersonal bureaucratic protocol, young people tried to realise personal relations with care providers: they used pre-existing connections to health or NGO staff or tried to develop new ones where they could.

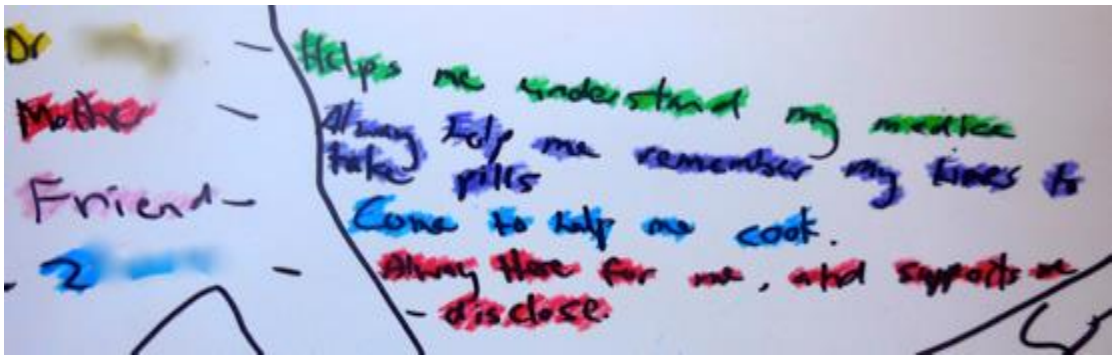


Figure 21: Adolescent bodymap: "Dr X (blurred for anonymity) helps me understand my medicine; Mother always helps me remember my times to take my pills; friends come to help me cook; Z (blurred for anonymity) always here for me and supports me [to] disclose [my HIV status]".

Adolescents also had a way of imagining their bodies that spoke very directly to a life on treatment — and that was through measures. Young people in this study were regularly weighed and observed, and their blood tested (see Figure 22). Some adopted these indices as a way to talk about the direction that their lives and bodies were taking (see Figures 22 and 23). Bodymapping therefore elicited themes about the ways that adolescents in this study lived and imagined their bodies. Many of these are re-iterated in the included papers.

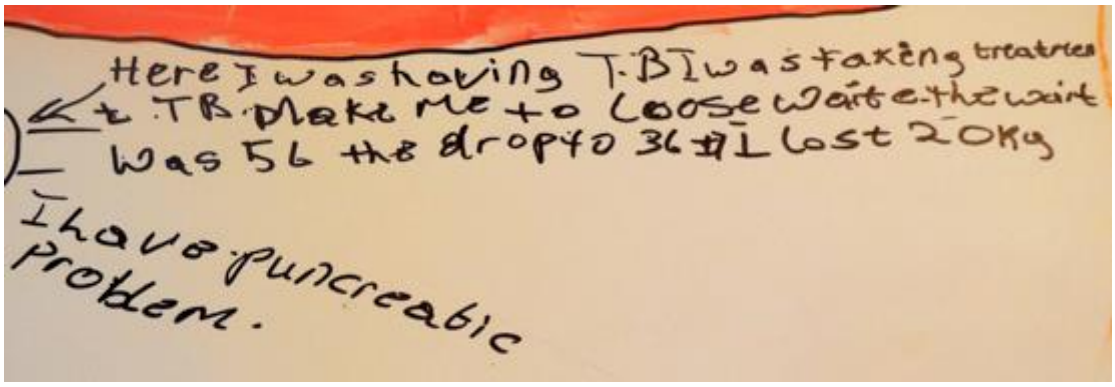


Figure 22: Adolescent bodymap: "Here I was having TB. I was taking treatment. TB make me to lose weight. The weight was 56 and dropped to 36. I lost 20kg".

Figure 23: Adolescent bodymap: "Dr X (blurred for anonymity) listens to my [heart], weighs me, takes my blood every 6 months".

POWER AND PARTICIPATION

Many of the research methods for this study were designed to resonate with key principles of 'participatory research'. Mildred and I sought to maximise opportunities for young people to direct the research process and encouraged youth involvement through a range of interactive activities. Including young people's voices in research is now a precedent in youth studies. With an emphasis on youth agency, researchers working in the "new social studies of childhood" have advocated child participation as

both an empirical and an ethical imperative (Gallagher 2008, p.137). Empirically, youth participation is thought to bring us closer to the "truth", increasing the reliability and validity of research, and thus allowing us to inform more effective youth policy. Here, it is often assumed that young people have a distinct, fixed and coherent voice that brings us closer to the 'authentic' youth experience (Gallagher 2008, p.139). This assumption negates both the heterogeneity of young people's voices, and the extent to which 'youth discourse' is shaped by adult agendas, that may give particular primacy to some accounts over others. We might ask, as does Mimi Orner (1992, p.76): "For whose benefit do young people speak?", "how is their speaking received, disciplined, controlled, limited and stylised by the listener or context?" and "what is the 'authentic' voice used for?" In the final article of this thesis, *Negotiations of Blame* (article four), I give particular consideration to the interests and authorities that might be shaping young people's narratives, reading in the interstices of their contradictory stories, omissions and performances.

Ethically, youth participation is regularly conceived as a way to transfer power from adults to young people, addressing the apparently inherent power imbalances between adults and children (Morrow & Richards 1996). Yet little attention is given to the meaning of power, how it operates, or how it is mobilised (Gallagher 2008). The notion of 'conferring' or 'giving' a voice to young people suggests that those with power can bestow the right to speak on those without it. On this view, power is a commodity held by dominant groups (adults) and not by their subordinates (children).

Treating power as a commodity obscures its complex multivalency as it is mobilised by both adults and young people in specific research spaces. Indeed, there is often messiness

and ambiguity in participatory practices. While adult researchers might, in general, appear more powerful than youth, this does not preclude points of tension and confrontation in which children exercise power over adults. Young people's power may take unexpected forms: children may refuse to participate, undermine the researcher's authority, or re-shape the research process in unintended ways. In these ways, and others, young people can exploit, appropriate, resist or redirect participatory research techniques. It is precisely because children do not always behave as adults wish them to that power tactics become necessary, through coaxing, cajoling, shouting, punishment and reward.

Over the course of my fieldwork, I learnt that there was little sense in the notion of a 'youth-friendly' method. Different participants responded differently to the research activities we proposed: some adolescents only wanted to play games, while others found these activities belittling. There were those that loved to draw and others that declined participation in drawing activities.

Adolescents asked their own provocative questions, redirected conversations, and came up with independent suggestions for research activities. Occasionally, young people disappeared despite having agreed to meet us. At other times, they showed up unannounced. Some participants deceived, concealed or did not respond to questions, perhaps to protect those close to them or evade stigma. Adolescents also appropriated the research for their own purposes: to escape chores, to express their frustrations, to play, or to feel recognised. I became a potentially important social connection, from which some participants sought to gain. This could entail particular contrived performances, whether of need, diligent adherence, upstanding character, or model

caregiving.

Lying, avoiding, resisting, redirecting and declining are often read as signs of 'non-participation'. Instead, I considered these as genuine forms of participation, indications of my immersion in the field, and signs of the research's voluntariness. Rather than viewing young people's appropriations of the research as obstructions to the collection of good data, I interpreted these actions as important data in themselves. Instances of 'non-participation' gave valuable insight into the ways that young people exercised power and negotiated their relationship to institutional spaces.

All of our study participants — adolescents, nurses, guardians, doctors and NGO staff — were tactically negotiating their relationship with us as researchers. Each had their own perception and understanding of the research process and their own interests in participating. Sometimes, participants may have attempted to tell us what they believed we wanted to hear. In other instances, they may have sought to present themselves in a particular way — as innocent or upstanding, as courageous or caring, as victims or leaders. As Mildred and I learnt more about participants' social worlds, the stakes of their survival, and their moral projects, we also sought to locate their research engagements within this matrix of relations. How might participants' research performances speak to their social, moral and material needs? How might their engagement with us form part of a larger social pursuit — whether for survival, care, recognition or connection? The data we collected was not a direct, uncomplicated reflection of participants' experiences, interests and perceptions. Acknowledging the performative, representational aspects of the data strengthened and complicated the analysis, while encouraging greater reflexivity.

DATA ANALYSIS

Data analysis for this study employed key principles of Grounded Theory (Glaser & Strauss 1967), building inductively from the data. Contemporary applications of Grounded Theory are varied and at times conflicting (Charmaz 2000; Suddaby 2006; Thomas & James 2006). Given discrepancies in interpretations of Grounded Theory, I articulate my application of the method in the following key principles:

1) Analysis began concurrently with fieldwork.

2) Analytic codes were developed inductively from the data, rather than from preconceived hypotheses.

3) Data were constantly compared[12] to limit bias.

4) Theoretical memos[13] were kept throughout.

Concurrent Analysis

Data collection and analysis for this study were conducted iteratively, informing one another at each subsequent stage of the fieldwork. Amid my field notes, I kept analytical memos, noting emerging themes and reflecting on contradictory or unexpected findings. Mildred and I also dedicated time every day to collaboratively reflect upon, and analyse, emerging data. Having two researchers involved in recalling and interpreting fieldwork data contributed to the accuracy and comprehensiveness of field notes. It also allowed

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

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

for more complex and nuanced analysis when our interpretations differed. Given that some research activities were conducted in both isiXhosa and English, our daily reflections also included consultations about how translated conversations had been captured in the field notes.

While in field, I circulated regular reports among the Mzantsi Wakho research team. These included methodological and ethical reflections as well as discussions of emerging themes. As such, my supervisors, principal investigators and fellow collaborators provided feedback on the preliminary analysis, pushing me to explore certain observations further, and identifying important questions for future examination.

In combination with these reports, Mildred and I presented preliminary research findings to NGO partners in the Eastern Cape, Western Cape and Gauteng provinces.[14] Audiences included health practitioners, programmers, researchers and community healthworkers, all of whom provided invaluable feedback on the emerging analysis. Finally, Mildred and I devised activities to consult with adolescents themselves on our initial findings. Two months after the completion of rural fieldwork, we visited Mtembu to share, and elicit feedback on, emerging themes. In Ridgetown, we explored preliminary findings in collaboration with the Care Project support group.

Retrospective Analysis

Once fieldwork was complete, I compiled case summaries for each adolescent

[14] A list of all presentations given over the course of my DPhil is included in the appendices of this thesis.

participant, amalgamating interview and field note data. Data from adolescents' caregivers and healthworkers were added to each summary, along with analytical notes. These notes gave particular attention to relational and contextual dynamics, as well as points of similarity and difference in adult and adolescents' accounts. This strategy for organising ethnographic data was also adopted by Bernays et al. (2015) in their study of HIV-positive adolescents in Uganda and Zimbabwe. These authors were similarly interested how adolescents' HIV experiences were made through situated, relational interactions between caregivers, health providers and adolescents themselves.

I began analysis by immersing myself in the case summaries, reading field notes and listening to recordings. Huberman and Miles (2002, p.312) refer to this process as "familiarisation". Although I had been close to the narratives for months, my recollection risked being selective or partial if I did not reimmerse myself in all of the data. By reading narratives in context, I aimed to avoid only paying attention to the "loudest bangs" and the "brightest lights" (Lincoln & Guba 1985, p.289) and made an effort to be sensitive and responsive to the data.

Drawing on guidelines from Miles and Huberman (1994), I then began manually coding the data. Coding qualitative data involves assigning labels to categories of information in the data. While initial codes are largely descriptive, as codes are refined and relationships between codes are explored, interpretive labels are also included. In analysing adolescents' case summaries, I combined thematic and narrative analytical approaches: identifying repeated themes and tropes in the data, while also paying attention to the ways in which people made their lives meaningful through narratives.

First-level Coding

'First level' thematic coding involved identifying broad themes in the data. During this initial coding phase, data was classified and named in a largely descriptive way. I labelled categories of data about 'death', 'pills' or 'family relationships', for example. While codes were developed from the data, they were also attuned to my research interests, which naturally signalled some passages more relevant than others. I was paying attention to what the data might reveal about young people as ART users as well as the conditions under which ART was achieved.

After identifying broad categories in the data, I sought to refine the codes. This involved the identification of subtopics, while also noting contradictory views within themes. The broader thematic category 'death', for example, might be refined to include themes about 'deceased parents', about the 'threat of dying' or about managing 'bereavement'. This process served to enhance and nuance emerging categories, revealing the depth and breadth of data within particular themes.

Second-level Coding

Once these initial codes had been developed, I engaged in a process of conceptual mapping, or 'second level' coding. While first-level codes summarise pieces of data, second-level codes identify patterns and explanations, noting clusters and hierarchies of information that might explain relationships between codes. A snapshot of the initial coding process is illustrated in the table below, although much of the analysis occurred in a less linear fashion, jotted in notebooks.

Table 1: Snapshot of Analysis Process

(Example coding table, with particular reference to article two, *Redeeming Lost Mothers*)

Reference	Data	1ST Level Code (Broad)	1ST Level Code (Refined)	2ND Level Code (Intention/Narrative Function)
November 2013 **Sitting on the porch overlooking the hills and watching the sheep.** ***Mtembu* Recording**	When we asked Aimee and Bongani what they thought would happen if they didn't take their pills, Aimee replied that she thought she would get sick. Bongani said, 'You can also die. My father had it, he didn't take his pills, and he died.'	**Death Talk** Pill Talk	**Talk of dead/absent parents**	Threat of death Deceased parent as moral lesson
24 March 2014 **Waiting at Nonkosi's grandmother's house for his mother.** ***Ridgetown* Field notes**	The mom never arrived and the grandmother was upset. She said Nonkosi's mom 'liked men' and that's why she 'behaved like this'. She told us that when this sort of thing happens she calls the police. She then showed us a picture of Nonkosi's younger brother at the age of about 1 year and explained that he had died.	**Death Talk** Across Generations	**Talk of dead/absent parent**	**Demonising mothers (in particular?)** (Promiscuity, recklessness, blame for familial loss? Criminalisation?)

It was at the point of 'second-level coding' that narrative analysis became an important asset, revealing how different themes and categories of data were woven to tell a story. In addition to their thematic content, I paid attention to the repetition of particular stories across case summaries. I took interest in how and why particular stories were told, exploring both the personal narratives through which participants described their experience, as well as the broader context in which these stories were told. By thinking about narrative, I considered how participants' stories reflected their socio-economic and political location, but also highlighted the norms and values that infiltrated their representations of HIV and ART. Adopting a narrative lens also entailed reflecting on how participants might have been performing for me as a researcher and 'affluent' outsider. Participants' narratives were not read as hyper-authentic, transparent reflections of experience, but rather as representations through which power was contested and negotiated.

Choosing What to Write

Throughout fieldwork, I collected an immense amount of data. As such, I was deliberately selective in choosing what to write about. I was led by areas of the data that were strong and complex, as opposed to those that were sparse and one-dimensional. My decisions on what to write were also naturally attuned to my research interests. I was concerned with what it meant to be a young ART user at the interface between multiple institutions of care. Consequently, each of the included articles has a slightly different institutional focus:

The first article, *Mobilising AID(S)* draws attention to young people as targets of social

welfare, as participants in HIV support groups, and as beneficiaries of a complex industry of HIV-related resources. It is further interested in how adolescents' positioning in these institutions may have complicated relationships with other sites of care, including family and neighbourhood. The second article, *Redeeming Lost Mothers*, investigates how adult caregivers inculcated the project of adolescent ART into the production of 'home' as an institution. In the third article *Bureaucracies of Blood*, I explore the experiences of adolescents in health facilities, as objects of medical and bureaucratic surveillance. The final article, *Negotiations of Blame*, investigates how medical procedures and categories are infused with social meaning, and therefore re-negotiated in their uptake. This article is primarily concerned with how institutions of HIV care become sites for blame, such that those who enter into them are also compelled to negotiate and redistribute recrimination. In speaking to this array of institutional settings, I sought to showcase the breadth of research data.

At the heart of these four papers is an attempt to explore a set of ambiguities about the lives of adolescents on ART. These ambiguities are best encapsulated as: The intertwining of care, agency and recognition, on the one hand, with blame, submission and discipline on the other. To work through these ambiguities is to show fidelity to a key pillar of qualitative analysis, which seeks to account for variation and conflict in the data (Patton 1999, p.1192). I wrote about findings that surprised and discomforted me. These were often the narratives that emerged unprompted, in the interstices of my direct questioning. As a result, they were also the data that I felt I had played the least role in directing, which added to their trustworthiness. In writing about some of the most unexpected findings, I hoped to avoid personal bias. But I also sought to contribute something novel, which I had not seen before in the literature.

To ensure that I did not overstate or oversimplify the findings, I iteratively returned to the data, considering rival explanations, looking for greater nuance of interpretation, and sometimes checking for the frequency of particular narrative accounts.

Writing

While I spent time organising the data thematically, and plotting their conceptual links, much of the intricacies of the analysis emerged through the writing itself. As I wrote, I sought to ask myself a series of analytical questions: 'What are the implications of this?' 'Where's the evidence for that?' 'What else could this mean?' or 'How exactly do these ideas relate?' Miles and Huberman (1994) advocate this process as a means to guard against interpretive "premature closure". In my attempts to be a reflexive researcher, I sought not only to ask 'What do I know', but also to question how those interpretations came about: 'How do I know what I know?'

To this end, my supervisors played an invaluable role, pushing for further evidence and highlighting assumptions and contradictions. Through this process of rigorous questioning, journal reviewers and past examiners also contributed in important ways to the analysis. Refining the papers was an iterative process that emerged out of a continuous process of writing and returning to the data, while also engaging with peers, academic audiences, supervisors and reviewers on the emerging analysis.

Although I took deliberate steps to ensure rigour and credibility, qualitative analysis is also inevitably a creative process, shaped by the insights and conceptual resources of the analyst (Patton 1999, p.1190). In each of the articles, I have explicated my analysis

methods and also sought to address the limits of my interpretations.

Anonymity in the Write-up

In order to protect anonymity, pseudonyms are used in place of participants' names. I have also attributed pseudonyms to the research sites and the organisations with whom we worked. Occasionally, I have changed aspects of adolescents' biographical details, without altering the information that is important to understanding their life trajectory or interpretations.

Limits of interpretation

My interpretation of young people's experiences of ART-taking was limited by my ability to fully step into their worlds. Despite spending months with this group of young people, my age, race, gender, language and HIV-negative status designated me an outsider and limited the extent of my participation. But, as already mentioned, being an outsider also had its benefits, sometimes allowing participants greater anonymity and therefore fostering trust. While staying in a rural Mtembu village, I attended isiXhosa lessons with a local teacher. Learning and practicing with participants also contributed to rapport building. Although I had a rudimentary understanding of isiXhosa before starting fieldwork, which grew over the research period, my engagements in the research field were severely limited by the fact that I was not competent in speaking the language. As I have said in each of the included articles, many research activities involved real-time translations from English to isiXhosa and back. In the process, there may have been misinterpretations. The data was, in effect, coproduced by Mildred, our participations and myself and is the output of a situated interaction.

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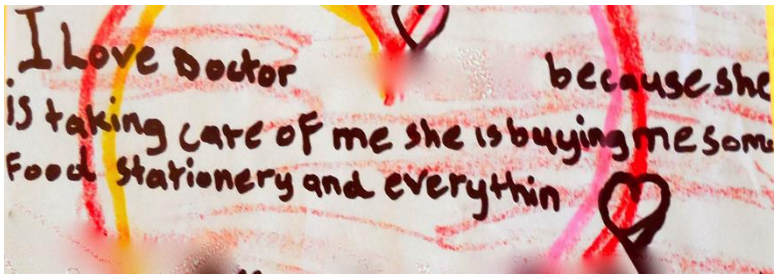
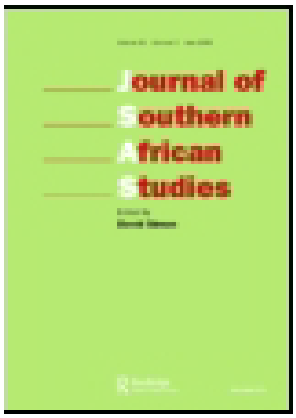
Mobilising AID(S)? Contesting HIV as a social and economic resource among youth in South Africa's Eastern Cape





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Mobilising AID(S)? Contesting HIV as a Social and economic resource among youth in South Africa's Eastern Cape

ABSTRACT

This article explores how some perinatally-infected youth in the Eastern Cape province of South Africa tactically engage with both the burdens and potential resources of growing up with HIV. Further, it asks how this might shape their interpretation and practice of antiretroviral treatment (ART). By activating particular categories of need – related to death, illness and orphanhood – these HIV-positive youth and their families are able to access vital health and social care, sometimes in unprecedented and privileged ways. This has been enabled by the profound effect that HIV/AIDS has had on how state and donor resources are allocated.

Drawing on eight months of qualitative fieldwork, I examine the ambiguous position of young ART users. While many perinatally-infected youth endure compounding burdens of chronic morbidity, daily medication-taking, and parental loss, some also capitalise on the particular weight ascribed to these burdens within South Africa's care economy. The additional assistance they receive can produce community and family resentments, born out of the disquieting confluence of resource-access with a stigmatised and incurable illness. Thus, in addition to its scientific properties, HIV treatment also has symbolic and social roles for youth. The ways in which young people use ART should be interpreted amid a wider social order, in which post-apartheid communities participate

in contentious struggles for survival and upward mobility. Future policy and programming can benefit from a deeper understanding of the social stakes involved in young people's engagement with ART support services.

YOUNG ART USERS IN A YOUNG DEMOCRACY

This article explores how some perinatally-infected youth in the Eastern Cape province of South Africa mobilise their position as ART users for survival and social mobility. These young people are among the first generation of HIV-positive babies to benefit from the national rollout of ART and reach adolescence alive. Today, they form part of the estimated 300,000 adolescents (aged 10–19) living with HIV in South Africa (Kasedde & Olson 2012). Their health, longevity, and reduced infectiousness will depend on strict adherence to medical treatment. In addition to being among the first generation of ART recipients in South Africa, these young people are also members of the 'born free' generation and are coming of age alongside the country's new democracy.

Over the course of their lives, therefore, young people in this study have seen a radical expansion not only of HIV treatment, but also of social welfare, driven by democratic aspirations of social justice and redistribution. While inclusion in the social grant system has defined liberation for many South Africans, producing new forms of citizenship and patronage (Bähre 2011, p.3), it has also been concomitant with widespread unemployment and deepening inequality. As a result, the apportioning of social assistance, and indeed broader questions of resource access, produce new cleavages and contestations. It is in this context that young people's positioning within a proliferating

national and global AIDS economy becomes contemptible, over and above the traditional stigmas of HIV.

The advent of AIDS has seen a dramatic increase in disability, care dependency and foster-child coverage in South Africa (Booysen 2004, p.46). Today, these join the retirement pension as the most generous social grants in the country. In comparison to the conventional childcare grant (R280), the foster-child (R840), care-dependency (R1, 350) and disability (R1, 350) grants offer significantly higher monthly rates. This creates a household economy in which death and illness sit uncomfortably as both material linchpins and heavy burdens, attributing paradoxical value to AIDS orphans, and thereby new social meaning to their position in many homes.

In addition to their unique position within the social welfare system, perinatally-infected youth have also spent much of their lives under the aegis of public health, as long-term ART users. While enrolling in state ART programmes, many youths in this study have also been privileged to join non-governmental support groups, directed at AIDS-affected and orphaned children. The proliferation of AIDS-care initiatives in South Africa has involved complex networks of local, national and international actors, which all contribute to signifying the problem of HIV/AIDS and how its associated resources circulate. Importantly for our purposes, youth in this study are not simply repositories for the biomedical, social and behavioural interventions outlined above. They, and their families, also mobilise linkages to AIDS-intervention programmes, making tactical moves in order to secure resources and benefits.

This article explores how youth membership to the scientific category of ‘HIV-positive

ART user' can become a source of gossip and resentment. Here, antipathy stems not only from the traditional sex- or death-related stigmas of HIV; it also relates to the assistance that HIV-positive status attracts when coupled with youth and orphanhood and brought under the auspices of state and donor care programmes.

(ART)FUL TACTICS: CONTRIBUTING TO EXISTING LITERATURE

The mobilisation of health or biological status to claim material benefits has been a topic of growing import in the medical humanities. Adriana Petryna (2004) first introduced the concept of "biological citizenship" to explore how victims of the 1986 Chernobyl nuclear disaster mobilised evidence of their damaged biology to claim compensation. Richard Rechtman and Didier Fassin (2009) have more recently examined how trauma survivors use and construct their "victimhood", this time across a range of historical and geographic contexts. Like Petryna, their interest is in the ways that suffering is mobilised to "testify to experience, excite sympathy and merit compensation" (Fassin & Rechtman 2009, p.5). Following its original introduction, Nikolas Rose and Carlos Novas (2005) reconceptualised the term "biological citizenship" to refer to biological identities, positing that contemporary identity might be increasingly linked to biological consumption, whether in the form of pharmaceuticals or enhancement technologies.

Vin-Kim Nguyen's seminal research introduced the related concept of 'therapeutic citizenship', to describe how ART users articulate the rights and responsibilities of medical treatment, and thereby garner material and social benefits (Nguyen 2005). Nguyen's work has explored the formation of therapeutic communities in which ART patients employ solidarity and 'self-help' techniques to garner food, medicine, and social

ties. These patient groups enact performances of 'empowerment' that give testimony to the struggles of HIV and profess the revelations of biomedicine (Nguyen 2011, p.429).

Similarly, I explore how ART users mobilise health categories to make resource claims. Like Nguyen, I also give import to the ways that HIV is performed and narrated in this claims-making process. Yet, where Nguyen's 'therapeutic citizens' seem primarily concerned with building collective solidarity and empowered HIV identities, those in this study were more likely to appropriate these discourses instrumentally in a bid for care. These frequently contingent forms of ART participation are gaining growing attention from anthropologists in contexts of severe economic constraint (Cassidy & Leach 2009; Colvin et al. 2009; Frank & Rödlach 2013; Mattes 2011). In Tanzania, Dominik Mattes (2011) explores how poverty and the deterioration of kinship-based support networks determines people's engagement with ART support groups, over and above claims to the rights and responsibilities of treatment. These groups offer an additional social support network, which members can rely on should they fall ill or need someone to watch their children. Similarly, Rebecca Cassidy and Melissa Leach (2009) show how Gambian ART users masterfully appropriate funder and non-governmental organisation (NGO) discourse to access lunches and *per diems*. They describe the utilisation of HIV identities as conditional and fragile, reflecting a less empowered form of 'getting by'.

What sets these accounts apart from Nguyen's original explication of 'therapeutic citizenship' is their attention to the social stakes involved in operationalising ART identities. To this end, Emily Frank and Alexander Rödlach (2013) explore both the new opportunities and new stigmas generated by ART enrolment in southern African

contexts: while ART support programmes enable access to privileged resources, the attainment of these advantages, in a context of generalised poverty, also attracts resentment from neighbours, thereby threatening informal support networks. Here, ART users receive resources on the basis of their biomedical categorisation. This undermines historically entrenched practices of soliciting neighbourly assistance in times of hardship. Central to ART usership, then, is the ongoing mediation of cross-cutting imperatives, born out of social tensions unique to the ART era.

The above literature centres on the experiences of adult ART users. Youth appropriations of ART interventions are interesting not only because of their implications for the position of young people within families, but also because 'youth', as a category in itself, can be tactically deployed in the context of these interventions.

Literature on AIDS-affected youth has revolved around the 'tragic' image of the AIDS orphan: first reflecting moral anxieties about the imminent social breakdown that was expected to result from rising numbers of parentless children (Bray 2003), and later concerning itself with psycho-social distress among orphans (Atwine et al. 2005; Cluver & Gardener 2007; Makame 2002). Much less attention has been paid to the tactical, even ambiguous, agency deployed by young people in conditions of heightened vulnerability.

In an effort to address this oversight, Helen Meintjes and Sonja Giese (2006) offer a provocative account of the tactical agency exercised by South African children and their families, who used categories of 'AIDS orphanhood' in order to win gains from NGOs and international donors. While these 'orphans' are not dislocated from adult care, as dominant policy and donor discourses presume, using AIDS-orphan rhetoric allows

access to a range of material benefits and social interventions. Importantly, this tactic is employed in spite of local stigmas surrounding orphanhood: the term 'orphan' is used pejoratively in many local languages to describe children who are "destitute", "unloved" and deserving of pity (Meintjes & Giese 2006, p.422). In this context, AIDS-affected families must precariously straddle two socio-cultural value systems: while the former attributes orphanhood unique clout, the latter positions it as a source of shame. Consequently, the meaning of 'AIDS orphan' is rendered ambiguous, demanding careful, frequently perilous, negotiation.

Young people's attempts to mobilise ART usership for survival and social mobility can be similarly precarious. In deploying categories of 'HIV' and 'orphan' as potential resources, adolescents not only take on the derisive connotations of the categories themselves – as Meintjes and Giese (2006, p.422) aptly point out. But more so, the activation of these traditionally stigmatised categories for special assistance can also become contentious, giving rise to new dilemmas and vulnerabilities.

Meintjes and Giese are concerned with the 'spin' placed on orphanhood in international development discourse, which, they argue, has often homogenised and mischaracterised the experiences of children with deceased parents. Rather than focusing on external definitions of AIDS orphanhood, I concentrate on how young people themselves have sometimes responded to, and mobilised, public meanings of 'HIV' and/or 'orphan' status. In doing so, I further explicate the nuances and ambiguities of young people's access to social services. Additionally, I am concerned with HIV-positive youth not only as victims of bereavement, but also as ART users, navigating multiple public health and social care institutions.

INEQUALITY AND SUSPICION IN THE EASTERN CAPE

Democracy has had profound implications for the social imaginaries of black South Africans. Legal and political rights have been accompanied by new material aspirations, in response to the visibility of a growing black middle class and the African National Congress mantra of "a better life for all". Yet "glimpses of vast wealth", which are seen passing into the hands of a few South Africans, are accompanied by a wider sense of desperation at being excluded from the promise of prosperity –"the *telos* of liberation" (Comaroff & Comaroff 1999, p.284). Indeed, enduring structural legacies of apartheid, together with deepening poverty and unemployment, undermine the possibilities of the 'new' South Africa. Thus enfranchisement, a rising black middle class, and the 'freedom' to accumulate have also been attended by extreme poverty and exclusion. These contradictory trends have amounted to a dramatic increase in inequality among the black populace (Steinberg 2008, p.45).

The Eastern Cape remains the poorest province in South Africa, and poverty continues to deepen (Eastern Cape Government 2013) along with income inequality (ECSECC 2012, p.17). Fieldwork for this study was conducted over eight months, among 22 Eastern Cape households, located in two research sites: one rural and the other peri-urban. Data collection was conducted in partnership with a talented research assistant, Mildred Thabeng, who not only assisted with translation where necessary, but also played an invaluable role in research design and concurrent analysis. We worked for the first four months in rural villages of a municipality that I call *Mtembu*. The second four months were spent in peri-urban informal settlements on the outskirts of a small town in

the adjacent municipality. I refer to this town as *Ridgetown* and its municipality as *Masola*.

In Masola, 15.3 per cent of households live below the multi-dimensional poverty line, which is based on health, living standards, education and unemployment (Statistics South Africa 2014b). This is also true of 30.4 per cent of Mtembu households (Statistics South Africa 2014b). Only 34 per cent of Masola residents, between the ages of 15 and 64, are employed (Statistics South Africa 2014a). In Mtembu, this figure is less than 10 per cent (Statistics South Africa 2014a).[15] In both Mtembu and Masola, participants' families struggle to find stable employment, with some reporting that they occasionally go without food. In rural villages, these families lived off a combination of subsistence farming and social grants: only one household in the research cohort had a permanently employed resident. In Ridgetown, those able to find jobs had posts as domestic workers or security guards, while others served short-term positions on municipal projects and nearby farms. Young people in this study worry about basic needs, but many are also excited about consumer goods, including brand-name clothing and cell phones. Access to the latter remains limited in both research sites, particularly since many adolescents are interested in only the latest smart phones. Acquisition of consumer items not only facilitates young people's imagined transition into adulthood, but also their perceived linkages to global modernity.

Both the urban and rural communities in which we worked are visibly unequal, with middle-class and poor residents sometimes living in close proximity. In two Mtembu

[15] In reference to this particular age bracket denoting 'youth', globally, youth unemployment is measured from the age of 15, to denote when mandatory schooling ends and to recognize young school-goers who are also actively seeking full-time work.

villages, these inequalities and their accompanying patronage networks were partially attributable to AIDS interventions. Middle-class NGO workers form a new social class, linking local spaces to global development circles and altering village power relations as residents attain more or less access to the networks and resources of intervention programmes.

Among those enrolled in HIV programmes, some were able to access transport, food, pocket money, and even housing from their NGO friends and carers. With scarce job opportunities in their villages, community healthworkers, HIV educators and counsellors were often among the few employed, even with their meagre stipends. In some villages, then, AIDS interventions became one of the primary sites through which employment, material support and access to well-networked outsiders was negotiated, mapping a new geography of inequality.

Questions of access to resources are highly contested in democratic South Africa. Indeed, researchers have described a "collective race" for limited resources in post-1994 communities. Here, relationships between "winners" and "losers" become poisonous (Steinberg 2008, p.25), undermining the potential for social solidarity. This discrepancy in people's fortunes unfolds in intimate spaces: between and within families, and among long-standing neighbours.

The social stigmas attached to young people's mobilisation of HIV-related resources emerge amid this pre-existing politics of resentment. In many South African communities, these politics play out in suspicions and accusations of witchcraft (Ashforth 2002). The better off fear bewitchment by jealous and less fortunate

neighbours, while the latter accuse the former of prospering through illicit, magical means. These discourses signal moral struggles over the distribution of scarce resources, and contestations over the ways in which flows of power operate within intimate communities.

In this study, anxieties about palpable and proximate inequality could certainly be read in local discourses of witchcraft. These were voiced in both research sites, but were more prevalent in rural areas. Some adolescents described witches and their animal familiars roaming the villages after dark (field notes, Mtembu, 31 January 2014), while others professed to have been targeted by jealous witches because their family was building a new house (field notes, Ridgetown, October 2013). In Ridgetown, an NGO worker told an elaborate story of youth spirit possession: for a R100 bottle of alcoholic drink to a local traditional leader, young people could ask to be overtaken by ancestral spirits, who would help them to "do well in school, at sports, and everything" (field notes, Ridgetown, 8 February 2014). The accusation of spirit possession designates young people's success as suspicious in a context in which youth aspirations are all too often unrealised.

The proliferation of witchcraft discourses, in response to the contradictions of the post-1994 period, has coincided with a flood of AIDS deaths. It is unsurprising then that these deaths should at times have been read as an epidemic of jealousy among neighbours. 'Jealousy' and 'bewitchment' also serve as the lens through which some youth receiving ART understand the stigmas of their survival and perceived success. Here, youth who are perceived as better off, despite (and at times because of) their HIV status, feel susceptible to envy-fuelled bewitchment. These witchcraft concerns take a familiar

form, marking social tensions about resource distribution within families and intimate communities.

The tensions associated with adolescents' mobilisation of HIV-related resources are not isolated. The fragile and varied means by which people gain access to resources in post-1994 South Africa have at times produced fraught cleavages, often along gender and generational lines (Mosoeta 2011). These broader politics of need, acquisition and resentment play out in the lives of youth on ART as they manoeuvre to gain from a range of social care institutions – both state and non-state. In this article I am concerned with the new signification that this attaches to HIV, its treatment, and the place of youth within the epidemic.

GROWING UP WITH HIV

I draw on eight months of qualitative research with 23 Xhosa-speaking adolescents (aged 10–19) on antiretroviral treatment. I focus on 19 of these, who are perinatally-infected. Adolescent participants were recruited through non-governmental ART support groups and public health clinics. For the purposes of this article, I give particular, though not exclusive, attention to youth enrolled in two such groups – one rural and one peri-urban. I refer to these as *Kholo* (Faith) and *Care Project* respectively.

The proportion of young participants enrolled in support groups biases the sample, since many HIV-positive youth remain undiagnosed and untreated, and very few have access to additional ART support. In sub-Saharan Africa, children and adolescents who are eligible for ART are half as likely to access it as their adult counterparts (UNAIDS

2013). Participation in these therapeutic communities may have cultivated a particular aptitude in this group of young people, who have learnt to 'work' systems of care and have mastered the discourses and currencies that carry import in these institutions.

As a result of delayed treatment, most perinatally-infected youth in this study have lost mothers to AIDS-related illness, and a few more have lost fathers. Eight of these participants had no contact with one or more of their living biological parents. Consequently, only four perinatally-infected adolescents in this cohort live with a biological mother or father, while the vast majority stay with close relatives. Most often, these are female-centred homes in which grandmothers head the household and administer social grant income.

Indeed, elderly pension recipients are frequently at the centre of household economy in the 'new' South Africa, given the extent of joblessness and the absence of social assistance for able-bodied, working-age, male adults. More specifically, women and children have been brought under state protection through old-age and child-support grants that privilege matrifocal domestic arrangements (Ferguson 2013, p.231). Meanwhile, men have been increasingly delinked from wage labour, leading to a drastic decline in marriage (Ferguson 2013, p.231). There are only two perinatally-infected youth in this study who are living with their fathers, and in only one of these cases was the father involved in deliberations about household spending.

In addition to many of their parents having died as a consequence of delayed ART rollout, perinatally-infected participants have suffered in other ways owing to late treatment: being small for their age, experiencing severe learning difficulties, and

afflicted by a range of chronic conditions. Rural respondents travel long distances to health facilities and carry heavy financial costs. Peri-urban youth are closer to services, but spend long hours in clinics as a consequence of overcrowding and understaffing.

Adolescents in our study lament being dependent on long-term daily medication, even when they take it diligently. ART-related support has by no means transformed a positive HIV status into a privileged position. HIV continues to compound social and economic pressures on some of the country's most marginal families. It also remains a source of perceived, internalised and enacted stigma. I argue that in a context of generalised vulnerability and severe socio-economic inequality, ART might be attributed new meaning because of the resources associated with it. Being able to navigate this contradictory terrain is central to young people's ART practice. Further, the delineation of 'HIV'- and 'orphan'-related needs, as distinct from those of the broader community, whose lives have also been deeply affected by HIV/AIDS, may produce new stigmas.

LOOKING AND LISTENING AT THE INTERSECTIONS BETWEEN STATE, CLINIC AND HOME

Throughout fieldwork, Mildred and I visited young people regularly, immersing ourselves as far as possible in their everyday lives. We spent time cooking, washing clothes and walking through neighbourhoods. More structured activities were also incorporated into these visits, including semi-structured interviews with young people and their families. Despite this, the research only touches the surface of day-to-day life

in young people's homes, a greater exploration of which might have further uncovered the relationships and contexts that shape the experiences of youth on ART.

To observe young people's engagements with institutions of care, we accompanied them to clinic and hospital appointments, attended support group meetings and facilitated trips to the social grants office. This was complemented by semi-structured interviews with village healthworkers, nurses, doctors and social service providers, and observation in nurses' consultation rooms.

The findings presented here derive from engagements with those who deliver or benefit from ART programmes. There is a need for further research on how outside perceptions of ART users, particularly young ART users, are changing, as the epidemic takes new forms amid shifting political, economic and social conditions.

All research activities were conducted in English and isiXhosa. The data are limited by complex *in situ* translations, which may have given rise to misinterpretations. Participants' responses were also shaped by their interpretation of us as researchers, and the perceived risks and benefits of participation. The author holds all recordings and field notes.

Analysis methods were based loosely on Grounded Theory (Charmaz 1995; Glaser & Strauss 1967). Given what is now a vast, varied and contested literature (Charmaz 2000b; Corbin & Strauss 1990; Glaser 1978; Thomas & James 2006) on the applications of Grounded Theory, I identified key associated principles, which were appropriated for this study: participants were sampled not for representativeness, but for theory

construction; data collection and analysis began concurrently, as emerging findings were discussed and infused into ongoing fieldwork; and finally, the analysis emerged not from preconceived hypotheses, but instead from an iterative process of 'building up' from the data. Following Miles and Huberman (1994), I identified and refined emerging categories of data (first-level coding). These themes were compared and contrasted across the data, as I searched for patterns, relationships and explanations (second-level coding).

Participants and research sites are referred to by pseudonyms. Locations and identifiers are kept deliberately vague in order to protect anonymity. This study forms part of a collaborative, mixed-methods research project on adolescent health in the Eastern Cape – titled *Mzantsi Wakho* (Your South Africa). Mzantsi Wakho's extensive ethics protocol was approved by the Universities of Oxford and Cape Town, and by the Eastern Cape Departments of Health, Education and Social Development.

THE RESOURCES AND NETWORKS OF AIDS INTERVENTIONS

"I'm going to get a bicycle", Anele (aged 11) bragged. The group of adolescents, still dressed in their school uniforms, were sprawled on the concrete outside the small meeting room where they congregate every week for a support group. They were eagerly anticipating their *indodla* (social grant), which is deposited around the first of every month. It was five days before grant day – when the clinics are emptied as families spill into town and join the long queues for the cash machines. "People don't get sick on payday", the local nurses jested (field notes, Ridgetown, 2 February 2014). At this support group meeting, a lively discussion had ensued among the adolescents about what

they hoped to buy with their grant money. Sitting on the chair in the centre of the courtyard, Mpho (aged 12) announced with a wide grin on her face that her fridge is always full because there are so many grant recipients in her home. Mpho lives with an aunt, who receives, in addition to Mpho's grant, a child support grant to help fund the upbringing of Mpho's younger cousin. In addition, Mpho's grandmother receives a pension. "We also have dish [satellite TV]", Mpho added cheekily. She said she would make sure her grant went towards maintaining this household standard and then she would use the excess to buy a cell phone. "Me too, I also want a phone", exclaimed Thandi (aged 10). Throughout the conversation, the group made reference to *indodla uyagula* or disability grants, despite the fact that most were benefiting from foster-child grants. The tone was playful, but also brazen, as the group laughed, gossiped and teased (field notes, Ridgetown, 26 March 2014).

This informal conversation between adolescents at a Care Project support group meeting provocatively captures the ambiguity of their position as HIV-positive youth: all have been enrolled in the support group because of their vulnerability. Having contracted HIV at birth, most have also lost parents to the virus. Yet it is their 'sickness' that has enabled access to disproportionate social welfare. Indeed, by referring to their grants as 'indodla uyagula', the adolescents identify their illness as the source of currency. Even those who, in reality, benefit from foster-child grants receive this money as a consequence of their parents' untimely death.

This unique access to some of the highest-paying social grants in South Africa has situated sick and orphaned children as primary 'breadwinners' in many households – paradoxically rooting their power and their subjection in the self-same place. Indeed,

over tea with a grandmother in Mtembu, I witnessed her celebrating the fact that her grandson's illness, and the "disability grant" he would access, would help alleviate poverty in her home (field notes, Mtembu, 8 November 2013). Their position as household providers endows the adolescents who receive these grants with a perceived, perhaps subversive, authority. Indeed, their discussion at the support group unsettles conventions about the nature and content of 'youth talk', as adolescents stake their claim in conversations about household resources and spending, which are usually reserved for adults.

While grandmothers most often manage adolescents' social grants, young ART users – some of whom describe illness or child grants as 'my money' – also influence spending decisions on grant day. Anele's grandmother, for example, complained that Anele could always persuade her to buy more than she intended, and made sure that they went to Kentucky Fried Chicken before visiting the grocery store (field notes, Ridgetown, 2 April 2014).

Although youth under the age of 18 are strictly ineligible for disability grants, young support-group members may have been referring to the care dependency grant, which serves as the child equivalent. Yet many HIV-positive youth, including those at the support group, are similarly ineligible for this assistance, as they are not dependent on adult care. Relationships with sympathetic doctors have allowed organisations like Care Project occasionally to bypass the system for 'their' adolescents. Thus NGO workers have sometimes negotiated access to the more generous illness grants, even when adolescents are strictly eligible only for childcare or foster-child assistance.

This has required that youth utilise their HIV illness, often using scientific markers as reference. Thami, the support-group facilitator, explained that Care Project used CD4 counts, which measure the number of T-helper cells in the body, to prove eligibility for both disability and care dependency grants, sometimes instructing social grant officials to "go and visit this patient and see how sick they are" (field notes, Ridgetown, 2 May 2014). CD4 counts serve as a marker of immunological health in HIV-positive patients and often determine social and clinical responses to them. CD4 counts, among other things, are used to determine the following: if a patient can initiate ART, if they are succeeding on their current treatment regimen, if they have clinical AIDS, and if they are eligible for a disability grant.

In addition to blood tests, medical records and doctors' assessments, eligibility criteria for illness grants also demand the meticulous compilation of a plethora of legal and registration documents. Scientific and identity documents are brokered within the social security system, giving rise to new forms of "biological citizenship" (Rose & Novas 2005). Here, documents themselves are embedded with distinct power in a system of bureaucratic governance. Youth on ART, despite being ineligible to vote, claim these forms of citizenship by mastering bureaucracies of state welfare.

Access to foster-child grants is similarly mediated through a range of official documents. These include birth certificates, biometrics, identity documents, child medical records, school enrolment certificates and affidavits. Claimants also require a statement of support from a reputable social service provider or community leader and, where relevant, parental death certificates. The application is further subject to a social worker investigation and a ruling from the court, both of which entail subjective interpretations

of whether the child has any "visible means of support" (Hall & Proudlock 2011). This list of bureaucratic and legal requirements produces significant delays in access. Applicants for foster-child grants must decode these complex requirements and compile a mass of documents, despite many being illiterate grandmothers. Linkages to non-governmental ART programmes, which facilitate strong relationships with providers and assist with grant applications, are particularly advantageous, given these bureaucratic and procedural hurdles.

As an indication of how the category of 'foster parent' has gathered rhetorical power and prevalence within state and NGO care programmes, an adolescent guardian in Ridgetown once announced to Mildred and I that she was not the biological parent of her child, but the "foster parent" (field notes, Ridgetown, 8 March 2014). Importantly, the whole statement was made in isiXhosa, except 'foster parent', which was said in English. This is significant not only because we had never heard this participant speak English before, but also because the very concept of 'foster parent' has been manufactured by an external frame of reference. Like many others in South Africa, she is caring for the child of a close relative. Using the term 'foster parent' to describe this arrangement arises from its circulation and valence within health and social welfare programmes.

Let us reflect further on the paradoxical resources associated with parental death: Care Project has often been intimately involved in caring for dying parents. Indeed, it is through death that many orphaned youth are first enrolled in the support group. Immersing itself in the deeply private and guarded spaces of AIDS deaths within families, the organisation negotiates with relatives about who will take in orphaned

children, and also assists dying parents in accessing life coverage (sometimes by setting aside portions of their disability grant). Through foster-child grants, life coverage, and links to future NGO support, dead parents may be said to continue to provide for their children from beyond the grave. Indeed, in some homes, the dead are primary contributors to household income.

In a context of joblessness and economic marginalisation, dead parents may, unsettlingly, be more successful providers than the living. Indeed, adolescent and adult respondents alike equated 'good' parenting with material support. While income from dead parents did not eliminate the internal shame or social anxieties surrounding parentlessness, it did add tenuous ambiguities to conceptions of parenthood, which, as I will show later, are further sharpened by the assumed parental roles of social care providers.

Over the course of our fieldwork, Mildred and I saw Care Project support families by donating clothes, linking them to food programmes, and locating missing relatives. Enrolment in Care Project also enabled privileged access to health services. As Mpho's grandmother explains:

> There are benefits. You can get transport to the hospital, and when you get discharged, they can pick you up. Because sometimes you don't have money to go to the hospital, or if you get discharged [and] you don't have money to get back home, or if it's late and you need to go to the hospital. If there's something wrong with Mpho, I will be able to take her to the doctor because of Care Project (interview, 5 March 2014).

Access to doctors is significant in a nurse-run public health system, in which doctors' appointments would need to be made well in advance.

Like Care Project, Kholo's adolescent support programme also enables privileged access to doctors, provides transport to clinics and hospitals, and distributes intermittent food parcels and clothing. Further, both Kholo and Care Project have established ways of manoeuvring within the health system to their own, and their patients', advantage. This is often through personal connections to health personnel and astute knowledge of the system. For example, some lay caregivers have learnt to dress like ambulance drivers as a tactic for skipping hospital queues (field notes, 23 September 2013).

In addition to enabling easier, and exceptional, access to health and social services, both Care Project and Kholo also link young people to a range of middle-class networks and spaces. Care Project youth have gone on beach trips, visited the nearby university campus, and watched films together. Kholo has facilitated trips to urban centres, during which young people share their experiences of HIV. Here, living with the virus is converted into a travel ticket, dependent on one's ability to wield the rhetoric of HIV activism and disclosure.

The following is an illustration of the role of AIDS interventions in young people's social imaginations: youth at the support group made reference not only to their unique position as household providers (who helped to keep the 'fridge full'), but also to their material aspirations. Adolescents celebrated the satellite TV, new cell phones, and bicycles they hoped to purchase with their special grants, although many may never have acquired these things. By offering (limited) linkages to middle-class spaces, networks, and modes of consumption, AIDS interventions (and, paradoxically, illness itself) entail a re-imagining of young people's relationship to centres of power.

MOBILISING AIDS INTERVENTIONS

While enrolment in ART support programmes enables immediate access to their associated resources, youth also mobilise these linkages in artful ways. Thembakazi (aged 18) has travelled to major cities to share her experiences of living with HIV, and has educated children at the local clinic about ART. She cites these occasions as the times in her life when she felt "most powerful" (interview, Ridgetown, 27 October 2013). By giving 'testimony' to life with HIV and the revelations of AIDS science, Thembakazi selectively deploys performances of 'therapeutic citizenship'. Indeed, Thembakazi is celebrated as a model of 'positive living' by local NGO staff, who advocate for HIV disclosure, treatment literacy, and adherence.

In addition to frequent travel, Thembakazi receives repeated praise from ART support staff because of her success on treatment – affirmation which, she reports, is absent from her home life. She is a regular visitor at the houses of NGO careworkers and is, in many ways, parented by many members of staff of the local AIDS organisation.

But despite outward appearances, Thembakazi does not exemplify the typical health citizen. She is not especially treatment-literate and sometimes struggles to interpret blood-test results (interview, Ridgetown, 27 October 2013). She also carries HIV-related body shame, and is particularly self-conscious about what she believes is uneven weight distribution (field notes, Ridgetown, 9 September 2014).

Yet Thembakazi has capitalised on her position within ART support programmes and learnt how to tap into selected discourses and practices in order to gain privileged

support. Similarly, it became increasingly evident that none of the adolescents who attend Kholo's support-group retreats do so in response to an empowered HIV identity. Rather, they see it as an opportunity to escape their homes, see friends and eat good food.

Illustrating this, but referring this time to a weekend away organised by our research team, Andisiwe (aged 11) said she had been spoilt by her grandmother and excused chores after returning from the weekend with a hamper of leftover food (field notes, 24 October 2013). When we asked how other children in her house had felt about her privileged treatment, she said that they too believed she should be rewarded. Here, Andisiwe is recognised for her contribution to the household economy – for her ability to bring in food by virtue of her relationship with us as researchers, which was itself dependent on her HIV status.

At times, maximising one's engagement with AIDS interventions demands a particular performance of need. Such performances are most evident not in the social grant system, but in the ways that adolescents and their families make themselves visible to AIDS organisations, healthworkers, and potential patrons. This was provocatively illustrated in a story told to us by Zandile, a lay counsellor at Kholo. On one of our many long drives to visit a young patient, Zandile gave an account of a game she had played with adolescents at a recent Kholo retreat.

Zandile said that she had wanted to do something that was fun with the kids – to ensure that they would look forward to camps and would always come back. She vividly described how she had dressed up like a *makhulu* (grandmother) with a *doek* (cloth) wrapped around her head and 'Ponds' (face cream) slapped over her face. Imitating an

old woman, Zandile's recalled how her body and voice slowed and trembled as she moved through the corridors of the Kholo building. She visited the offices of each of the Kholo staff asking for money. The kids followed her, highly amused. At each office, Zandile pleaded with Kholo staff, saying that she was old, with many grandchildren to look after. The staff did not recognise her. Eventually, she arrived at the office of Kholo's primary administrator, Cally. Sympathising with the 'makhulu's' plight, Cally started writing her a cheque. To Cally's embarrassment, Zandile then revealed herself! Zandile laughed out loud as she relayed to me her stellar performance (field notes, 5 November 2013).

Zandile's role-play was entertaining for adolescents at the camp, not only because of the hilarity of her 'makhulu' impersonation, but also because it had been carefully selected to resonate with adolescents' own experiences. The character of the grandmother, single-handedly caring for her many grandchildren, is familiar. So, too, is the act of performing one's neediness to the organisation as a plea for money. This is not to say that such families are not needy, but rather that a particular, artful performance is required in order to mobilise this need effectively and access essential resources. This vision of the archetypical AIDS-affected family, in which the middle generation is absent, leaving the grandmother to care for many grandchildren, carries a particular weight within AIDS intervention programmes. While migrant labour and old-age pensions make this a common family arrangement in South Africa, with or without AIDS, families located in AIDS interventions are better placed to capitalise on this position, because of the way in which these institutions have characterised the 'needy' and 'deserving'.

Zandile's story recalled another occasion, in which a family in our study was recounting to us their daily struggle to put food on the table, while one of the women shoved a bag of meat out of view (field notes, Mtembu, 11 September 2013). Undoubtedly this family did struggle with food security, but in order for their audience to buy the story, the performance demanded that the meat was out of sight. Similarly, part of the entertainment in Zandile's role-play is the success of the ruse. Food insecurity is a particularly potent subject for AIDS interventionists, given the prevalent prescription to eat before taking HIV medicines.

In addition to mobilising performances of need, young people in this study also brokered their youth for special treatment in clinics. Many left consultation rooms with pocket money from health staff, while others used their position as 'school-goers' (who needed to return to class) in order to skip queues. Wearing a school uniform was a particular asset in campaigning for this privileged treatment. Importantly, the modes of therapeutic citizenship at work here diverge from the foundational literature, since hierarchical relationships with sympathetic patrons are privileged over horizontal solidarity with fellow ART users. Such relationships may be particularly prevalent among adolescent ART users, whose youth compounds their position as dependents, as opposed to participants, within health and social welfare programmes.

CARE CONTESTATIONS

I have discussed how some adolescents on ART mobilise their illness, orphan status and youth as currencies within state and non-state institutions of care. This endows them with particular forms of power. But this power is inherently unstable, and regularly

contested. In the discussions that follow, I describe the conflicts and tensions that arise as a result of the particular recognition and assistance granted to these youth on ART. These contestations are evident within homes, between families, and in the community-ascribed meanings attached to HIV-positive youth.

On that same journey, Zandile, the Kholo lay counsellor, told another poignant story, this time about a child from a nearby village who had attended the organisation's most recent adolescent retreat.

The child, we were told, was very poor and did not look like other adolescents in the group. Zandile used her own money to buy her toiletries, gave her clothes from the Kholo garage, and fixed her hair to look "as nice as the other kids". But at the next retreat, she returned in her old clothes and without her hair done. A while later, Zandile visited the child's family, concerned that she kept returning to the retreat without the toiletries or clothes that had been given to her. The family said that whenever the child returned from retreat, she was always nicely dressed. This made her older siblings jealous. Believing that they deserved first access to nice things, the siblings had taken the clothes and toiletries for themselves. To which Zandile replied: "This is my child and I bought her these things" (field notes, 5 November 2013).

This story points to struggles over resource allocation within homes, which unsettle, and give rise to, internal hierarchies of power. The child in the story is awarded disproportionate assistance as a result of her enrolment in an HIV support programme. This privileged access unsettles pre-existing systems of resource allocation within her home, which appear to function according to an age-based hierarchy. Conventionally,

older siblings would have had first access to external resources by virtue of being first to enter the job market. But diminishing job prospects, along with the special resources awarded to their younger, HIV-positive sibling, have called this assumption into question. I observed that tensions over household resources were often sharpened when the HIV-positive sibling was a foster child and a latecomer to the family. Here, both biological and foster-siblings purported to be unequally treated.

Some HIV-positive adolescents also came into conflict with their guardians over household resource allocation – particularly grant money. Thembakazi, who was born with the name 'Lulama', has quite literally had her identity shaped by conflicts surrounding her grant (field notes, Ridgetown, 12 November 2013). While it remains unclear whether Thembakazi's family were receiving a disability, care dependency, foster- or child-support grant for her care, both Thembakazi and her aunt attach the money to her HIV status. Indeed, Thembakazi says that conflict in her home arose after her diagnosis.

When she was young, Thembakazi/Lulama's mother received the child's grant money, which she later took with her to Cape Town, leaving Lulama in her aunt's care. Angered by the mother's selfishness, the aunt changed her niece's name to 'Thembakazi' so that the social security agency would be able to issue an entirely new grant speedily, and she, as the legitimate primary care giver, could manage it.

Thembakazi says that she never benefited from her grant while growing up and believes she should have controlled how it was spent. Having turned 18, she now intends to make an independent application, so that the funds are directly deposited into her account.

Thembakazi believes that her aunt kept her apart from her estranged mother for fear that she might relocate to her mother's home and "take her money with her" (interview, Ridgetown, 27 October 2013).

I observed that conflicts over grant money occurred both within homes and between households. Most notably, maternal and paternal grandmothers battled over orphaned children, and who had legitimate access to their foster-child grants.

These cases speak to struggles over resources, but also over parenting. Contestations over child care arose between family members, as well as between families and social service providers. Zandile's story about the newly clothed child reveals a tension about who the rightful care giver is: as Zandile asserted, "this is my child". Indeed, AIDS has not only invited health and social-care programmes into intimate spaces of birth, death, and sex, it has also co-opted their careworkers into the parenting of AIDS-affected children. NGO workers from both Kholo and Care Project take on a variety of parental roles: feeding and clothing adolescents, following their schooling, supporting them through criminal cases, advocating for them in disputes over grant money, and mediating inter-familial conflict. While the support offered by these pseudo-parents has been a great asset to young people and their families, it has also given rise to deep tensions. The aunt of Naledi (aged 16), for example, had a fraught relationship with NGO staff, whom she resented for having become Naledi's first port of call, over and above her own family (field notes, August–October 2013).

SURVIVAL, SUCCESS AND SUSPICION

Cognisant of perceptions that she was using Thembakazi as a source of income, Thembakazi's aunt was adamant about insisting that she "loved Thembakazi deeply", and not because "she's sick and getting a grant" (interview, Ridgetown, 10 September 2013). Similarly, when the grandmother of Siya (aged 18) returned home with a sick baby (Siya) after the death of her daughter, neighbours accused her of "liking money" (field notes, 7 October 2013). Young people are equally sensitive to resentments over disparate resource access. Amanda (aged 13) reports that since becoming part of Kholo, she is accused of acting "too big for her shoes". As a consequence, she was nervous to be seen with Mildred and me in public, given our position as well-resourced outsiders (field notes, Mtembu, 24 September 2013). In order to grapple with how such resentment operates, I turn attention to two youths in the study who believed they had been bewitched.

Khaya (aged 18) is considered a model patient by nurses at his clinic and has been tasked with educating others in his neighbourhood about HIV. He is also a youth leader in a number of community and religious organisations. Khaya has travelled to Johannesburg with the local HIV organisation and is in regular contact with their staff, often making requests for material support. In October 2013, he told Mildred and me that he was having nightmares about an old woman in his community killing black cats, which he took as a sign that he had been bewitched. "People are jealous of my success", he said (field notes, Ridgetown, 19 October 2013). But while Khaya believes that he is envied, he also feels judged because of his HIV status (field notes, Mtembu, 8 November 2013).

Initially, it seems paradoxical that these two sentiments of repudiation and jealousy could co-exist. But the ambiguity arises from the fact that Khaya is successful with HIV – from the pairing of these seemingly opposing positions.

Similarly, Thembakazi has been able to capitalise on ART support programmes in order to access travel, clothing, praise and grant money. Yet both she and her priest had dreams suggesting that she was bewitched. When we asked why people were bewitching her, she responded, "They are jealous. When I got diagnosed with HIV people thought I wouldn't cope, but I did" (interview, Ridgetown, 27 October 2013). Thembakazi locates others' resentment in her ability to do well in spite of, and perhaps because of, HIV.[16] Here, it is not only disproportionate resource access that attracts resentment, but also the conditions and means by which access is attained.

Thembakazi's community might ask how someone like her survives, and (in relative terms) prospers, despite her circumstances. Her mother left her with a lifelong, stigmatised illness; she has never known her father; she is one of four children being cared for by her elderly aunt; and none of her family members is employed. Given her parentlessness, impoverishment and stigmatised condition, Thembakazi's survival, and relative success, are rendered mysterious – even controversial. Although witchcraft discourses in South Africa have generally been characterised as malicious jealousy levelled at those who are conspicuously better-off, suspicion and resentment can just as easily revolve around impoverished people who have managed to survive despite being

[16] This may also be linked to a form of survivor's guilt: amid widespread and proximate death, one might ask, 'why have I lived while others have died?'

noticeably 'people poor' – that is, without able-bodied or working household members to support them.

In KwaZulu-Natal, Isak Niehaus (2005) observed that such people, rather than feeling vulnerable to witchcraft (as was the case in this study), might be accused of witchcraft – namely zombie-keeping. Zombie-keepers employ the labour of the dead as an illicit means of survival. Here, the inexplicable survival of impoverished families is explained though public revelations and accounts (including in the media) of this scandalous trade. The resentment that circulates around the mysterious survival, and even relative success, of AIDS-affected households might be similarly associated with perceptions that they are brokering the dead. Even where adolescents' parents are not deceased, families' attempts to win gains from AIDS interventions could be read as a trade in bodies – of blood results, death certificates, and scientific categorisations.

I had no evidence to suggest that Thembakazi's family or those like hers, had been accused of witchcraft or zombie-keeping. Indeed, there is an important difference between Niehaus' alleged zombie-keepers and families like Thembakazi's. In Niehaus' narratives, it is because someone's means of survival is mysterious that they are accused of zombie-keeping: those people most likely to be accused were also those without paid work or access to remittances. HIV-positive adolescents in this study who felt vulnerable to jealousy and resentment had very apparent sources of income: the state and well-networked NGOs. While the source of Thembakazi's survival is more apparent, resentment may still attach to the fact that her family survives, despite being without any employed members. Most South African families that have little or no access to paid work cannot turn to the state for care. Hence, the potential source of disquiet is this:

Families like Thembakazi's are better positioned to access this much-sought-after support precisely (and perversely) because they have been afflicted by a stigmatised illness.

NAVIGATING A PLURALISTIC SOCIAL WORLD

Following the dreams of her bewitchment, Thembakazi was referred to a local prophet for treatment. The prophet presented two different explanations for what she described as the "black spots" she saw in Thembakazi's brain, each explanation stemming from a different world view. She said that doctors would have diagnosed Thembakazi as having "stress", but she believed that these "black spots" were better explained by a witch's curse. The latter version resonated with Thembakazi.

Like other adolescents in this study, Thembakazi is manoeuvring precariously between multiple epistemological and moral communities – each with different, and sometimes contradictory, imperatives. As an ART user, Thembakazi pays great attention to "what doctors say". Indeed, it is according to "what doctors say" that she measures her health and success as a model patient. "What doctors say" also facilitates her access to a state disability grant. It was through the local doctor that Thembakazi was enrolled in the adolescent ART support programme, along with its associated networks of patronage. Thus, Thembakazi is funded, parented and given guidance on how to live, all on the basis of "what doctors say". ART mediates her relationship to state welfare, local support programmes, and even global development networks.

To access these myriad resources and networks, Thembakazi must perform versions of therapeutic citizenship to AIDS interventionist audiences. These audiences hold different cultural and moral views, compared with the audience that might view Thembakazi's resource access with resentment. Yet both operate within the same physical and temporal spaces in Thembakazi's life. "What doctors say" has no relevance for Thembakazi's attempts to understand the moral economy of her local community, nor does it contribute to her efforts to negotiate community belonging amid her perceived difference. For her, the "black spots" in her brain are not about stress, but a sign of her tenuous, fragile relationship with family and neighbours.

In contexts of local scarcity, resource disparity breeds conflict and undermines social solidarity, making discretion an important virtue in close-knit communities like Thembakazi's. Yet in the wider context of modernity and new democracy, the value of discretion sits uncomfortably with the imperative to express freedom, aspiration and belonging –through both material consumption and association with middleclass networks.

The juxtaposition of these cross-cutting imperatives is characteristic of the post-apartheid moment. Young people's success as ART users may rest on their ability to negotiate these multiple, sometimes conflicting, moral economies. They negotiate these imperatives through a distinctly modern biotechnology in response to a modern epidemic, which has deepened the contradictions of post-apartheid South Africa. In this study, ART takes centre stage in young people's pursuit of survival and belonging, both within democratic modernity and within their families and neighbourhoods.

CONCLUSION: THE SOCIAL STAKES FOR YOUTH IN USING ART

In this article, I have sought to illustrate the ambiguous agency of young people on ART, who are made deeply vulnerable by their chronic condition, but may also be able to mobilise their position as ART users to access privileged resources. Given that these young people live in communities in which many families are in dire need, the particular attention given to youth on ART is resented, giving rise to new social tensions. The antipathy is deepened by the fact that it is death and illness that are facilitating the linkages from the socio-economic margins to centres of power. So navigating ART programmes entails real social and emotional stakes for young people.

Understanding complexity and contradiction in young people's engagement with ART programmes can help to attune interventions to the social contexts of youth. I have illustrated that enrolment in ART-related care, in the form of support programmes or associated social grants, has implications for young people's position within families, the ways in which they are perceived by neighbours, and even their sense of social belonging. Hence, the targeted attention given to young ART users, while entailing clear benefits, has also produced new struggles on the ground. These struggles have the potential to affect young people's adherence to ART and their retention in care.

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Redeeming Lost Mothers: adolescent antiretroviral treatment and the making of home in South Africa

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Redeeming Lost Mothers: Adolescent Antiretroviral Treatment and the Making of Home in South Africa

ABSTRACT

In this article, I explore how adolescent antiretroviral treatment (ART) might be signified to repair sociality in Eastern Cape homes, ruptured by HIV/AIDS and maternal loss. The post-apartheid period has exposed these families to new forms of social fragmentation, propelled by the disintegration of wage labour, declining marriage rates, and a rampant HIV/AIDS epidemic. Drawing on eight months of qualitative fieldwork, I show that in the homes of some adolescents born with HIV, these present-day domestic ruptures were discursively connected to the past shortcomings of their dead and absent mothers. Some familial narratives accused lost mothers of disobeying their elders, neglecting their children, and flouting custom — their social transgressions made manifest in their child's inherited HIV. By signifying adolescent ART-taking as an enactment of the discipline and care purportedly absent in their mothers, these families might also attempt to imbue ART, beyond its biomedical function, as a means of social repair.

Keywords: *adolescent, antiretroviral treatment, HIV/AIDS, mothers, orphans, South Africa.*

PAPER 2: REDEEMING LOST MOTHERS

In this article, I explore how adolescent antiretroviral treatment (ART) might be established as a site to ritually augment familial ties, in homes fractured by HIV/AIDS and maternal loss. This study forms part of a collaborative research project, *Mzantsi Wakho* (Your South Africa), which investigates adolescent ART and sexual and reproductive health in the Eastern Cape. Mine was a small qualitative study, investigating how HIV-positive adolescents and their families appropriate ART, amid the social complexities of their everyday lives.

The analysis presented here draws on eight months of qualitative fieldwork with 18 perinatally-infected adolescents (age 10–19) and their families, in households in which the biological mother was either dead or absent. These Eastern Cape families have had to re-imagine and reshape practices of care amid profound social and household rupture. This has been precipitated by a long history of migrant labour, and compounded more recently by pervasive AIDS deaths, deteriorating agrarian livelihoods, and deepening unemployment (Bank 2001; Bank & Minkley 2005; Reddy et al. 2005). More so, households in this study have carried the dual burden of maternal loss and maternal inheritance: that is the departure of a caregiver and loved-one, and the simultaneous arrival of a child with a life-threatening and lifelong illness.

Those who have assumed the role of caregivers are tasked with rebuilding sociality in the home, while also integrating HIV treatment into its domestic rituals. The problem is distinctly generational: first, because the loss of the mother often entails the loss of the middle generation, demanding that ties of mutuality and respect be re-threaded across the generational divide; and second, because to treat an inherited illness is precisely to attend to the misfortunes of the past in the present.

I am interested in how adolescent ART-taking might be signified to bridge these temporalities: how the biographies of children are invoked in providing ART care for children's children; how modern medical technology might be taken up as a paradoxical vehicle to re-instate imagined tradition; and how contemporary bio-medicine can be re-invented as a social treatment for the shortcomings of the past.

My concerns in this article have another generational aspect. Adolescents in this study are among a cohort of South African youth born since democracy. While the 'new nation' has brought fresh entitlements, liberties and hopes, it has also been attended by its own disruptions and uncertainties. These have included an extraordinary decline in wage labour, shifting marital practices, and newfound democratic rights, all of which have contributed to profound fractures of gender and generation (Budlender & Lund 2011; Ferguson 2013, p.231; Neves & Du Toit 2013). In some South African localities, an HIV/AIDS epidemic has been interpreted as symptomatic of this societal tumult (Posel et al. 2007), for which young women are held especially culpable (Albertyn 2003; Joffe & Bettega 2003; Leclerc-Madlala 2001).

In her seminal KwaZulu-Natal study, Susan Leclerc-Madlala's (2001) explored the misogynist iconographies of HIV/AIDS in South Africa. She found that local interpretations of HIV/AIDS posited women's 'pollution' not only as a biological contaminant that created and spread HIV, but also as a causal agent in the misfortunes that befell families and neighbourhoods (Leclerc-Madlala 2001).

In the homes of some adolescents in this study, these public discourses took private expression in family narratives that demonised dead and absent mothers. Here, the

purported negligence and misconduct of missing mothers was sometimes seen as a catalyst of domestic disrepair. By implication, adolescents' inherited HIV was a maternal failure – both of biological and social reproduction. In these predominantly matrifocal homes, it was nevertheless women who policed misogynist gender norms, positioning other women (occasionally their own daughters) as deviant and disruptive.

As well as being part of an age cohort, adolescent ART users in this study constitute what Susan Reynolds Whyte and colleagues (2014) have called a "bio-generation". This is premised on their shared biological status and having lived their life course under a biotechnological programme. Reflecting on the meanings and possibilities of HIV treatment for the first "bio-generation" of ART users in Uganda, Whyte and her co-authors employ the concept of "second chances" as an analytic tool. In its most banal form, ART offers a "second chance" at life where death was once inevitable. But there is also a stronger interpretation, in which a "second chance" might denote "a spoiling of life, followed by the opportunity to try again and to live better" (Whyte et al. 2014, p.19).

What is unique for adolescents in this study is that this "spoiling of life" precedes their birth. Born with HIV, the very existence of this cohort of perinatally-infected adolescents testifies to the shortcomings of their preceding generation. Their lifelong illness, and in some cases their parents' deaths, are attributable to prior failures in public policy and political will. These oversights delayed South Africa's ART rollout and thwarted the prevention of parent-to-child transmission (Nattrass 2008). But the survival of this cohort into adolescence also bears witness to a new era of ART availability.

I suggest that, for some adolescents born with HIV, ART sits at a fraught temporal intersection between the 'new life' offered by the present, and the past misfortunes of a previous generation — that of their dead and missing mothers.

ART AND BIOSOCIALITY

Following a period of widespread, unavoidable AIDS death, the public provision of life-preserving ART was a watershed moment for the developing world. Research has documented the frequently evangelical idiom in which ART is articulated among those with newfound access (Dilger et al. 2010). ART users in West and Southern Africa have been described as giving "testimony" to the "revelations" of AIDS science (Nguyen et al. 2007; Nguyen 2009), "resurrected" from near death to "new life" on treatment (Robins 2006; Robins 2009). From support groups in Burkina-Faso (Nguyen et al. 2007), to Treatment Action Campaign members in South Africa (Robins 2006), to the social movements of Brazil (Biehl 2004), treatment activists have narrated their illness experiences, galvanised collective identities, and drawn on their biological status to make claims on both public and donor resources. Accordingly, AIDS activists have been cited as primary examples of "biosociality" (Rabinow 1996; Rose & Novas 2005, p.449) — organising self-help and solidarity premised on shared biomedical diagnoses.

As ART rollout has expanded, so too has the thrust of modern biopolitics increasingly urged patients to become active and 'responsible' medical consumers. ART users are pressed to comply with a set of self-help behaviours that signal "positive living". These include treatment adherence, safer sex, restricted alcohol consumption, regular clinic appointments and HIV status disclosure (Dilger 2012, p.70; Richey 2012). Hence,

alongside their 'empowered' testimony and activism, ART users have become known for their docility in conforming to prescribed "regimes of care" (Marsland 2012, p.471). As a biopolitical project, ART has worked "through the practices and desires" of its "target populations" (Li 2005, p.383), managing bodies, selves, and societies as interrelated ends (Prince 2012, p.5).

ART has therefore given rise to new modes of biosociality, sometimes depicted as enabled, rights-driven citizenship, and at other times as dependent, disciplining clientship (Mattes 2011; Meinart et al. 2009; Richey 2012).

While this literature has explored the appropriation of ART as rights, relationships, and responsibilities vis-à-vis state and donor programmes, less attention has been given to how ART might serve as an expression of obligation, relatedness, and dependency in the home. This is despite the fact that the home is a primary site for ART, and is a fundamentally 'bio-social' entity. Here, mutuality, obligation and identity are premised on biological categories.

As a virus transmitted through sex and blood ties, HIV troubles the very sites of familial connection and relatedness. Hence, while serving as a biomedical treatment for the blood, ART might also work symbolically to repair social damages — to bloodlines and blood ties. Values of discipline and obedience, traditionally invoked in producing a self-reliant ART user, might be re-signified to strengthen relatedness and reciprocity among relatives. In some households in this study, these ideals were asserted and inculcated into adolescents' ART-taking precisely because they were purportedly lacking in their dead and absent mothers. As such, the ritualised consumption of ART was signified not only

for the 'resurrection' of adolescents' health, but also for the 'resurrection' of 'home' as a biosocial project, stretched across time and space.

As a virus steeped in social interpretations (Treichler 1999, p.11), it is unsurprising that treating HIV would be as much a social act as a biomedical one. My concerns in this article are situated amid a wider literature on the 'social lives of medicines' (Whyte et al. 2002). These authors have investigated pharmaceuticals for their social uses and implications, rather than simply their biological effects (Whyte et al. 2002, p.3). Contributing to this work, I explore how medicine is appropriated not only for the control of physiological symptoms, but also of social situations (Whyte et al. 2002, p.15).

RESEARCH SETTING AND METHODS

Between August 2013 and May 2014, I conducted multi-method ethnographic research alongside my research assistant Mildred Thabeng, with 23 adolescents in two Eastern Cape sites. The first four months were spent in rural villages of the municipality I call *Mtembu*, and the second in peripheral informal settlements of a peri-urban town I name *Ridgetown*. In December 2014, we conducted once-off follow-up interviews with two additional adolescent girls, who were recruited as part of Mzantsi Wakho's quantitative cohort. Both were living in an informal settlement on the outskirts of one of the province's largest cities.

The majority (18) of adolescents in this study were recruited through non-government (NGO) ART support programmes with help from NGO staff. Participants were purposively sampled for variation in age and gender, with the further intention of

including harder-to-reach subgroups. These included adolescents who did not know their status, those infected sexually, and those known to be defaulting on treatment. Additional adolescent participants (7) were recruited through public health clinics, with nurses and data capturers facilitating referrals. Clinic-based recruitment helped fill gaps in the sample and allowed for the addition of adolescents excluded from NGO support.

Of the 25 adolescents recruited for this study, 21 were perinatally-infected, and among these, 18 had dead or absent mothers. These 18 adolescents, who contracted HIV at birth and had also experienced maternal loss, are the focus of this article.

In rural Mtembu, a small development NGO was facilitating adolescent ART support workshops a few times annually. These were complemented by intermittent visits from the organisation's village healthworkers. In Ridgetown, a hospice organisation facilitated weekly ART support groups for adolescents. In line with existing literature on ART redemption narratives, adolescents in both support groups occasionally gave 'testimony' to their positive transformations on treatment.

Throughout fieldwork, we visited adolescents and their families regularly, immersing ourselves as far as possible in their everyday lives. Many informal conversations were had while cooking, washing clothes, playing sports, or sharing meals. We also accompanied adolescents and their relatives to medical appointments and support groups to observe how HIV treatment was narrated in these institutional settings. This was complemented by semi-structured interviews and informal conversations with professional and lay healthworkers.

For almost every adolescent participant, semi-structured, recorded interviews were conducted privately with their guardians to trace adolescents' care trajectories. Where both biological parents were absent, these interviews began with the prompt "Can you tell me how you came to care for X?" Conversations were intended to explore experiences of caregiving, charting adolescents' HIV diagnoses, ART practices, and present-day home lives.

Engagements with adolescents were more ongoing, but also comparatively informal. In addition to casual conversations with adolescents, visits sometimes included explorative interviews, occasionally using games and pictures as prompts. One such activity encouraged adolescents to act out and narrate their pill-taking using sweets as props. Another asked participants to reflect on a series of pre-selected generic images depicting children at home, in clinics, and with friends. Emerging discussions covered adolescents' family relationships, daily lives, pill-taking practices, and HIV illness history. While some ethnographic observation involved family, friends and healthworkers, the vast majority of interactions with adolescents were private.

Research methods were adapted in field according to the age, communicativeness and attention span of participants. Many adolescent respondents were deemed by their healthworkers and guardians to have severe cognitive and learning difficulties. Consequently, the richness of responses varied greatly among participants. Methods were designed to create a non-threatening, stimulating research environment, balancing non-invasive participation and guided interaction. The use of multiple methods helped guard against bias and allowed us to test the efficacy and acceptability of research tools.

All research activities were carried out in both English and isiXhosa, with real-time translation. This allowed for instantaneous interpretation of participants' responses, which in turn informed follow-up probing. Unless otherwise stated, interview quotes do not reflect participants' responses verbatim, but are instead a re-presentation of respondents' perspectives through the words of the translator. Although we conferred regularly about captured translations, the emerging data was undoubtedly coloured by complex *in situ* interpretations, which may have given rise to misconceptions.

Data collection and analysis occurred simultaneously, with field research and emerging themes mutually informing one another. Recurring, unprompted references to missing parents, and mothers in particular, encouraged us to ask some adolescents and guardians the open-ended question: "What do you/your child know about your/their mother?"

Following fieldwork, data was thematically coded in preparation for write-up (Miles & Huberman 1994). In this article, I reflect on interconnections between emerging themes related to death, intergenerational care, pill-taking, and missing parents. Paying attention to how, and in what contexts, participants invoked missing parents, I discovered overlaps in how dead and absent parents were narrated, and that mothers, in particular, were demonised. Participants' invocation of dead and absent mothers in the context of adolescent ART-taking was unexpected. When related to other pill-taking narratives, the analysis revealed recurrent appeals to intergenerational reciprocity to signify and support adolescent ART.

Pseudonyms are used for both participants and research sites. Locations and identifiers are kept deliberately vague in order to protect anonymity.

HOUSEHOLDS

Apart from those in Ridgetown, most participants in this study were living in former Eastern Cape 'homelands'. Designated by the apartheid government, these self-governing territorial reserves were allocated exclusively for black residents. Consequently, they were deliberately under-developed and under-resourced (Nell et al. 1997, p.58). The Eastern Cape remains one of South Africa's poorest provinces with a 30.6 percent unemployment rate (Statistics South Africa 2015). Among the few adult carers in this study who were able to find work, most occupied short-term contracts as domestic workers or casual labourers. The majority of households were reliant on the post-1994 social grants economy, as recipients of foster child, disability, pension or child support grants.

Among the 18 adolescent participants who had been born with HIV and were living without their mothers, all but two continued to live in female-headed homes. In 2011, 49.6 percent of households in the Eastern Cape were headed by women (Statistics South Africa 2014). Under apartheid labour laws, black men travelled from the country's homelands to work in urban areas and were mandated to leave their families behind (Richter & Morrel 2006, p.4). Coupled with pre-existing gender norms, childcare in South Africa has increasingly been accepted as the exclusive responsibility of women (Richter & Morrel 2006, p.4).

In the post-apartheid period, female-centred homes have only been further entrenched (Walker 2013, p.84), while men are increasingly peripheral to the project of domestic reproduction (White 2001). Plummeting employment opportunities, particularly in the

industrial economy, make it increasingly difficult for men to occupy the position of patriarch and breadwinner (Bank 2001, p.145). Meanwhile, the number of women in the labour force continues to rise (Casale & Posel 2002), accompanied by a decline in marriage rates and the resulting "uncoupling of motherhood and marriage" (Walker 1995, p.431). Female-headed homes are further supported by an expanded social security system, for which women, in their position as carers, are primary recipients (Patel et al. 2012; Statistics South Africa 2010, p.5). Older women have found their position particularly bolstered by state pensions, which until very recently, were set at a lower age eligibility criteria for women than men (Schatz et al. 2012, p.3).

The post-apartheid shift in household income, away from migrant remittances towards welfare grants, has translated into a shift in many Eastern Cape homes, in which women are increasingly central to domestic economies (Bank 2002, p.641). In many households, grandmothers have replaced wage-earning men as economic lynchpins. These 'granny-focal' domestic arrangements are further necessitated by a frequently-missing middle generation, some of whom have been lost to AIDS and others to the perpetual search for work (Schatz & Ogunmefun 2007). Of the 18 adolescents under discussion here, 11 were cared for by grandmothers, sometimes in combination with other relatives.

In light of these structural conditions, it is not uncommon for South African children to be raised without social or financial contribution from their fathers (Richter & Morrel 2006). Among the 18 adolescents in this study who were living without their mothers, 16 were also living without fathers, with 7 having never known their fathers. The diminishing role of South African fathers in child rearing has also lessened the care

contribution of patrilineal kin (Anderson 2005, p.25). Thirteen adolescents in this study continued to stay with maternal relatives after the death or departure of their mother, with many having lost contact with paternal kin altogether.

Death and Dispersal

HIV prevalence in the Eastern Cape is 11.6 percent and the province is home to 23 percent of South Africa's AIDS orphans (HSRC in Hayward 2014). Of the 18 perinatally-infected adolescents in this study living without their mothers, 9 had lost mothers to AIDS illness, while a further three had lost both parents to AIDS. These deaths had irrevocably destabilised their lives, producing immense emotional trauma and often a deterioration of their life circumstances. Among the perinatally-infected adolescents in this study whose mothers had died, nine had to move homes soon after, posing challenges for integration into a new family. Amid death, dispersal and scarcity, there were shared and shifting caregiving arrangements, conflicting claims to care, and shaky transitions from one caregiver to another. Ntombi's case is illustrative here:

During an interview with Ntombi's uncle, he recounted how he and his wife came to care for Ntombi (age 14). They had taken Ntombi in after a series of deaths in her mother's family, and the purported failure of her surviving matrilineal kin to assume responsibility for her care.

> Ntombi's mother died [in] 2009. She was my sister-in-law. Then after her mother died, the sister of her mother took over [her care]. But again she also died […]. And then no-one wanted to take Ntombi. I don't know why, because Ntombi has a grandmother, an aunt and other family (interview, 21 February, 2014).

Ntombi's uncle was one of very few men in our study who had assumed care of a perinatally-infected adolescent after the loss of their mother. In all other cases, grandmothers carried or shared the caregiving burden. Because his wife worked, Ntombi's uncle was the primary caregiver. In relaying the story of how he, a male relative, came to care for Ntombi, he recounted a legacy of lost and negligent female kin: first, the death of Ntombi's mother and maternal aunt, both of whom he described earlier in the interview as reckless alcoholics; then, the failure of Ntombi's maternal grandmother and maternal aunt to assume responsibility for her care. In the wake of these sudden losses and the perceived abandonment of caregiving responsibilities, the remaining family were left to 'pick up' the social strands.

Reflecting on her own struggles to integrate into a new home after her mother's death, Wandi (age 19) described how she received inferior care living without her biological parents: "[Before her death] my mother loved me and spoilt me. Now my aunt sometimes shouts at me and I feel pain. And she's choosy. There's unfair treatment between me and her children" (interview, 10 December, 2014).

While AIDS deaths had an immensely destabilising effect on many adolescents in this study, the loss occasioned by AIDS was also rarely isolated. These adolescents had suffered many losses. Some had parents killed in violent crime, while many more experienced loss in the form of estranged or absent family. As I have already suggested, households in the Eastern Cape have been spatially-stretched for decades (Neves & Du Toit 2008). Among the 18 perinatally-infected adolescents under discussion here, four were rural adolescents with parents living and working in urban centres. A further four

adolescents were living in the same peri-urban neighbourhoods as their biological parents, but had little or no contact with them.

In the minds of those living through them, AIDS deaths might not be delineated from other forms of loss. Instead, they might be understood as part of "a long procession of misfortunes" (Becker & Geissler 2009, p.11). In this study, familial responses to dead and absent mothers were not always neatly separated.

Like those whose mothers had died, Naledi (age 18) worried that her mother's absence had damaged relationships in her home. When Naledi was still a baby, her mother left home to find work in the city, purportedly upsetting intergenerational conviviality. While I drove Naledi from school one afternoon, she narrated her relationship with her grandmother. Naledi seemed to believe that her grandmother viewed her as a living instantiation of her absent mother: the resentment she bore towards her daughter (Naledi's mother) taking expression through interactions with her granddaughter (Naledi). Naledi said her grandmother was angry with her mother, and "took" this anger "out" on Naledi. Reflecting on how she was regularly substituted for her mother in the eyes of her grandmother, Naledi asked, "How can she [my grandmother] hate my mother and love me?" (informal conversation in English, 14 October, 2013). For Naledi, then, familial sociality was mediated by the spectre of her absent mother, who continued to act as an interlocutor between herself and her grandmother. Given this circumstance, mending what Naledi described as a fraught relationship with her grandmother, might entail a re-evaluation of her missing mother.

Just as adolescents were concerned about attending to the social damages of their mother's death or absence, some of their caregivers worried about their ability to substitute for biological parents. A few expressed anxiety about the effects of adolescents growing up "parentless": Mpho's aunt, for example, worried that feelings of "parentless-ness" might lead Mpho (age 13) to a premature sense of "independence" and lawlessness (interview, 5 March, 2014). In a family interview, she cited an occasion in which she had tried to discipline Mpho, who responded by shouting: "Why are you beating me? Why can't you take care of your own child and leave me alone?!" (5 March, 2014). Interestingly, Mpho's support group facilitator also explained the anger Mpho expressed towards her family as a symptom of "parentless-ness" — an indication that she "misses her mother" (interview in English, 9 April, 2014). The implication seemed to be that attending to the missing mother was crucial for maintaining harmonious relationships in the home.

Thus far, I have described how familial death and disappearance – particularly of mothers – is perceived to threaten domestic conviviality. In the life trajectories of adolescents in this study, care has been tractable, mutable and migratory, buffering multiple losses. Other researchers have explored how Eastern Cape families have attempted to socially and ceremonially sustain the home, amid chronic economic insecurity and domestic fragmentation. Zolani Ngwane (2003), for example, examined the ritual return of urban-based relatives to the countryside over Christmas time. This "ritualised drama" signalled a performance of coherence, through which families "approximated imagined households" (Ngwane 2003, p.688). Similarly, Andrew Ainslie (2014) described Eastern Cape families' relentless enactments of ancestral rituals as tenuous attempts to sustain social ties. I am interested in how ART might be inscribed

into familial repertoires of care that seek to rebuild sociality amid domestic fragmentation. My findings suggest that, among some families in this study, the appropriation of ART within these care repositories might be discursively mediated through stories that demonise dead and absent mothers.

GENDERING THE HIV/AIDS EPIDEMIC

Despite the prevalence of estranged and deceased fathers in this study, stories about mothers were significantly more pervasive and tangibly more emotive. Notwithstanding similarly high levels of paternal absence, accusations of reckless negligence always circulated around mothers. This may be because fathers have historically been removed from caregiving contexts, but I expect it is also because mothers are attributed the weight of blame for their child's HIV status. Even "prevention of mother to child transmission" (PMTCT), which is now a default phrase in ART programs across the world, arguably assigns blame to mothers in place of more neutral alternatives like "prevention of vertical transmission" (Young et al. 2011, p.225). At 24.6 percent, the HIV prevalence among young women (age 25–29) is higher than any other population group in South Africa (Department of Health 2011). Women have also been especially targeted by HIV services, with many initiating ART through antenatal care (Cornell et al. 2011, p.628; Mills et al. 2009).

The coupling of higher prevalence and higher clinic attendance makes women the more visible HIV carriers, while also being the most stigmatised. The feminisation of HIV has seen the cultural transgressions and 'excessive' sexual desires of women blamed for both the cause and the spread of HIV (Leclerc-Madlala 2001; Leclerc-Madlala 2002). Similar

maternal blaming is evidenced in other genetic conditions: researchers examining sickle cell disorder in Kenya (Marsh et al. 2011), as well as those exploring kinship and the 'new genetics' in the West (Arribus-Ayllon et al. 2008), have shown that women are apportioned the bulk of blame for the inherited conditions of their children.

Since the early 2000s, research has made us aware of the astonishing misogyny in which South African AIDS stigma is embedded. This situation has largely been depicted as a case of men levelling accusation at women (Campbell et al. 2006, p.134; Denis 2014; Dilger 2003, p.34; Leclerc-Madlala 2001; Leclerc-Madlala 2005). Most recently, Philip Denis' research among support group members in KwaZulu-Natal found that women continue to be seen as vectors of AIDS, impugned for infecting men (Denis 2014, p.290). Many women remained silent about their status, for fear of being abandoned by their male partners (Denis 2014, p.290). In this article, I turn attention to how this misogyny might take expression in underexplored matrifocal spaces.

The Demonisation of Dead and Absent Mothers

In telling us how they came to care for an adolescent with inherited HIV, many families recounted stories of their dead or absent mothers. While this was perhaps foreseeable, more surprising was that families rarely spoke well of missing mothers, even when referring to their own daughters. In their conversations with us, guardians seemed to castigate dead and absent mothers, both to explain the family's current burdens and to present themselves as comparatively praiseworthy. For grandmothers whose daughters had died, anger towards the deceased may have constituted a form of bereavement, in

which the dead are characteristically blamed for being careless, neglecting their health, or abandoning the bereaved (Archer 1999, p.70).

Over time, it appeared that demonising talk about mothers was also being narrated to adolescents themselves. Here, the mythologies constructed around mothers seemed to serve as cautionary tales with an implicit mandate that adolescents not repeat their mothers' mistakes. These stories invoked a notion of 'home' that stretched multiple temporalities, demanding that the social damages of the past be compensated through practices of intergenerational reciprocity in the present.

Of course narratives of maternal loss were imbued with deep pain. This stemmed from the premature death, or persistent absence, of a family member, as well as the weighty inheritance of an orphaned child with a life-threatening condition. Mothers were also not wholly condemned. While learning the mistakes of their mothers, some adolescents were also told that their mothers "loved them" and were ultimately "good." This variance is important, since by conjuring stories of the depravity but fundamental goodness of mothers, families implicitly encourage adolescents to redeem their mothers' memory.

While stories of dead and absent mothers carried both variation and sadness, most dominant in these narratives was the purported recklessness of mothers, whose behaviour was spoken of with regret and at times resentment. Many mothers had been completing school during pregnancy and were considered too young to properly care for their babies. Others were accused of promiscuity and heavy drinking. Most commonly, families spoke of mothers who abandoned their children — fleeing the homestead in pursuit of work, or dropping their child off with relatives only to disappear soon after.

Citing this maternal neglect, Bongani's (age 17) paternal aunt once declared in an interview: "I would never give him [Bongani] away to his mom because she never really looked after him" (5 March, 2014).

Mpho's absent mother was depicted as similarly uncaring and was said to be constantly reneging on her promises to Mpho. In her interview, Mpho's aunt described an occasion when she had run into Mpho's mother in town: "I said, please help your child. You don't have to have money or anything. Maybe you can buy her a packet of 'Simba' chips or go to 'PEP Stores' and get her some 'panties' (underwear) […] just to show that bit of love" (5 March, 2014). But despite promising to be in touch, Mpho's mother never contacted her.

In the few cases in which paternal family were caring for adolescents with lost mothers, accusations of negligence occasionally extended to the maternal lineage. Before moving in with his paternal grandmother and aunt, Xhanti (age 13) had been living with his maternal grandmother, who his current family described as "very cruel" (field notes, 16 October, 2013). One day, Xhanti's mother arrived at the door of his paternal family and asked them to take over Xhanti's care, since her own family was mistreating him and she was still in school. Xhanti's family told us that young Xhanti had arrived at their house "drunk" after being "fed alcohol". He was reportedly so sick they thought he would die (field notes, 16 October, 2013). Through narratives that demonised his maternal relatives, Xhanti's family sought to demonstrate, both to Xhanti himself and to us as researchers, that they were the more capable caregivers. Having been involved in contestations with his maternal kin over the rightful recipients of Xhanti's foster care grant, this performance was very important.

While the full extent of accusations levelled at dead and absent mothers cannot be captured here, the stories told by Nonkosi's (age 17) grandmother are a fairly typical example. Unlike many other instances, tales of Nonkosi's missing mother were not delivered through messy, disparate references over time. Instead, they dominated the only meaningful interactions we ever had with his grandmother.

Nonkosi's grandmother was single-handedly caring for five grandchildren — two on ART. None of her own children lived with her any more, but two of her daughters, including Nonkosi's mother, visited intermittently. During her interview (11 March 2014), Nonkosi's grandmother recounted how sick his mother had been before being diagnosed with HIV. She recalled particularly her difficulties in moving from her bed. Soon after this interview, another of her daughters was hospitalised for tuberculosis (TB).

Reflecting during our first meeting on her family's current circumstances, Nonkosi's grandmother said she blamed her daughters; they should not have had babies outside of wedlock, before they had homes of their own. "They should have followed my example," she said, asserting that she had waited until moving in with her husband before having children (9 March, 2014). It is worth noting that Nonkosi's grandmother was still a teenager when she married. She had been given away to a much older man after a series of pre-arranged agreements between their two families. Despite significant hardship, Nonkosi's grandmother insisted that she "loved her grandchildren" and "would do anything for them, even though their parents did not send any money" (field notes, 9 March, 2014).

Here, Nonkosi's grandmother recounts the burdens of raising five grandchildren and nursing their AIDS-sick mothers. She attributes the families' misfortune to her daughters' inability to follow the example of their elders. Instead, they broke with tradition, having babies outside of marriage without a home in which to raise them. She further referenced her daughters' present-day neglect of their children, saying that they "did not send money." Typically then, these mothers were painted as deviant and reckless — perhaps even as symbols of modernity's moral corruptions.

Nonkosi's grandmother once remarked that all her eight children had been well and healthy, "until Nonkosi's mother got sick" (9 March, 2014). Since then, she had suffered the death of a child and a grandchild. Additionally, another child, along with two grandchildren, had been diagnosed with HIV. While her reflection recounted a chronological sequence of events, it also suggested that Nonkosi's mother might be the catalyst for a series of misfortunes.

One morning (24 March, 2014), we sat in Nonkosi's lounge, waiting for his mother to arrive so that we could transport her to the clinic to collect Nonkosi's medicine. Nonkosi's grandmother busied herself with ironing, while we sat on the couch waiting. As time passed, the grandmother became increasingly upset. She commiserated that Nonkosi's mother "liked men and that's why she behaved like this". "When this sort of thing happens", she went on, "I sometimes call the police." Her grouping of these statements made it unclear whether calling the police was a concerned response to her daughter's disappearance, or (as was suggested by her tone) a criminalisation of her daughter's 'behaviour'.

Immediately after, Nonkosi's grandmother showed us a picture of Nonkosi's younger brother, who she explained had died as an infant. While this sequencing may have been coincidental, it seemed to draw an implied link between the reckless, 'promiscuous' behaviour of Nonkosi's mother and the death of her youngest son. In households like Nonkosi's, where frequent death and illness have been concomitant with changing practices of marriage and childbirth, mothers are perhaps doubly incriminated; not only for the physical transmission of a life-threatening illness, but also for the moral and social offenses that gave way to this calamity.

Like Nonkosi's mother who was accused of breaching marital customs, Ntombi's mother was similarly indicted for having flouted traditional practices. In his interview, Ntombi's uncle relayed Ntombi's struggles since her mother's death as such:

> She [Ntombi] suffered really, a lot, because she doesn't know her father. Ntombi's mother died and never told Ntombi who is her father. She [Ntombi's mother] was drinking, too much drinking. That is why we are not sure who is the father of Ntombi (interview, 21 February, 2014).

Not knowing her father was cited as a problem because, without this knowledge, Ntombi could not be introduced to her patrilineal ancestors, and thus could not be afforded their protection. While the loss of her mother and father each had their own ramifications for Ntombi's personhood, it was Ntombi's mother who was ultimately blamed for the severance of ancestral ties: too reckless to recall the father's identity.

Mothers on ART

In the few cases in which dead or absent mothers had been able to access ART, accounts of their deviance often circulated around their miss-use or neglect of treatment. In the most extreme of these cases, we were told that Mpho's mother had tried to kill Mpho when she was a baby by deliberately overdosing her on ART pills (5 March, 2014). But the most common accounts of mothers' negligent ART-taking were of those who failed to take their own pills properly and had since lost their lives.

Returning from a funeral to meet with us at her house, Nonkosi's grandmother announced: "Every Saturday there are funerals and they are always for young people". She explained that some of these funerals were mourning AIDS deaths — those of young people who had "left their treatment". "Bayadefaulta!" (They are defaulting!), she exclaimed (11 March, 2014). By identifying these dead as "defaulters" who had consciously "left their treatment", Nonkosi's grandmother also seemed to be signalling something disgraceful, even blameworthy, about their deaths. Here, blame comes not from the moral corruptions that have traditionally designated AIDS deaths as shameful, but from an additional moral order assigned by AIDS science. A new kind of 'sinner' is articulated in the scientific language of "defaulter". While the misdemeanour of 'defaulting' might be sufficiently commonplace to have entered common parlance, this did not seem to diminish its derision. In a context of ART access, the offense of defaulting might not only be a case of individual negligence, but also of historical ignorance: the individual fails to show gratitude for newfound treatment, and in doing so, fails her generation. This further demonises mothers who died because they did not

adhere to newly acquired ART and sets a moral mandate for adolescents not to make the same 'ungrateful' mistake.

New Context, Old Patriarchy?

In these homes, where men were largely absent, why might women still impose patriarchal norms, both in their representations of other women and in their imagined vision of 'home'?

Earlier, I described a new domestic terrain in South Africa: the role of adult men in domestic life has declined and marriage has rapidly disintegrated. Meanwhile, ties of female filiation buttress not only the material composition of many households, but also their social fabric. The country's homes are increasingly headed by women and comprised of multiple generations of mothers and their children. Between 1996 and 2001, the number of South African households headed by women rose by more than 10 percent (Odimegwu & Kekovole 2014, p.183). In 2011, 50 percent of homes in the Eastern Cape were female-headed (Statistics South Africa 2014).

Under apartheid migrant labour, absent men were still able to appropriate female-headed households under their name through the circulation of bride wealth (White 2001, p.467). The more recent decline of wage labour has meant that many men can no longer afford bride price, nor can they contribute wages to build the family homestead. As a result, many men no longer have access to the means by which they had historically been incorporated into kinship arrangements. Persistent and deepening unemployment since democracy, combined with an absence of social security for the jobless, has further

eroded possibilities for the archetypal male breadwinner. It seems then that older versions of domestic patriarchy have lost "their fundamental conditions of being" (White 2001, p.467).

One might ask how families have sought to make this emerging matrifocal order workable. And further, why the practice of blaming and demonising women might be reproduced in homes where women are central? Like many other households in South Africa, those under discussion in this article were largely female-headed and men were, for the most part, absent. Women were the primary earners (often as grant recipients). They also took the lead in administrating household income, providing care, and acting as moral authorities.

Yet this matrifocal arrangement had not necessarily been kinder or fairer to women. In the homes considered here, it was perhaps precisely because women carried so much responsibility that they were held so responsible. Their weighty burden of care translated into a heavy moral and social responsibility. Perceived to have failed in their obligations, some dead and absent mothers were considered deserving of harsh recrimination. So, in an increasingly matrifocal order, in which kinship obligations fall most heavily on mothers and matrilineal lineages, women may be especially vulnerable to blame.

In a recent publication, Cecile Jackson (2014) explores the feminisation of kinship under modernity. "Changing gender relations", she argues, "are not linear moves between poles of more or less gender equity" (Jackson 2014, p.21). Instead, they entail incremental reconfigurations over time and across generations. Transformations of gendered power are often uneven and accompanied by changes in the nature of that

power. For Jackson (2014, p.21), this process inevitably "exposes new ways in which old orders may be re-asserted".

Some families in this study have continued to reproduce seemingly patriarchal tropes despite the absence of actual patriarchs. They have done so in ways that often intertwine with gerontocracy, working to bolster the authority of older (mostly female) caregivers. By demonising adolescents' missing mothers, some guardians have sought to position themselves as comparatively praiseworthy.

In other words, through the 'old' misogynistic practice of blaming young women, guardians might seek to make a 'new' matrifocal order practicable, buttressing adult authority and intergenerational respect. Their invocation of 'tradition' or patriarchal values, rather than being viewed as anachronisms, are perhaps best understood as productive and reflective of very contemporary meanings.

In the remainder of this article, I explore how ART became embedded in the practices through which some adolescents and guardians sought to restore and re-imagine the family institution. These families seemed to be simultaneously re-instating and remaking notions of 'home' in the face of significant loss and uncertainty. I will consider how stories about ART were told to attend to maternal loss, encourage adolescent obedience, and foster intergenerational reciprocity. As I hope to show, these familial ART narratives often drew on muddled appropriations of the 'old' and the 'new' as ART was signified to bridge multiple temporalities.

ART AND THE RETHREADING OF FAMILY TIES

In this study, fractures in domestic sociality were articulated as damages to intergenerational reciprocity — for which mothers were often held responsible. Missing mothers, as I have shown, were accused primarily of generational offenses. Most commonly, they were charged with neglecting responsibilities to their children. Some mothers were further chastised for disrespecting their elders and customs: having a child out of wedlock, not introducing their child to her father's ancestors, or engaging in promiscuous sex. Finally, there were those few mothers who, by failing to adhere to ART, might have been considered ungrateful for their generation's unique access to treatment. These demonising narratives relayed a particular temporal circumstance, in which the past transgressions of dead and missing mothers continued to trouble domestic life in the present.

It is not uncommon, either in the Eastern Cape or in South Africa more broadly, for a household's contemporary misfortunes to be read through shortcomings of its ancestral past. In KwaZulu-Natal in particular, anthropologists have documented how the incomplete or inappropriate actions of past relatives are taken up by their kin to be attended to in the present (Henderson 2012; White 2001; White 2010).

Hylton White (2001) relayed the story of a young man, S'Khumbuzo, who had been unable to find work in the city and was thought to be descending into a life of thuggery. S'Khumbuzo's present-day misfortunes were perceived to be linked to those of his estranged migrant elder, who left his rural home to work on the Johannesburg mines, only to be killed and buried in an unmarked grave. In order to attend to the troubles of

the present, which were connected to those of his forefathers, S'Khumbuzo was required to ritually "fetch" the spirit of his elder and bring him home. Throughout White's (2001; 2010) narratives, living relatives serve as proxies for their alienated and estranged dead, "carrying their absent bodies" through the actions that might complete their unfinished work and thereby diminish the inherited burdens of surviving kin (White 2001, p.464).

In line with major themes in White's work, Patti Henderson (2012) has documented how AIDS-orphaned children in KwaZulu-Natal ritually substitute for deceased adults in an attempt to re-inscribe "live-able sociality" within the family. Henderson cites a case in which a young boy and a grandmother stood in for a deceased bride and groom, who had intended to marry before losing their lives to AIDS. In doing so, they not only attended to the incomplete desires of the deceased couple, but also cemented relationships and obligations between the two families, which would bear fruit for surviving kin.

In this study, rather than completing the work of dead mothers, the living may seek to undo or rewrite their mistakes in the present. In White's narratives, one of the obligations of the living is to give peace to their deceased by undoing the causes of their restlessness and distress. Among those in this study, attending to dead and missing mothers was less about respecting the interests of preceding generations. Instead, it was primarily about cleaning up the mess they left behind and potentially refashioning their legacy. Here, adolescents might "carry" their mothers' "absent bodies" through disciplined pill-taking and sanctioned behaviour. Similarly, some adolescents attested to the ways in which grandmothers "became mothers", substituting for failed or absent motherly care:

When I was growing up, I was calling – even now I am calling her [my grandmother] mom. Because I see her. She's the one [...] who is looking after me, and then I call her mom (Siya, age 18, interview in English, 3 September, 2014).

In serving as proxies for dead and absent mothers, both adolescents and their grandparents might seek to reshape space and time — invoking those dead and gone to tackle the mistakes of this missing generation and, in the best cases, strengthen intergenerational ties. I am interested in the appropriation of ART for these rituals of care and home-making.

Undoubtedly, families in this study were invested in the health and futures of their young members and had myriad reasons for supporting ART, particularly as a route to long-term health and a 'normal' adolescent life. In this article, I am interested in only one aspect of how adolescent ART-taking is signified and promoted: That is, how families might inscribe ART as part of a tenuous attempt to reconstitute fragile and fragmented generational ties. And more so, how stories of dead and absent mothers might mediate this work.

Avoiding My Mother's Fate

Our conversations with Wandi (age 19) illustrate one of the ways in which tales of lost mothers might urge adolescents to recall and rewrite their mothers' past mistakes through present-day ART-taking. In her interview, Wandi described the day her aunt told her that her HIV was a maternal inheritance (10 December, 2014). Directly after informing Wandi of her mother's HIV status, Wandi's aunt had told her that her mother drank excessively and had failed to adhere to the pills that would have prevented Wandi from contracting HIV. This was followed by a moral message: "She [my aunt] explained

that my mom did not last long because she did not accept her status. She said if I also don't accept my status, I won't last" (10 December, 2014). When we asked Wandi why she thought her aunt had told her these stories, she said, "My aunt wants me to be strong so that I can stop thinking about this thing about being HIV [positive] and take my medicine" (10 December, 2014).

Here, Wandi's aunt offers a warning to Wandi that she should "accept her status" or risk her mother's fate. Wandi interprets this as an instruction to "be strong" and "take her medicine". In doing so, she might also confront, even rewrite, her mother's mistakes.

While driving with Andile's aunt to Ridgetown, she relayed a similar narrative. We asked whether Andile (age 13) had ever had questions about his mother. "No", his aunt replied, "But he knows about his mother's death. I sometimes tell Andile when he doesn't take his pills that his mom also didn't take her pills and that's why she died" (7 March, 2014).

In these cautionary tales, it was not only the invocation of the dead mother (and her mistakes) that was important, but also the appeal to death itself. By recounting the death of adolescents' mothers, these aunts highlighted the proximity, and thus the real risk, of death. In taking ART, Wandi and Andile might embody their mothers' 'second chance' — to live, to adhere to treatment, and to care for their family. Not the same as a 'fresh start,' a 'second chance' is a do-over, an appeasement, a way of making amends for the deceased.

ART availability, and the ongoing transformation of HIV from a terminal to a chronic illness, was expected to reduce stigma by disentangling associations between HIV and death (Ashforth & Nattrass 2005; Castro & Farmer 2005; Preston-whyte 2003; Steinberg 2008). Yet the findings presented here support other anthropological work in South Africa, which suggests that, even 10 years into ART rollout, the association between AIDS and death remains vehemently stubborn (McNeill & Niehaus 2009; Niehaus 2007). Death, rather than being pushed offstage, has simply occupied new roles.

Not only did persistent, often pejorative, talk of AIDS death serve as a warning for adolescents on treatment, but some who contracted HIV from their now-deceased mothers also continued to confront, incorporate and rewrite the dead through their pill-taking. Rather than associating them with "living corpses", as Isak Niehaus has suggested, ART allowed those in this study to repair the legacy of their dead and strengthen familial ties. This underscores preceding anthropological findings, which suggest that ART enables people to restore life projects, including raising children, affirming kinship ties, and marking themselves as morally legitimate despite the impacts of AIDS (Campbell et al. 2011; Smith & Mbakwem 2010). In doing so, ART users reconstruct their shattered sense of social value. However, this regeneration of social life has been perversely interlaced with the demonisation of missing mothers. Rather than being dissolved, blame and stigma instead take new expression in family stories that signify ART.

Associations between AIDS and death may weaken with time as memories of AIDS deaths become more obscure. For now, pre-ART deaths are not only a very recent memory, but AIDS deaths in South Africa also remain the most prevalent worldwide

(Murray et al. 2014). Arguments that link ART availability to the diminishing prominence of death therefore demand modification or at least qualification.

Mediating Taboos

As I have shown the invocation of deceased mothers in relation to adolescents' ART sometimes served as a cautionary tale. But tales of missing mothers also had other social roles, occasionally mediating sensitive intergenerational conversations about HIV.

Although she had never spoken to Andile directly about his HIV status, Andile's aunt had constructed a narrative to explain to him the origins and purpose of his pill-taking. Andile was told that he had "chest problems", which he inherited from his deceased mother. In fact, as we now know, all Andile knew of his mother was her failure to adhere to ART and her consequent death. Similarly, given that Andile's family did not discuss his HIV status, their only discussions about Andile's pill-taking were of the illness he shared with his deceased mother. Thus, not only was pill-taking one of Andile's only associations with his mother, his mother was also one of his only associations with pill-taking. ART might therefore serve for Andile as a mode of maternal remembrance.

Xhanti (age 13), who was similarly unaware of his HIV status, had been told that he took medication for "heart-ache", which his family presented as a maternal inheritance. During a game that encouraged participants to enact their pill-taking using sweets, we prompted Xhanti to tell us what he thought about before taking his pills each day. Without hesitation, he responded that he thought about his dead mother: "She took pills too — the same ones I am taking." "What else do you know about your mother?" we asked. "I only know this," he responded (field notes, 2 February, 2014).

Both Andile and Xhanti's families were too afraid to speak explicitly with them about HIV or the cause of their mothers' deaths, believing them to be "too young". The supplementary narratives they told served as euphemistic ways to explain adolescents' lifelong illness, without explicit mention of HIV. As such, stories of maternal inheritance mediated, or tempered, traditionally taboo conversations about HIV, helping to maintain the bounds of what they considered appropriate intergenerational talk, and thereby preserve domestic conviviality.

Intergenerational Reciprocity

Below their surface reading, the demonising narratives under discussion in this article function with greater depth and complexity than the simple dictum: 'Take your pills so as not to be like your deviant mother.' Recall that mothers were primarily charged with having damaged intergenerational reciprocity — failing obligations to their children and elders. On many occasions, ART appeared to be discursively imbued to nurture these generational ties.

In line with many of the other charges levelled at missing mothers in this study, Naledi's (age 18) mother was accused, by her grandmother, of having been sexually reckless, abandoning her AIDS-sick child and failing repeatedly on ART. But in her interview, Naledi's grandmother was deliberate in showing us that Naledi was not the same as her mother. She illustrated this with explicit reference to Naledi's ART-taking. "She [Naledi] loves her treatment. She understands. She has learnt. She loves the treatment a lot. It's her mother who is bad at taking treatment. She throws them down the toilet. And that's why she got sick" (interview, 11 September, 2013). Naledi's concerted treatment-

taking was further contextualised amid other examples of her obedience and contributions to homemaking: "She cleans, she cooks, she put in the tiles in the doorway" (interview, 11 September, 2013). Thus, through investments in the homestead, also reflected in diligent ART-taking, Naledi demonstrates that she is not her mother and works to mend the familial wounds related to her mother's scandalous absence.

During a clinic consultation in Ridgetown, Anele's grandmother commiserated Anele's (age 13) recent struggles with pill-taking. She described this to the nurse as an instance of him "not listening to her" (field notes, 2 April, 2014). By implication, ART was imbued as a sign of respect to one's elders. Some adolescents similarly described ART-taking as a way to demonstrate deference towards adult guardians. Xolani (age 11), for example, told us that he "loved" his pills, and when we asked why, he said, "because *Makhulu* (Grandmother) tells me to take them" (field notes, 3 October, 2014).

Conversely, ART support from guardians was sometimes signified as a means of strengthening intergenerational reciprocity. The contrast that Bongani draws between the care of his aunt and that of his absent mother is illuminating here. During afternoon tea one day, we asked Bongani whether he knew his mother (3 April, 2014). He described how she lived in "Area 6" of the township. Sometimes he bumped into her on the street and people would tell him, "That's your mom". At other times, she would call and ask why he did not visit. His reply insisted on reciprocity of care: "I am always busy at school and you don't do anything for me". In contrast to the distant, uncaring, relationship he described with his mother, Bongani later told us that his relationship with his aunt was "good". To support this, he described how his aunt made sure he took his pills on time, sometimes coming to fetch him if he was out late playing (3 April, 2013).

Also citing ART support, and indeed reciprocity, as evidence of "good relationships", Anele (age 13) told us that he had a very good relationship with his grandmother because he made tea for her, and in return, she helped him with his medication (field notes, 7 February, 2014). Similarly, Nina (age 14) said her relationship with her grandmother was good "because she checks whether I have taken my pills" (field notes, 1 February, 2014). Thus, both ART-taking and ART support are signified as reciprocally important in nurturing intergenerational ties. Through ART support, grandmothers like Nina's might be able to redeem their own caregiving — protecting their grandchildren from the calamities that befell their own children.

Among families in this article, narratives that demonised mothers were appropriated to boost ART adherence, just as ART adherence was encouraged to instil obedience and intergenerational care. Appealing to familial relationships to support medication-taking may not be uncommon. Similarly, bolstering familial ties in the wake of maternal abandonment is not specific to families with adolescents on ART. What is novel and notable among families under discussion here is that the tasks of treatment-taking and home-making were often reciprocally intertwined. More interestingly, both seemed to pivot around the story of a mother who was no longer present.

Temporality and the Ritual of ART

Although some families in this study had inscribed on ART-taking a familiar mode of ritual temporality, in which the troubles of the past might be attended to in the present; ART was not a ritual in the ceremonial sense described by Henderson (2012) and White (2001). Instead, it was a ritual in the habitual sense of being ritually practised. It formed

part of domestic rhythms of mutual caregiving and household maintenance — boiling water, baking bread, cooking and cleaning. Through these seemingly mundane domestic rituals, adolescents and their elders practised relatedness and reciprocity. More so, this regimen of ritual activity approximated social order, amid the profound uncertainties and fragilities of home.

The stories relayed by White (2001) and Henderson (2012) explored how pre-existing ritual repertoires were mobilised to attend to new social ills like HIV/AIDS and joblessness. In this study, some families, and more particularly some women, seemed to appropriate the comparatively-new ritualised activity of ART consumption for the re-instantiation of an imagined 'old' order — one of obligation, authority and mutual care. More so, the re-assertion of these values was sometimes articulated in a misogynist idiom, which posited mothers as the source of moral disintegration. ART might therefore work symbolically to bridge three distinct temporalities: the present-day consumption of a new biotechnology, the immediate past of dead and missing mothers, as well as an imagined 'traditional' past, characterised by obedience, discipline and a commitment to the rituals of home. Here, ART is signified as one of the means through which relatedness is practised and constituted as a social reality, attending to the perceived deficiencies of contemporary life.

The appropriation of ART technologies for projects of domestic reproduction might reflect a wider political economy shift in South Africa. In many homes, domestic life is patterned less by wage remittances, and increasingly by the 'stuff' of welfare programmes and development networks. This might include social grant income, state

housing — or in this case pharmaceuticals. Significantly, these development circles are ones in which female affiliations predominate.

LIMITATIONS

This study reflects an isolated moment in a much longer trajectory of chronic medication-taking for these adolescents. It remains unclear whether symbolic confrontations with dead or absent mothers will continue to play such a prominent role in their ART-taking practice, particularly as they grow into adulthood and family relationships change. Drawing tentatively on longitudinal research with diabetic teenagers suggests that adherence to chronic medicine declines over time, alongside parental involvement and family cohesion (Hauser et al. 1990; King et al. 2014). Similarly, as different social groupings or networks of belonging take prominence for adolescents in this study, narratives that situate ART-taking as a family obligation may not be as powerful. This was a small, context-specific sample, recruited predominantly through support groups. It may not be representative of the broader experiences of adolescents on ART. Those who remain in support groups into their adolescents (as the majority in this study had), are perhaps more likely to have families who are also especially involved in their care.

CONCLUSION

The interpretations that these perinatally-infected adolescents and their families bring to ART are distinct from what we know about adult ART users. This is largely due to the position of children and youth within families and the frequent involvement of their

caregivers in administering treatment. Here, ART becomes a vehicle to reproduce household culture — cementing domestic routines, hierarchies and care obligations in contexts of familial insecurity and loss.

Having inherited HIV at birth, perinatally-infected adolescents articulate different meanings onto the virus and its treatment than those who contracted HIV sexually. These meanings must come to terms with their dual position as both 'innocent' and 'shamed' — and thus make sense of their received 'pollution', frequently perceived as a maternal inheritance.

Through familial narratives that demonise adolescents' missing mothers, the 'redemption' narratives typically associated with ART take new form, implying four possible modes of atonement. First, adolescents are compelled to succeed at treatment where their mothers have failed or take pills that their mothers did not have access to. Second, in taking ART, adolescents suppress the HI-virus and thereby gain mastery over their received maternal illness. Third, as ART-taking forms part of ritualised respect shown to one's elders, it also serves as a means to atone the 'deviant' mother through socially-sanctioned behaviour. By demonstrating obedience through ART, adolescents also show gratitude for the care they are now receiving, which, in stark contrast to their mother's purported neglect, has 'saved' them from near-death and granted them a better life. Finally, by promoting ART, grandparents might redeem their own parenting, protecting their grandchildren from the calamity that plagued their lost sons and daughters. By weaving narratives that demonise lost mothers together with ART-taking practice, families in this study have therefore sought to re-inscribe relationships of care, obligation and indebtedness.

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Bureaucracies of Blood and Belonging: what documents tell us about the relationship between HIV-positive youth and the South African state

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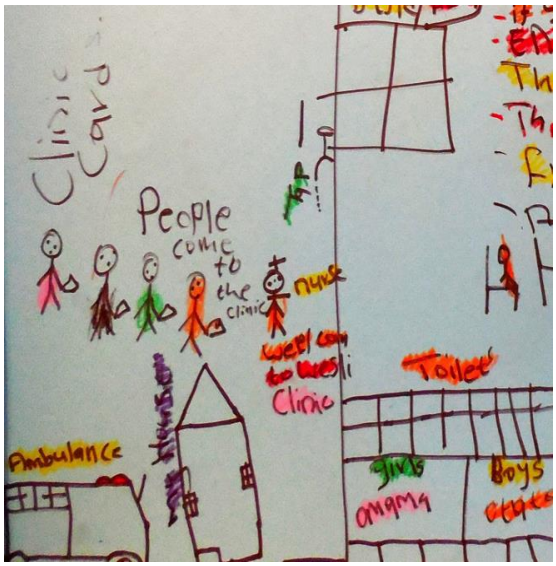

Bureaucracies of Blood and Belonging: what documents tell us about the relationship between HIV-positive youth and the South African state

ABSTRACT

In response to the social welfare imperatives of new democracy, the South African state is increasingly called upon to provide for the life and livelihoods of its citizens. These demands have intensified with escalating joblessness and an HIV/AIDS epidemic. Over the past decade, antiretroviral treatment (ART) has been incorporated into an expansive welfare bureaucracy, in which access to state assistance is mediated by registration, biometrics and medical records. To be brought under bureaucratic governance is also to gain symbolic access to the benefits of liberation. Drawing on eight months of ethnographic research in the Eastern Cape, this article explores how state documents work in the lives of youth on ART to bring them into an ambiguous relationship with the state — one that is at once disciplining and enabling. For some young ART users, negotiating care and recognition in the 'new' South Africa entails a bureaucratically-mediated, dependent relationship with state institutions. The receipt of state protection could produce concomitant feelings of subordination and dignity, scrutiny and safety. Because the health citizenship literature reflexively condemns submissive relationships with the state, the forms of agency, identity and moral connection implicit in such hierarchical participation remain underexplored.

INTRODUCTION

It was mid-November 2013 when I made the slow 50km drive with Thembakazi (age 18) from her rural village in the Eastern Cape province of South Africa to the nearest town, where the hospital is located. Like many others in this study, Thembakazi had been living with HIV since birth. When I met her, it had been nine years since she started taking antiretroviral treatment (ART). On this day, Thembakazi hoped the doctor would refer her for a disability grant: having recently turned 18, she was newly eligible. Mildred, my research assistant, accompanied us on the journey. After collecting Thembakazi from school, we stopped first at the village clinic to collect her medical records and then at the social services office for the grant application forms. Before three o'clock, we were seated in the hospital foyer, clasping Thembakazi's folder and the documents we had collected over the afternoon.

When we were finally called to the nurses' desk, we were told the doctor had left, and then sharply reprimanded for having come to the hospital "so late". I asked what time we should return to secure a doctor's appointment. "It depends", one nurse responded, barely looking up from her paperwork. Exasperated, I persisted: "We don't want to come here again, using time and petrol money, if we aren't going to see a doctor". At this point, I knew very well that many people spent their livelihood money travelling to clinics and hospitals and could not afford to be turned away. "Come by 11 or 12 [o'clock] at least", the nurses replied. This prompted me to raise an auxiliary line of questioning about whether school-goers, like Thembakazi, would be expected to miss class to attend doctor's appointments. But I was quickly silenced by Thembakazi and Mildred and lead out of the hospital doors. I continued to mutter about the barriers to

access, while Thembakazi and Mildred insisted we stop pressing the nurses and resign ourselves to leaving.

Back in the car, Thembakazi explained that by "causing trouble", she risked being punished or refused treatment at her next visit. "But patients should stand up for their rights!" I protested. "You are entitled to this health service. It's [intended] for you!" Over the journey home, Thembakazi and Mildred argued persuasively that rights were privileges for those with "money and power". By confronting state patrons with rights-based claims, the less-fortunate risked losing the few services they had access to.

As a privileged South African, it was far less risky for me to take a rights-claiming position when public services were not delivered as expected. An 'empowered consumer-citizen', I had the "luxury of exit" — able to purchase what the state failed to provide. Those in Thembakazi's position, however, were obliged to expend their resources in order to gain "poor services for poor people" (Robins et al. 2008, p.1074).

Thembakazi's strategic submission to the hospital nurses, which she believed secured her access to essential services, was not uncommon. A few weeks before, another rural family in the study had told us that, in the presence of nurses, they "just keep quiet, otherwise they won't get what they need". This access, they told us, also entailed silently submitting to nurses' punitive reprimands (field notes, 16 October 2013).

These interpersonal interactions reflected a wider phenomenon among participants in this study, in which "getting what you need" (and often what you want) meant negotiating for, and amid, a paternalistic, disciplining relationship with state welfare

institutions. These acts of submission might appear to the liberal mind as disturbing echoes of a paternalist colonial past. The analysis presented here, however, supports arguments that present-day "dependency politics" in South Africa are in fact historically novel, uncovering "very contemporary needs for care, moral connection, and responsible obligation" (Ferguson 2013, p.237).

Discipline and care were often interrelated in the lives of young ART users. In Thembakazi's case, this may initially appear as a straightforward transaction: discipline in exchange for care. But there were also instances in which the distinctions between care and control blurred even further — to the point of mutual dependence. To be more explicit: benevolence and coercion could be two sides of the same coin with variable consequences for young people's experiences of ART care.

This care-control nexus is productively explored through the everyday employment, and deployment, of state documents. As a governance technology, the South African welfare bureaucracy both reflects and reproduces state capacity. As tools for citizens, bureaucratic records make people's needs and entitlements legible to the state, granting inclusion and recognition under its protectorate. The workings of state welfare documents mark a paradoxical encounter between techniques of governance and subject self-making. These ends are often interconnected as bureaucratic power increasingly relies on subjects' consensual participation, and subjects in turn seek bureaucratic signifiers of their personhood.

Our trip to the hospital was illuminating in this respect: we accompanied Thembakazi on visits to both public health and social welfare institutions, watching her navigate the

links between them. Each of these encounters was mediated by documents — folders, application forms, and blood test results. Even Thembakazi's rite of passage into adulthood was marked bureaucratically as her eligibility for social assistance changed.

The same documents that disciplined Thembakazi by setting her daily pill consumption, stipulating her medical appointments, monitoring the virus in her blood, and creating barriers to service access; also served as declarations of membership to a welfare system that enabled her survival. In addition to receiving state-provided HIV treatment, Thembakazi also benefitted from a child dependency grant, and her grandmother from a state pension. These were the only income in her home. Indeed, ART served as an ambivalent form of social incorporation, in which Thembakazi was recognised as a deserving state dependent, an entitled recipient of care, but also an object of discipline and scrutiny. Despite being a non-voting, non-working citizen, living in an isolated rural village, the state had permeated Thembakazi's life and body in extraordinary ways.

This article asks how young ART takers use, and are organised by, state documents as they navigate their relationship with state institutions. It explores how, and why, these adolescents are brought into a bureaucratically mediated, dependent relationship with the state — one that permeates both their everyday lives and their conceptualisation of their place in the world. Importantly, this dependency is not lacking in agency: young people are not automatons in an all-powerful, top-down system of discipline. There is often, as Thembakazi shows us, tactical agency implicit in acts of submission and moments of rebellion amid a system of overwhelming discipline. More so, the agency that participants exercise in their relationship with the state is frequently leveraged precisely off their dependent position.

As an example of post-apartheid state-citizen relations, ART participation has been read both as an empowered claim to democratic entitlements and as a form of patrimonial discipline. Treatment programmes place increasingly strong emphasis on fostering "therapeutic citizens" (Nguyen 2005), who can command AIDS science, profess the revelations of HIV treatment, and espouse empowered HIV-positive identities (Nguyen 2005; Robins 2006; Robins & Von Lieres 2004). Often communicated in the language of self-reliance, ART users are called upon to 'participate' in health delivery as 'responsible' citizens.

But while ART has been described as a project of empowered self-care, an emerging critical literature also recognises ART as a fundamentally disciplining project. This research argues that the production of adherent patients, now central to HIV care, rarely resembles the empowered claim making process so widely celebrated (Cassidy & Leach 2009; Colvin et al. 2010; Mattes 2011; Mfecane 2011; Richey 2012). Instead, clinics exert disciplinary power on ART users through techniques of surveillance and monitoring (Mattes 2011, p.158). Authors argue that 'self-responsibility,' rather than entailing empowered decision-making, often amounts to subjugation to medical authority. To control the escalating numbers of people on ART, patients are co-opted into a set of rigid conditions that determine treatment access and align their behaviour with what is deemed 'appropriate' and 'healthy' (Gagnon et al. 2013; Mattes 2011, p.160). Inclusion and connection to the state therefore rests on a particular performance of the deserving citizen-consumer. Patrimonialism in this context implies a system of social hierarchy in which patrons use state resources to secure the loyalty of 'clients', and for this reason, connections matter. As I discuss later in the article, it may also

intersect with forms of patriarchy (Weber 1978), in which the form of political administration mirrors that of a patriarchal family or household.

Whether citing ART as a site of discipline or empowerment, the literature on ART-participation is accustomed to viewing hierarchical relations with the state as undesirable institutional control. As such, it remains largely incurious about the political strategies, protection and social inclusion that might be implicit in vertical relationships with the state. While social research on ART addresses both the enabling and coercive aspects of treatment-taking, less attention has been given to how these modes of participation might be mutually constitutive: that is, how the same technologies that discipline might also support; how welfare dependencies can entail paradoxical forms of agency; or how the state's ability to control and to 'care for' citizens might, uncomfortably, be reciprocally dependent. To take up ART is to initiate a process of precarious and ambivalent social incorporation, in which agency, recognition, and care are enmeshed with submitting oneself to discipline and censure.

THE STUDY

The analysis presented here draws on eight months of ethnographic fieldwork with 23 HIV-positive youth (age 10–19) in the Eastern Cape. The Eastern Cape is the poorest province in South Africa. Close to 70 per cent of its people are believed to live below the poverty line (Eastern Cape AIDS Council 2012, p.10) and the provincial HIV prevalence (among 15–49 year olds) is 11.6 per cent (Human Sciences Research Council 2014). In 2013, more than 40 per cent of individuals in the Eastern Cape were receiving state grants (Statistics South Africa 2014a). Indeed, every household in our study

benefitted from government social assistance. This article draws on research from two Eastern Cape sites: one rural and one peri-urban. Fieldwork was conducted alongside my research assistant, Mildred Thabeng, who played an invaluable role in data collection and concurrent analysis.

Between August and December 2013, we conducted fieldwork in five rural villages of an Eastern Cape municipality I call *Mtembu*. Mtembu has a population of approximately 72,000 residents. Eighty-five per cent of working-age adults (age 15—64) are not employed (Statistics South Africa 2014b). Among the thirteen Mtembu families we worked with, only one household had a permanently employed member. She worked as a domestic worker in her village, but had lost her job before fieldwork ended. Most of these rural homes survived off a combination of social grants, subsistence farming, and irregular remittances from relatives working in nearby towns or farms.

Peri-urban fieldwork was conducted between January and April 2014 in the peripheral informal settlements of a small town I will give the name *Ridgetown*. With its sprawling informal settlement, Ridgetown has a population of approximately 125 000 people. Sixty-six per cent of working-age residents (age 15–64) in the municipal area are not employed (Statistics South Africa 2014b). Among the nine Ridgetown families we worked with, many adult members struggled to access stable work. Those fortunate enough to find jobs were most-often employed as contract workers on local farms and municipal projects, or as domestic workers.

Adolescent participants for this study were recruited through NGO-run ART support groups, as well as public health clinics. The length of time on ART varied within the

cohort (anywhere from 1–11 years), depending on when the young person was deemed treatment eligible. Given that all adolescent participants were enrolled in HIV treatment services, and in most cases receiving additional NGO support, the sample is likely to have reflected an especially compliant group of young ART users. Recruitment did not reach those who had long fallen out of care. Adolescents receiving inadequate ART support were also under-represented.

Within the research cohort, there was an almost equal distribution of male and female, as well as older (>15 years) and younger (<15 years) adolescents. The few adolescents in this study who had persistent struggles with ART compliance were often older adolescents, who were less subject to the authority of adult guardians.

Fourteen young participants had lost one or more parents to AIDS illness; a further three had parents killed in violent crime; and eight had a parent who was absent[17] or estranged. This explains why most young people in this study were not living with their biological parents, but rather with close relatives. As primary caregivers, female family members were principal grant recipients in participating households, receiving either foster child or child support grants. In addition to childcare assistance, a few youth in our study benefitted from care dependency or disability grants on the basis of their HIV status, with many more hoping to apply. Grandmothers on state pensions were most frequently household heads. Only four adolescents in this study were living with their fathers.

In addition to the ways in which social grants configured household arrangements, families' domestic lives were also orchestrated by public health technologies. Eleven

[17] Here, I am referring to parents who young people see no more than once or twice per year.

young participants lived with at least one other person on ART and many elderly caregivers took diabetes or high blood pressure medication.

Throughout fieldwork, we visited young people and their families regularly, immersing ourselves as far as possible in their everyday lives. Many informal conversations were had while cooking, washing clothes, sharing family meals, taking walks, and playing with friends. This was complemented by more structured research methods, including semi-structured interviews with both youth and guardians. Conversations centred on young people's HIV diagnosis, ART-taking practices, family life and interactions with healthcare. In addition to spending time with participants in their homes and neighbourhoods, we also observed their engagements with ART institutions. Over the course of our fieldwork, we visited nine community clinics and four hospitals, accompanying young people and their families on regular appointments. In addition to observing participants' consultations, we engaged in informal discussions with healthworkers, and in some cases conducted formal interviews.

Fieldwork was carried out using a combination of both English and isiXhosa. Translation occurred in real time to allow for immediate, follow-up probing. These complex in-situ translations have subjectively coloured the data and may have given rise to misinterpretation. Formal interviews were audio-recorded, while informal interviews, observations and ethnographic interactions were documented in field notes. Mildred and I engaged in regular concurrent analysis throughout fieldwork, adapting the data collection to further the development of emerging themes. Data were then thematically coded, comparing and contrasting themes that revealed young people's appropriations of ART care. State documents emerged as important mediators in participants'

experiences and interpretations of ART, illuminating links to the wider welfare system. This article is an attempt to put analytic themes of bureaucratic discipline and bureaucratic recognition into conversation, locating them within a history of welfare provision in South Africa. Ethical approval for this study was granted by the Universities of Oxford and Cape Town, and the Eastern Cape Department of Health, Social Development and Education.

Unless prompted, young people in this study did not regularly reflect on their position as public health users. Like other youth, they preferred to discuss sports, television, relationships and future aspirations. Their 'health citizenship' did not feature prominently in their identities, nor did they want it to. Despite this, I wanted to reflect on what young people made of their position as chronic medication-takers and regular users of ART services. The meanings participants ascribed to the documents and procedures of ART care seemed to transcend ART institutions, speaking to their broader relationships with state welfare. Indeed, young people and their families appeared to use and interpret ART technologies as part of a wider struggle for survival and recognition in democratic South Africa.

WELFARE AND DOCUMENTATION IN SOUTH AFRICA

The South African post-apartheid government delivers public welfare on an unprecedented scale. Most cited are the 16 million citizens benefitting from social grants (Statistics South Africa 2014c, p.20), the 3.1 million homes built since 1994 (African National Congress 2015), and more recently, the estimated 3 million people receiving state-provided antiretroviral treatment (Ramaphosa 2015). As government increasingly

secures legitimacy by "claiming to provide for the wellbeing of the population", so too does "good governance" come to rest on the "efficient management of [people] and things" (Marinetto 2003, p.109). Recording, measuring and tracing the biological data of welfare recipients— from biometrics, to identity documents, to blood counts — is now integral to the bureaucratic identity of the South African state.

Over the past decade, the national rollout of HIV treatment has grown into a bastion of state welfare provision. Public ART has produced a dramatic shift in South African HIV care, from sparse palliative services to a massive programme of chronic illness management. HIV treatment demands extensive bureaucratic and bodily surveillance: first, for the mass monitoring and support of patients' treatment adherence; and second because ART allows more people to live with an asymptomatic virus, which can only be observed through technologies that make visible the body's inner workings. Amid a largely 'invisible' HIV epidemic, scientific instruments analyse the blood of ART users, generating measures that can be made legible for bureaucratic monitoring. These indices not only trace the immunological health of patient populations; they are also the basis for incorporation in the broader welfare project. Blood-based markers are used to assess eligibility for HIV support programmes, ART, and disability grants.

Registration by biological markers, particularly biometrics, has been ubiquitous in South Africa for more than a century (Breckenridge 2005; Breckenridge 2015). Biometric registration served as the foundation of colonial and later apartheid administration, primarily for the regulation of black male labourers. The colonial 'Native Affairs Department' was obsessively preoccupied with biometric registration (Posel 2000), for which male migrants to the sugar plantations, and later the diamond and goal mines,

were primary targets. These registers grew into a detailed matrix of national record-sets, which would culminate in the 1950s Population Register — the core of apartheid racial classification (Szreter & Breckenridge 2012, p.15). Posel (2000) has described the apartheid state as having had a "mania for measurement". This bureaucratic obsession, she argues, characterises modern "governmentality", in which governance is about the "technically expert management of the 'problems of population'" (Posel 2000, p.118).

The apartheid government aspired to a thoroughly engineered society, premised on techno-scientific expertise and elaborate statistical data (Schitzler 2015, p.8). Yet grand imaginings of its own omniscience were in stark contrast to the administrative failures of biometric identification (Edwards & Hecht 2010, p.626). For obvious reasons, many illegal urban residents deliberately eluded state authorities, exhibiting a "reluctance to be counted" (Posel 2000, p.137). The stricter state controls became, the more people were classed as illegal, and the more difficult it was to monitor and police the population. The process of policing therefore entrenched forms of ignorance.

Hence, the apartheid state's knowledge production was partial and selective, working both to disregard and police the non-white population. In combination with the relentless surveillance of black labour and mobility, the apartheid state also adopted forms of deliberate ignorance, particularly with respect to welfare. From as early as the mid-nineteenth century, colonial health interventions were targeted towards the maintenance of labouring bodies, often neglecting the wellbeing of women and children. High rates of black infant mortality, as well as diseases affecting black residents on the 'reserves'[18], were thus largely unattended to. This was attributable, in part, to the fact that 'African'

[18] Territory demarcated by the apartheid government exclusively for black residents, to which many thousands of black people were forcibly deported.

deaths remained unrecorded (Reynolds 2014, p.140). By choosing not to collect certain data, colonial and apartheid governments also systematically excluded some lives from view.

Despite the selective vision of apartheid welfare, the democratically-elected government inherited a fairly well established social security apparatus. Since 1928, white South Africans had been registered for old age pensions, which were extended to black 'Africans' in 1948, and then increasingly deracialised in the lead-up to 1994 (Ferguson 2007, p.77). Nevertheless, democracy marked a dramatic shift in welfare provision. In its first decade, the number of social grant recipients more than quadrupled (Ferguson 2007, p.77).

Despite the country's long history of measurement, it is the democratic state that has been most successful at gathering population data. The successes of post-apartheid registration have been attributed to the ready cooperation of those registered (Szreter & Breckenridge 2012, p.19) — on people consensually giving over their information, and relatedly, the benefits of this bureaucratically signified membership.

Today, those who queue for social assistance, depending on their age, have likely been registered before — perhaps for apartheid labour control or more recently for the first democratic election (Donovan 2013, p.1). For those whose lives had been previously invisible to state bureaucracy, the simple act of being documented might entail a powerful sense of recognition.

Young people in this study are among South Africa's 'born free' generation, having lived their whole lives under a democratic dispensation. Over the course of their lifetimes, they have witnessed the dual expansion of the two largest state welfare programmes in South Africa's history — ART and social grants — and have been key beneficiaries of both. Biometrics once used for surveillance, to keep a firm grip on the population, are now also motivated by the project of redistributive justice, which seeks to deliver basic welfare to the most needy (Breckenridge 2005, p.270). In the post-apartheid context, the Population Register has served as a vehicle for allocating social grants to over a third of the country's populace (Breckenridge 2005, p.15). Traditionally coercive technologies have therefore been increasingly remade as technologies of care, distributing benefits to those they were originally designed to subjugate (Breckenridge 2005, p.15).

SOUTH AFRICA, WELFARE AND THE PATERNALIST STATE

Amid the devolution of the most prominent systems of racial classification, the post-apartheid period has also seen a withdrawal of capital from mass labour-intensive production (White 2012, p.399). The latter has produced extraordinarily high unemployment (Statistics South Africa 2015). After hundreds of years in which chiefs competed for followers, and then employers for labourers, wealth in people has since radically diminished: "People long understood as scarce and valuable, have instead become seen as lacking in value and surplus" (Ferguson 2013, p.231). This has significant implications for personhood since it effectively delinks people from historical forms of social membership, however unequal these might have been.

Along with the changing functions of civil registration — which have seen an amalgamation of technologies of surveillance with those of care — the post-apartheid period has also seen changes in who is registered. While men were disproportionately registered under apartheid pass laws or colonial labour registries, in post-apartheid South Africa it is women who are predominantly registered in their capacity as social grant recipients. Ninety-eight percent of child support beneficiaries are women (Wright et al. 2015, p.1). In 2010, women received 63.9 percent of state pensions (Tessier et al. 2013, p.11). And in 2005, women surpassed men as primary recipients of disability grants (Goldblatt 2009).

Amid deepening unemployment, social assistance frequently replaces labour registration as a means to recognition and resources, making women and children more visible to the state than ever before (White 2012, p.399). Old age pensions and child support grants have brought women and children under new forms of protected dependence. This system of welfare has privileged female-headed domestic arrangements, often with grandmothers as lynchpins (Ferguson 2013, p.231). Similarly, women and children make up the vast majority of patients in public health facilities, and in ART clinics in particular (Cornell et al. 2011, p.828).

Recipients of South African health and welfare — pensioners, children, the disabled, the infirm, and young, reproductive woman — therefore trace a rough "photographic negative" of the "able-bodied male worker" (Ferguson 2013, p.223). In addition to rising unemployment, the recent delinking of men from wage labour has contributed to a decline in South African marriage rates (Ferguson 2013, p.231). In this context, the state arguably occupies the symbolic role of husband or father, substituting for the growing

numbers of men who are disconnected from homes, workplaces and government services (Ferguson 2013, p.235).

To think of the state as husband or father implies a less-mediated relationship with the state, in which the receipt of material assistance functions as a mode of paternalistic inclusion. In the welfare system, this is observable in the regular dispensing of social grants. Families across the country spill into town on grant collection day, joining long queues for the cash machines. 'Grant day' was a celebrated ritual for many of the Ridgetown youth we worked with. On his most recent grant day, Anele (age 13) said he was taken to Kentucky Fried Chicken, after which his grandmother bought him Easter eggs and new school clothes (field notes, 2 April 2014). Similarly, Bongani (age 16) told us that on grant day, he and his siblings were given cooldrinks, potato chips, and Russian sausages (3 April 2014). Siya (age 18) was planning a trip to visit his grandmother based on when her pension would be paid out (field notes, 22 October 2013). Indeed, as Hylton White (2012, p. 418) has observed, "The moments when the state delivers money to its people […] are moments not of humiliation but rather of community and festival". In a context of great insecurity, stemming from illness or unemployment, "the call is for the state to be — if anything — not less but even more involved in the daily life of its subjects" (White 2012, p. 418).

Indeed, some families in our study were attempting to build closer connections to their state patrons. In her bid to skip the clinic queue one morning in Ridgetown (field notes, 13 February 2014), Saki's mother appealed to one of the nurses by pointing out that she and her son shared the nurse's surname. In doing so, she attempted to call upon a family-type obligation, which would entail that she and her son be privileged. Saki's mother

was therefore seeking a less-mediated, personalised relationship with state patrons. In the process, she also imagined state documents as a source of recognition and belonging, in a context in which they might also propel cruel, bureaucratic indifference.

TACTICAL SUBMISSION, QUALIFIED AGENCY

In becoming 'children of the state', families in this study not only enter into a hierarchical relationship with its institutions, but also one of strong social obligation. Indeed, the responsibilities of the paternal state to 'its children' might be so fundamental that they precede rights (Ferguson 2013, p.236). After all, it is well documented that Southern African kinship relations are precisely political relations and key mechanisms for resource allocation (Ferguson 2013, p.236). As I hope to illustrate, ART users occasionally mobilised their position as disciplined dependents to hold state patrons to their obligations, particularly with respect to material provision. Some ART providers were moved to take these claims seriously, despite patients' limited negotiating power and their inescapable dependence on state-provided medicines.

Nurse Hlope's strategy for retaining those HIV-positive patients not yet eligible for ART, in care, is illustrative here: Hlope told us that the only way to keep pre-ART patients returning for six-monthly blood tests was to give them BICO (Vitamin B Complex) and Folic Acid. "Even though the guidelines say this is not necessary", Nurse Hlope told us; she would nevertheless dispense the pills as a means of keeping patients in the system. "They need to feel like they are getting something", she said, "otherwise they come here and they think we are doing nothing for them [emphasis added]" (field notes, 17 March 2014). The success of pre-ART health monitoring was therefore

dependent on whether or not patients perceived a tangible benefit. Those who submitted to regular blood testing were in a position to claim pills precisely because they had acquiesced to surveillance, leveraging care off their subordinate position.

A rural health monitor, who we will call Zethu, once recounted her challenges working with one of the families in our study. Zethu explained that when she first started visiting with the family, they had expected material help in return, preferably in the form of food parcels. The mother of the house was described as "very cheeky", since she would not let Zethu check the family's clinic cards without receiving something in return (interview, 16 October 2013). The mother therefore implied that the family's submission to health monitoring should come with tangible benefits. She used her bureaucratically-signified membership — that is the fact that she was under surveillance — to hold her ART patrons to account.

But just as patients had expectations that the state would "do something" for them, the state also has expectations of its beneficiaries. Where government is primarily viewed as a material benefactor, the positive content of citizenship might increasingly depend on being a rightful and deserving state dependent (Ferguson 2013, p.236). In April 2014, African National Congress (ANC) MEC Meshack Radebe said that those social grant recipients who voted for opposition parties were "stealing from government" (ENCA 2014). In doing so, he also pointed to what he perceived as the implicit obligation of government dependents to 'return the favour' by voting for the ruling party. In an even more explicit image of state as patriarch, Radebe continued: "If you're in the opposition, you are like a person who comes to my house, eats my food and then insults me" (IOL News 2014). This aligns with Weber's (1978) description of patrimonialism — a form

of unequal reciprocity with patriarchy at its heart.

Some suggest a similar, implicit consensus at work in ART care. Dominik Mattes (2011, p.164), for example, describes ART as a "lifelong contract": the patient complies with a treatment regime and collaborates with health professionals, in exchange for biomedical technology that despite being very expensive, is freely provided. Ridgetown nurses sometimes cast patients' non-adherence to medical treatment as a failure to meet their end of this bargain. Here, nurses believed that patients' demand for drugs was not accompanied by appropriate levels of responsibility. The patients "always want drugs, drugs, drugs, drugs", we were told by Nurse Manyi, "and then the ones that are supposed to take them always take the drugs and put them inside the cupboard. […] Open the drawer: it's full of pills!" (field notes, 9 March 2014).

Becoming a recognised state dependent by virtue of one's HIV status comes with more cumbersome conditions than are expected of other welfare recipients. Social grants are largely unconditional and spending is not audited by the state. In contrast, those who take up ART are often compelled to commit themselves to 'living positively'. This includes adhering to treatment, meeting clinic appointments, practicing safer sex, disclosing HIV status and mastering basic AIDS science (Dilger 2012, p.70; Richey 2012). In this study and others (Mattes 2011; Richey 2012), not doing so occasionally provoked castigation or shaming from healthworkers.

Yet, for ART users, an attitude of subordinate compliance could also entail tangible rewards and subtle power. Take for example the act of queuing. The bureaucracy of ART

clinics takes physical instantiation in the lines of disciplined bodies that make up a clinic or hospital queue. Queues are long and the outcomes of queuing are not guaranteed. Queuing, by its very nature, is an act of submission, of waiting, of order — in the hopes of a reward at the end of the line. Yet, as with the possession of a medical document, holding a place in the queue is also to claim one's position as a rightful recipient of care. It is by virtue of acquiescing to the discipline of the queue that this status as 'deserving recipient' is granted.

In Ridgetown, clinic queues started forming from as early as 5am, three hours before the doors of the clinic officially opened. On one such morning, we sat with Saki's mother, waiting for opening time (field notes, 13 February 2014). When we finally gained access to the nurse's consultation room, we were interrupted by a young female patient who came pleading for the nurse's attention. Nurse Mtambo turned to her and said: "These people have been waiting in their car since early this morning for Sister Mtambo. Where were you?"

As it turned out, there had been a subtle power in our submissive, persistent waiting. In this case, 'out-waiting' one's 'opponent' became an important means of appeal. By mentioning that we had been waiting "for Sister Mtambo", Nurse Mtambo highlighted the personal patronage at work. She implicitly congratulated her clients for their patience and discipline. Hence, waiting can be read as a form of due diligence to show respect and recognition towards nurses. The regularly repeated retort, "Why do you come to the clinic so late?" might thus be interpreted as a way for nurses to indicate offense: it is an insult to demand, rather than wait for, care. On a few occasions, we heard patients use the phrase, "I have come to plead for my treatment", precisely so as to emphasise their

subordinate position and thereby bolster their ability to make claims on healthworkers. Through an exploration of the bureaucratic technologies of ART care, the remainder of this article explores how being a disciplined dependent can also bestow adolescents with seemingly paradoxical forms of care, recognition, and agency.

THE BLOOD PANOPTICON

In the bureaucracy of ART care, it is blood counts that make patients visible for monitoring and surveillance. In *Seeing Like a State*, James Scott (1998) develops the concept of "legibility" to refer to the bureaucratic strategies through which governments map their populations, simplifying state functions like taxation and conscription. In the governance of chronic illness, it becomes increasingly important that disease is made legible for monitoring and surveillance. For asymptomatic HIV, the course of the virus is illuminated and charted through readings of the CD4 count and viral load: while CD4 counts track immune cells, viral load measures the amount of HI-virus in the blood. The more viral load drops and CD4 count climbs, the better the patient was perceived to be taking, and responding to, their treatment.

Pill counts and symptom-based diagnoses were also used to assess medication adherence. Yet both caused dispute among healthworkers and ART users in our study, with each accusing the other of manipulation. The science of blood, however, was believed to give definitive proof of patient compliance. Produced by laboratory technologies that examine the blood, CD4 and viral load tests offered "a reading beyond the human eye" (Meinart et al. 2009, p.196). Every year, and sometimes biannually, those on ART should have been called for blood tests. Blood counts were the ultimate

"panopticon" — reading into patients' bodies and making inferences about past behaviour.

Michel Foucault (1979) described Jeremy Bentham's panopticon as the typical architectural structure of a prison, designed to make inmates visible to authorities at all times. Prisoners, conscious of this permanent scrutiny, would be compelled to self-discipline, unaware of whether they were being watched or not. The impending blood test served a similar panoptic function, prompting patients to take their treatment properly or be found out later. Interpreted as retrospective readings of treatment behaviour, blood tests made visible past indiscretions.

The date for the blood test was recorded in a small exercise book, which, across our research sites, was unilaterally referred to as a "passport". The terminology overtly signalled the document as an instrument of surveillance and discipline, embedded in a system of bureaucratic governance. These books contained the handwritten medical records of each patient, and were (as was so regularly enforced by nurses) prefaced by patients' national identity numbers. Instead of being kept at the clinic, these records were brought to and from medical appointments. As such, clinic surveillance penetrated the domestic sphere. Written prescriptions and appointment dates were carried home in "passports" and regularly consulted, as patients became archivists of their interactions with healthcare.

The impending blood test date — recorded in the "passport", taken home, and regularly consulted — served a powerful disciplining function. Despite there being no representative of the state present for pill-taking, the scheduled blood test served as a

constant reminder that ART users were being watched and that their indiscretions would soon be unmasked.

While blood tests are a central feature of the ART surveillance apparatus, they are not always regularly conducted. Only 50 per cent of South Africans on ART receive viral load testing (Motsoaledi 2014). In peri-urban Ridgetown, blood tests were significantly more accessible, and more regularly conducted, than in rural areas. As a result, they played a far greater role in how youth and their families related to ART care.

Young participants in Ridgetown often reflected on their pill-taking with direct reference to blood tests. Mpho (age 13) told us that on the days she decided not to take her pills, she worried that the nurses would "see it in her blood" (field notes, 9 March 2014). Interestingly, Mpho's concern was less about the health implications of the blood result, and more about being 'found out' by the nurses — that her bad behaviour would be revealed in her biology. Similarly, Nonkosi (age 17) said his grandmother would hold up the threat of blood tests to encourage his treatment-taking. He was told that if he did not take his pills, the nurses would "see it in his blood" (field notes, 10 March 2014). Although there was no-one watching when Mpho and Nonkosi missed their medication, the indiscretion was stored in their bodies, to be read later by the disciplining instruments of science. Nurses spoke of patients pre-empting the blood tests. "When they [the patients] are nearing the time to take bloods", they work to "make up" for past behaviour and produce a good test result. "[They'll think], 'my bloods are in May, I'll correct it [my pill-taking] at that time'" (field notes, 6 March 2014).

To speak about how ART surveillance works in the lives of these young participants is not to suggest that the state's performance in these areas has been an unqualified success. The state does fail, patients become lost to the system, and blood counts may not be taken for years. Young people's clinic visits were often limited, with many caregivers collecting medication on their children's behalf. Many rural youth continued to live long distances from the nearest health facility. Given this, it is even more remarkable that the state was able to permeate the lives of so many of our participants. It was often documents that made this possible. Tattered medical records were sometimes the only ongoing instruments of ART care in young people's homes, particularly in rural settings. But the surveillance and monitoring function of these documents only worked if families made them work, and saw the benefit in doing so.

In this respect, there is a vital distinction between Bentham's panopticon and the blood panopticon at work here: while prisoners are never sure if they are being watched, ART users know they are under constant (even if retrospective) scrutiny. Those retained in ART care consent to this watching and willingly participate in it. This agency is attenuated, since the cost of rebelling is to fall ill or die. Nevertheless, the efficacy of the blood panopticon relies on self-directed participation.

The indices of blood tests worked best when they produced patients that imagined themselves in biomedical terms — monitoring their bodies to align with desirable blood results. For those ART users who could not see or feel their illness, blood counts revealed 'how the disease was doing' and 'how they were doing' in managing it (Meinart et al. 2009). Lulama (age 18), for example, had never been sick with AIDS. Blood results served as the only means to access the reality of her illness. Lulama once recalled to us

how ill she had been during her pregnancy (field notes, 14 February 2014). I responded by saying that she looked very healthy now, to which she said, "Can you believe I'm about to die?" "How so?" I asked. "Because my CD4 count is low", she replied. "[It's] just over 200". For Lulama, the blood test revealed something about her fragile existence that could not be externally apprehended. In doing so, it made her illness readable. "I'm trying to improve my CD what what", Lulama told us.

Thembakazi (age 18) reflected similarly on the recent drop in her CD4 count (26 October 2013): "Maybe it's because I had fever [on the day I took the test]. That's why my CD4 dropped. It has dropped lower than that before". She paused and then exclaimed, "Imagine I wasn't on these pills!" As she said this, Thembakazi put her hands to her neck and pretended to choke herself. The implication (and indeed the reality) was that "these pills" were all that was keeping her from death. The CD4 count gave Thembakazi a way of visualising the progression of the virus in her body. For her, the drop in CD4 count signalled both her precarious position – as a chronically insecure, chronic pill-taker — and the life-saving power of ART. By visualising her body through fluctuations in CD4 count, Thembakazi perceived herself to be in a permanently precarious state of health — always able to be healthier, but also in danger of becoming sick. This prompted concerted self-discipline.

Part of the reason why many adolescents in this study submitted to the discipline was because those who did not had already fallen out of the ART system, from which we recruited. It seemed, then, that ART was only for certain people — those willing to participate, and be encompassed in, a programme that ordered and subordinated, but also protected and validated, them. This signals the particularity of my research sample.

There was a world, outside the reaches of discipline and beyond my ethnographic lens, in which adolescents were refusing care, staying away from clinics, dying or already dead.

SURVEILLANCE AS CARE

Of course there were a few young people in the study who missed scheduled clinic appointments, or fell off their ART-taking routine. Yet only two participants were consistently not adhering to ART: one had stopped attending medical appointments altogether. Why might some young ART users consent to, and actively participate in, this system of extraordinary discipline, while others do not? As I have already suggested, one answer might be that their survival depends on it. But given the numbers that drop out of ART, despite these risks, survival is not explanation enough.

Part of the answer, I think, begins with how young people and their families understand the relationship between discipline and care, or more specifically, whether they experience forms of discipline as care. By this I mean not only whether families recognise the material benefits of acquiescing to state discipline, but also whether the moment of discipline is itself received as caring or validating.

To further a conversation about care and discipline, one might consider how Nurse Thulani explained HIV to her patients:

[Imagine] there is this TV [in a house]. Someone is just passing by and [they] see this TV. Then they will come [inside]. [Because] they will know that 'Okay, there is nobody there'. They'll break in the house and take it [the TV] […] Maybe they'll break the

window or the door or whatever. At least then you see [that there has been an intruder]. The people that are passing by will see there's something wrong there. So HIV, when you are sick, it's when it is telling you there is something wrong inside […] (interview, 3 April 2014)

Through the metaphor of HIV as a burglar, Nurse Thulani draws a link between watching and protecting. It is valuable that the people passing by the house could see that something was wrong and mitigate further damage. Their watching served as a form of care. As "the security", CD4 counts watch over the body and protect it from invaders.

Nurse Thulani extended the metaphor to HIV testing, saying:

It's not all the time you can see that something is wrong. People can come here [to the house] and steal the TV. Meanwhile the window is fine, the door is fine. You won't tell up until you get inside [that there has been a robbery]. So you won't tell if you're [HIV] positive or [HIV] negative until you test.

Here, Nurse Thulani locates the value of blood tests in their penetrating gaze. Blood tests make visible the inner workings of the body and, in doing so, offer a form of protection: caring by watching.

This alignment of caring and watching was also reflected in the ways that some adolescents described familial care. Here, some young people cited the act of 'checking up' on pill-taking as a form of positive caregiving. Nonkosi appreciated that his grandmother "guarded him" when he took his pills, describing how she watched him consume his daily dosage (10 March 2014). Bongani recalled affectionately how he and his aunt did weekly pill counts to check that he was taking his pills properly (field notes, 3 April 2014). Reminiscing fondly about her deceased mother, Lisa (age 19) said: "My mom was always someone who knew where I was. Even when I went to play, she looked

where I was playing […]" (interview, 10 December 2014). Conceptions of 'watching as caring' therefore transcended both the home and the clinic space, aligning ART surveillance with modes of paternalistic inclusion.

Where clinic surveillance technologies worked best, they were imbued as interpersonal tools, rather than disembodied bureaucratic instruments. Recall that Mpho and Nonkosi were concerned with the nurses who administered blood tests, just as pill counts served for Bongani as an act of care enacted by his aunt. Discipline and policing formed part of the terms of this personalised care.

Paying attention to these protective, intimate aspects of surveillance might nuance our understanding of ART care beyond the panopticon. Here, Foucault has another conceptual offering in the form of "pastoralism" — a mode of surveillance that pivots on notions of care. Pastoralism is evident in the shepherd who watches his flock. The shepherd's power comes from this watching, just as the safety of his flock depends on his diligent vigilance (in Moore 2011, p.258). While the assemblage of watchers and watching technologies is much more complicated in ART care, with features of both panopticon and pastoralism, the tethering of care, power, and surveillance is certainly a central part of the matrix. Becoming visible to state ART programmes is to step into an ambiguous form of spotlight — one that simultaneously recognises and regulates.

AMBIVALENT RECOGNITION

To illustrate how bureaucratically-signified membership might prompt important forms of recognition, one might look to another example in the South African welfare system

— housing. Millions of government houses have been built since 1994. But there is also widespread dissatisfaction with their construction: first because of their location on the outskirts of cities, removed from social amenities; and second because shoddy building often produces significant health risks. The distribution of housing is bureaucratically managed on the basis of a waiting list. Once a house is handed over, the resident's name is removed from the list and, from the municipalities' perspective, their case is closed. Residents lose an important, bureaucratically signified entitlement and their needs are no longer visible to the state. As a result, the struggles of those in shoddy housing become effectively invisible to government. "Removal from the waiting list, without receipt of houses that they consider tolerable, is akin to dismissal and marginalisation" (Levenson 2014). Here, not being recorded is not only a barrier to entitlements. Rather, it suggests a more profound lack of recognition, in which one's existence becomes invisible, and one's struggles illegitimate.

In one Ridgetown clinic, access to a doctor's appointment was dependent on getting one's name onto a similar list, marshalled by two female healthworkers. I observed one afternoon as they announced to the queue: "You need to make an appointment with the doctor and if you are not on the list you cannot see the doctor" (field notes, 7 March 2014). Two older women in the queue protested that they had made a booking, although their names did not appear on the list. "I don't see your name here", said one of the healthworkers, agitated. "You didn't book. You'll have to book for next time". Without bureaucratic visibility, the claims of the two older women were invalidated.

In many Ridgetown clinics, documents seemed to mediate every point of access. They therefore served as symbols of membership to the institution and its associated entitlements. Bongani's (age 17) description of the pill collection procedure illustrates exchange at each point of service, where the transaction is mediated by documents:

> At the clinic, I retrieve my folder, I ask who the last person in the queue is and join the queue. Then I go into the consultation room and give the nurse my folder and my passport**.** The nurse asks if I am taking my pills properly and I say yes. Then they [the nurses] write on the passport. Then they tell me to go to the pharmacy. I go there, give them the folder. I am told to sign and then the pharmacist tells me which pills to take at which time [all emphases added] (field notes, 3 February 2014).

Xhanti's (age 13) story about a traditional healer (*iqhira*) being turned away from a clinic in rural Mtembu is similarly revealing of how documents serve as gatekeepers to access: Xhanti described an incident in which the iqhira had come to the clinic to "make trouble". When we probed further about the "trouble" he had made, Xhanti explained that the iqhira had come to request medicine for his family, but had been chased away by the nurses. "What do you think about that?" we asked. "I think the nurses were right," he replied, "because he didn't have a clinic card" (field notes, 2 February 2014). Given what is sometimes a fraught relationship between traditional healers and public health institutions, the nurses' refusal to serve the iqhira may have been more complex than this. But for Xhanti, it is the possession of documents that is the ultimate signifier of rightful access. Scribbled with nurses' shorthand, these documents remained largely indecipherable to patients, who nevertheless protected them until they were worn and flimsy.

Yet, if bureaucratic membership served as a way for patients to be seen — to make themselves visible to others — the nature of this visibility was also highly ambivalent and potentially costly. To be seen is also to be exposed. The bureaucracy itself can facilitate this exposure.

While all patients at Ridgetown public health clinics carried "passports", ART patients had an additional folder. Unlike passports, ART folders are kept at the clinic and dispensed on arrival by the clinic data capturer. Much larger than passports, these folders, and the queues to collect them, quickly organised bodies in the clinic, marking out HIV-positive patients. As a consequence, both the folders, and the room in which they were stored, carried immense stigma and obliterated confidentiality.

This was palpable when we arrived with Lulama (age 18) for her clinic appointment (field notes, 13 March 2014). Upon seeing the busy waiting room, Lulama asked that one of us carry her passport and collect her ART folder to signal that she was not the patient. On another occasion, Lulama refused to enter the clinic altogether for fear of the dangerous visibility this entailed. The head nurse at Ridgetown clinic once explained that the extra paperwork required for HIV-positive patients meant healthworkers often perceived them as an extra burden (field notes, 3 April 2014). The folders that mediated patients' HIV care could therefore also attract resentment from those who provided it.

The precarious recognition that participants in this study received through state documents not only had instrumental worth, mediating access to services. It also seemed, for some, to have a profound intrinsic value. In recounting her daughter's death and how she came to care for an orphaned grandchild, Anele's (age 13) grandmother was insistent

on bringing out a box of meticulously compiled documents (interview, 30 January 2014). These included Anele's birth certificate and medical records; his mother's death certificate, identity documents and medical records; and affidavits from the social worker to support his grandmother's application for state child support. It was through this collection of documents that Anele's grandmother narrated the family's history, determined to stick to the chronology of the documents, and handing us paperwork intermittently as a form of illustration. The documents were a record of their existence, their struggle, and their status as worthy state dependents. But the documents themselves had also played an active role in moving their story forward: allowing Anele's grandmother to take him in and opening doors to services and benefits. In some ways, these documents had come to stand in for Anele's dead mother.

Relatedly, some of the young people in our study had been involved in "memory box" programmes, which aimed to attend to parental bereavement by allowing youth to create a memorial to their deceased parents. One of our respondents described what went into the box: "You put your ID, your certificate, your mother's certificate or your mother's what what… Your birth certificate, your mother's died […] certificate […]" (4 September 2013). Here documents offer a profound form of recognition and dignity — a testament to the life of a person.

Siya's story provides another account of how participants reflected, through documents, on their life's chronology. While young men in post-apartheid South Africa have been increasingly detached from wage labour and are largely removed from the social grant system, ritual initiation continues to be an important source of recognition and belonging for male youth, particularly in the rural Eastern Cape. A few months after undergoing a

traditional initiation ceremony, which marked his right of passage into manhood, Siya (age 18) was issued a new medical folder at his local hospital. As we left the waiting room, he kissed the document and exclaimed, "It's new, like me! I am also new. I am a man now!" (field notes, 23 September 2013). The medical document was believed not only to reflect his biological record, but also his social record – his transition to manhood. As such, the document offered a powerful form of recognition. Importantly, it is the document itself that is doing the recognising. It is not in the exchange of surveillance for services, but in being recorded, that Siya feels validated.

Similar forms of social recognition seemed to be at work in the ways that bureaucratic markers were appropriated as symbols of achievement and approval. During a clinic visit with Buhle (age 17) his nurse flicked through his folder. Upon discovering his undetectable viral load, she remarked, "You see kids like that, they give you pride!" (field notes, 12 September 2013). Thembakazi attached great importance to her CD4 count as a site of personal achievement. Excited to show me her medical folder, she was quick to celebrate that her CD4 count was "so high" (23 October 2013). As I hope I have illustrated, these forms of bureaucratic recognition are connected to dependence in important ways: people are being recognised by virtue of being encompassed into a hierarchical order to which they belong (albeit in qualified ways).

There is also ambiguity in this bureaucratic recognition. Documents granted important acknowledgement and approval, but in a way that was often profoundly, and paradoxically, impersonal. Patients could be recognised as documents — as a bureaucratic categories, numbers on a list, or diagnostic results. Hence, while documents could serve as testimonies of membership, through which people compelled the state to

see them, they could also swallow people up in their capacity to simplify and homogenise.

Siya, for example, was occasionally resentful of how documents amalgamated his identity with a population of patients. During one visit to the hospital, when healthworkers were referring to him in the third person as "the patient", he muttered under his breath, "I am not a patient, I am a human being" (field notes, 22 October 2013). Although, on this occasion, his material needs and treatment access had been swiftly addressed, his moral and social needs remained unmet. In instances like these, discipline seemed to become unhinged from care. Rather than being humanly social, Siya's relationship to state patrons was rendered technocratically 'asocial' and impersonal. Relatedly, Hannah Arendt (1970), describes bureaucracy as an engine for "the rule of nobody", which as Michael Herzfeld (1992) suggests, can produce a detached indifference to people.

Some clinic staff also begrudged being viewed as bureaucratic automatons, professing, in their own way, their status as human beings. Responding to patients protesting being sent away from the clinic at closing time, one pharmacist said: "You guys think we don't do anything. We are so tired. It's almost 4 o'clock and we still have to go home and cook. I'm also a mother and have a family that's waiting for me. You think I have nothing to do but be at the clinic" (field notes, 6 March 2014).

How is it that bureaucracies can sometimes recognise and dignify human beings, and at other times make them invisible and inhuman? Being registered in a bureaucracy could grant a person access, entitlement, and validation. It could draw one under the state's protective 'wing'. But by 'belonging', one also risked being 'lost in the crowd'. This was especially so if membership was signified through standardised bureaucratic recording. In order to be acknowledged, cared for, and protected by state patrons, one had to be made visible to them as clients, subordinates or entitled claimants. Bureaucracy made people legible, but it did so in homogenised ways. As a consequence, many found themselves striving and yearning for more personalised, or individualised, relationships with providers. Recall how Siya had celebrated that the receipt of his new clinic folder coincided with his status as a 'new man', thereby signalling something personal about him. Siya was also known to disregard hospital rules by carrying his medical folder to and from appointments. This, he told me, was so that his records did not get lost among those of other patients. He would be 'found' and 'seen' more quickly, and would thus be more able to step out from the crowd.

That the ART bureaucracy could simultaneously recognise and subsume, validate and stigmatise young people, highlights the ambivalence of being incorporated into it. In an earlier article (*Mobilising AID(S)*), I showed that protective, paternalistic relationships with state or NGO patrons could involve real social stakes for young ART users and their families. Adolescents' ability to mobilise HIV-related resources attracted resentment from neighbours, sparked intra-familial tensions, and produced contestations between familial caregivers and NGO careworkers. Similarly, being recognised by the state could make one visible, and vulnerable, in unwanted ways.

Where access to services was not a barrier, young people's retention in ART seemed to depend on how they experienced ART, socially. Being an ART user could entail resentment, exposure or indifference. It was when young people felt recognised by the state that the state-citizen relationship, and indeed discipline, seemed bolstered. Paying attention to bureaucracy in the lives of HIV-positive adolescents situates ART as an ambivalent process of social incorporation, marked by rich and dangerous potential.

CONCLUSION

By exploring how bureaucratic documents operate, and are operationalised, in the lives of youth on ART, this article has sought to complicate the relationship between care and discipline. Many young ART users in this study seemed to enter into their relationship with the state in a position of disciplined submission. Hierarchical dependence also characterised the relationship that some of their families held to the state as welfare recipients. Paternalistic state-citizen relations are particularly pronounced in the context of ART clinics. Unlike in the social grant system, state providers set prescriptions for how their beneficiaries should conduct themselves and concertedly monitor their behaviour. ART surveillance not only orders and categorises bodies in the clinic, but is also brought home in the form of prescriptions, impending blood tests, and clinic return dates.

In the face of these realities, the question seems to be not whether dependent relationships with the state are good or bad. Rather, we might ask what these

relationships tell us about the material and moral needs of those that enter into them. In the process of condemning the subordinating effects of state discipline, the health citizenship literature often misses something important about it: that people consent to, and wilfully participate in it. Of course there is significant duress, given the survival needs of many families in this study. But since retention in ART programmes is by no means a given, the question of why some people submit to state surveillance, while others do not, remains pertinent.

I have shown that state documents serve not only as instruments of surveillance and control, but also as testaments to entitlements, markers of recognition, as well as sources of approval and care. Wilful subordination to the state entailed tactical forms of agency, in which young ART users and their families compelled the state to recognise them as loyal, deserving subjects. While sometimes serving as disembodied governance technologies, state documents were also mobilised as part of a bid for less-mediated relationships with clinic staff.

The system of bureaucratic state dependence was not always stable. There were significant stakes involved in compelling state patrons to see you, including unveiling a stigmatised status. Some also experienced state discipline as purely subjugating and coercive. State documents mediated a precarious and frequently costly process of social incorporation. In the lives of young ART users in this study, there were not neatly demarcated zones in which 'caring' or 'controlling', 'protection' or 'vulnerability' could be discerned. Complicating the neo-Foucauldian literature, discipline and care hung uncomfortably together. A better understanding of how state documents are received

and appropriated by young ART users can inform the future implementation of ART surveillance technologies as mass rollout continues to expand.

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Negotiations of Blame and Care among HIV-positive Mothers and Daughters in South Africa's Eastern Cape

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Negotiations of Blame and Care among HIV-positive Mothers and Daughters in South Africa's Eastern Cape

ABSTRACT

In this article, I explore how some HIV-positive mothers and daughters navigate ubiquitous blame, as it has permeated relationships of care in their homes and clinics. The analysis draws on ethnographic vignettes from four HIV-positive adolescent girls (age 15–19) and their HIV-positive mothers, collected during eight months of Eastern Cape fieldwork. HIV services offered adolescent girls essential care, but many were also impugned in the process of their incorporation. Some risked indictment for their perceived licentiousness and the viral threats they allegedly posed to their babies and male lovers. An adolescent's HIV diagnosis could also implicate their mothers, whether as 'failed' moral authorities or as sources of their children's HIV. Amid seemingly intractable blame, mothers and daughters instead participated in the economy of its distribution. Blame was shifted between generations and genders, between adolescents who contracted the virus sexually and those who inherited it at birth. In the process, bodies became key sites to distribute or shirk opprobrium, exposing or concealing secrets of illness and sexuality. In their attempts to negotiate and distribute blame, mothers and daughters seemed primarily concerned with protecting bonds of care. In both homes and clinics, distinctions between caring for and censuring young women were occasionally rendered opaque. Additionally, by shouldering blame, some adolescent girls sought to protect their mothers' standing, thereby enacting a volatile bid for their care.

Keywords: mothers, HIV/AIDS, transmission, gender, blame, stigma, South Africa, antiretroviral treatment, body.

INTRODUCTION

Over the past decade, antiretroviral therapy (ART) has become increasingly accessible in sub-Saharan Africa, attended by declining HIV/AIDS morbidity and mortality (Todd et al. 2014). As public ART has expanded, many have expected the shame and recrimination of HIV/AIDS to dissipate along with the association between HIV/AIDS and death (Ashforth & Nattrass 2005; Castro & Farmer 2005). Yet studies from sub-Saharan Africa suggest that stigma remains a core feature of the HIV experience (Campbell et al. 2011; Denis 2014; Gilbert & Walker 2010). Indeed, it may even be on the rise, despite prevention and treatment efforts (Maughan-Brown 2010; Roura et al. 2009). My aim in this article is not to account for this persistent reproach, but rather to elucidate the economy of its distribution. How does blame manifest in relationships between patients and nurses, parents and children, men and women? And how do people salvage or petition for care amid seemingly intractable blame? Drawing on eight months of ethnographic research in the Eastern Cape, I examine the case studies of four HIV-positive adolescent girls (age 15–19) and their HIV-positive mothers, charting their frequently inseparable negotiations of blame and care.

Women in the HIV/AIDS Epidemic: Entanglements of Blame and Care

In sub-Saharan Africa, distributions of HIV-related blame remain starkly gendered and generational. Young women are frequently positioned as vectors of AIDS, attributed to

their "contaminating sexual promiscuity" and perceived disavowal of 'traditional' values (Campbell et al. 2006; Denis 2014; Leclerc-Madlala 2001). More so, the burden of South Africa's HIV/AIDS epidemic is conspicuously borne by young women. Almost twice the numbers of women live with HIV than men (Human Sciences Research Council 2014). As a consequence of antenatal screening, women also access HIV services in far greater numbers. In 2011, 60 percent of eligible women were receiving ART, compared to 41 percent of their male counterparts (Cornell 2013). It is therefore predominantly through pregnant women's bodies that HIV diagnoses are produced. More so, epidemiological trends in the epidemic are frequently apprehended through antenatal sentinels. Women's disproportionate presence in HIV services has granted them ambivalent visibility in the HIV/AIDS epidemic. By presenting themselves for HIV care, women compel others to see them – as rightful claimants of essential medicines, as deserving recipients of care, but also as objects of scrutiny and accusation.

Through HIV testing and treatment, women are brought under clinic surveillance in which the boundaries between risk management and blame are often ambivalent. As an example: a common corollary of treatment programmes to decrease the risk of vertical HIV transmission is that mothers are indicted as "disease carriers" (Stevens 2008). This is compounded by experiences of recrimination in clinic spaces. The subtle identification of HIV-positive patients through demarcated clinic queues or medical folders can expose ART users to blame and gossip in the process of accessing care (Okoror et al. 2014; Vale 2016a). In some South African clinics, this is compounded by healthworkers' discriminatory attitudes for which teenage girls are primary targets (Okoror et al. 2014; O'Reilly & Washington 2013).

Perhaps most illustrative of the dialectic between care and blame is the widespread prescription that ART patients disclose their HIV status to others. In doing so, ART users simultaneously enact a bid for care and expose themselves to possible indictment. Many ART programmes in South Africa require patients to disclose their HIV status to at least one person who can serve as a "treatment buddy" (Deacon 2005, p.77; Mills & Maughan-Brown 2009). Because it is largely women enrolled in ART care, the risks and responsibilities of disclosing HIV are frequently gendered. While disclosure can augment familial support, facilitate access to social security, and consequently improve ART adherence (Mills & Maughan-Brown 2009, p.2), it can also be met with condemnation or rejection (Mills & Maughan-Brown 2009, p.2). Even without verbal disclosure, the intake of daily medication can attract interrogation from relatives, friends and lovers (Mills 2008, p.16). Hence, ART itself has powerful, but ambivalent, potential — as a source of healing and hurt.

For many young women then, presenting oneself for care, and getting seen by those who can provide it, entails being brought under a particular kind of spotlight: one that both protects and indicts, sometimes in the same breath. This circumstance, as well as the ways in which young women have sought to mediate it, is the central problematic for this paper.

Bodies and the Categorisation of Adolescent HIV

The opprobrium of HIV/AIDS is often imbued with iconographies of how the virus exhibits physically. Stigma frequently attaches to wasting, scarred bodies (Dago-Akribi & Adjoua 2004; Gilbert & Walker 2010, p.140). The relationship between blame and

bodies also colours the categorisation of adolescent HIV, which distinguishes epidemiological groupings based on their corporeal manifestations. Much of the literature delineates HIV-positive adolescents into two groups (Evans et al. 2013; Ferrand et al. 2012; Li et al. 2010; MacDonell et al. 2013; Nglazi et al. 2012; Petersen et al. 2010): those who contracted the virus at birth (perinatally) and those who contracted it sexually (or horizontally). Each is associated with its own bodily symptoms.

In Southern Africa, most perinatally-infected adolescents would have spent their early years deprived of ART, with lasting physical consequences. Stunted growth and pubertal delay are considered primary indicators of perinatal infection (Lowenthal et al. 2014). As such, the bodies of perinatally-infected youth often betray them to the stigma of HIV (Dago-Akribi & Adjoua 2004), while also giving away their mode of infection. Orphaned adolescents may become associated with the stigma of their mothers' deaths (Cluver et al. 2007), while mothers are especially shamed, or ashamed, for transmitting HIV to their children (Lowenthal et al. 2014, p.11; Vale 2016b).

Having contracted HIV more recently and at a time of greater treatment availability, sexually-infected adolescents are generally healthier than their perinatal counterparts. Their asymptomatic bodies are better able to mask HIV. Not only are sexually-infected adolescents less conspicuous in public, they are also largely invisible in ART programmes, since most are not in immediate need of treatment. Further, research from South Africa reports that, once in care, sexually-infected adolescents have much lower rates of ART retention (Nglazi et al. 2012; Snyder et al. 2014).

PAPER 4: NEGOTIATIONS OF BLAME

The production of HIV knowledge through pregnant bodies reflects in the epidemiological categorisation of adolescent HIV, which is sometimes laced with maternal blame. Now a default phrase in HIV programmes, "mother to child transmission" arguably assigns blame to mothers in contrast to more neutral alternatives like "vertical transmission" (Young et al. 2011). Mothers and motherhood carry similarly important symbolism for sexually-infected adolescents on ART. Because they remain healthier for longer, many do not present in South African HIV clinics until their twenties. That is unless they fall pregnant (Li 2008, p.64). Derisive public discourse around teen pregnancies in South Africa, coupled with the stigma of HIV mean that these young women often initiate prevention of parent to child transmission (PPTCT) as "deviant" mothers (Hodes 2013).

Knowing adolescents' mode of infection has taken on particular valence in the research and practice of adolescent HIV care. These categories are read on the surfaces of pregnant or stunted bodies, and implicated in intimate appropriations of blame and shame.

In what follows, I explore how some mothers and daughters have negotiated pervasive blame as they engage, or disengage, with institutions of ART care. Blame never seemed to dissipate. It could only ever be redistributed — between parents and children, women and men, those who contracted HIV sexually and those who inherited it from their parents.

Among the mothers and daughters under discussion here, bodies became key sites for the negotiation of opprobrium. The parameters within which one could evade or

dismantle categories of blame were often defined by adolescents' bodies, and what they did or did not conceal. Recent anthropological research from Africa explores the centrality of bodies in the making and unmaking of secrets (Hardon & Posel 2012; Kyakuwa & Hardon 2012; Rhine 2014). These authors give particular attention to the ways in which 'unruly bodies' (including those AIDS-sick or pregnant) subvert individuals' will to conceal by giving away secrets of illness or sexuality. Similarly, bodies that appear 'healthy' can disguise interior confidences.

As mothers and daughters engaged in tactics for distributing blame, it appeared that one of their key priorities was to preserve bonds of care. This project was made deeply ambivalent by the fact that structures of care and stigma seemed to rest on very similar scaffolding — as processes for bringing young women to order. Blame and care therefore seemed to serve as interrelated social practices, aimed at maintaining relations of power, authority and respect.

METHODS

The findings presented here form part of a collaborative mixed-methods research project, titled *Mzantsi Wakho* (Your South Africa), which investigates ART adherence and sexual and reproductive health among Eastern Cape adolescents (age 10–19). In 2012, the Eastern Cape's HIV prevalence was estimated at 11.6 percent (Human Sciences Research Council 2014) with 29.1 percent prevalence among its antenatal attendees (Department of Health 2013). My analysis derives from a small ethnographic study, which explores appropriations of ART care among 23 HIV-positive adolescents and their families. Data was collected alongside my research assistant Mildred Thabeng.

Between August and December 2013, we conducted fieldwork in rural villages of an area I call *Mtembu*. Peri-urban fieldwork ran between January and April 2014 in the informal settlements of a small town, dubbed *Ridgetown*.

Adolescent participants were purposively sampled with the intention of varying age and gender, while also incorporating harder-to-reach subgroups. The latter included adolescents infected sexually, those unaware of their HIV status, and those who had defaulted on treatment. The majority of participants were recruited through non-government (NGO) ART support groups. These catered predominantly for younger, perinatally-infected adolescents that had been followed since birth. Clinic-based recruitment helped fill gaps in the sample. Assuming that we were more likely to find older, sexually-infected adolescents in antenatal are, we gleaned the records of Ridgetown and Mtembu health facilities for PPTCT initiates. Not only were there very few adolescents on the roll, but most remained 'too healthy' to initiate lifelong ART.

Only four adolescent participants, all girls, were assumed to have been sexually-infected. I call them Lindiwe (age 15); Koketso (age 18); Yoliswa (age 19) and Nokutula (age 18). These participants are the focus of this article. Lindiwe was recruited through a Ridgetown ART support group that convened a few times annually. She was reportedly among its few sexually-infected members. Koketso was referred by a rural nurse who had initiated her onto PPTCT a few years prior. With her virus still supressed, Koketso was not yet eligible for lifelong ART. Nokutula (age 18) and Yoliswa (age 19) were referred by a Ridgetown clinic and had each started ART while pregnant. When I met them, all four of these adolescent girls were living with their biological mothers, three of whom we also knew to be HIV-positive. All but one lived in households of only

women. Male relatives or boyfriends visited occasionally, but were otherwise entirely absent. Rampant unemployment and declining marriage rates have contributed to the diminishing role of men in South African domestic life (Ferguson 2013, p.231; Walker 1995, p.431). Meanwhile, the mass distribution of state social grants, for which women are primary recipients, has bolstered many female-centred homes across the country (Patel et al. 2012; Walker 2013, p.84).

Throughout fieldwork, we visited participants and their families regularly. Semi-structured interviews were conducted with three of the young women's mothers. These explored mothers' caregiving experiences by tracing their daughters' life histories, including their HIV diagnoses, ART initiation, and present-day pill-taking. The adolescent girls themselves were engaged on a much more regular, but also much less formal basis, with informal conversations taking place over multiple visits. Conversations were had over meals, on the streets, while washing clothes, in the park, and at the beach. To observe their interactions with ART care, we also accompanied participants on regular health appointments. This was complemented by informal and occasionally interview conversations with healthworkers. Research activities were conducted in both English and isiXhosa. Real-time translations allowed for immediate interpretation and follow-up questions. While the researchers conferred regularly about how translations were captured, data have undoubtedly been coloured by subjective readings.

The assumption that these four participants contracted HIV sexually was premised on the stories that they, and their mothers, relayed to us; their having been diagnosed with HIV after a positive pregnancy test; and their healthy bodies which showed no signs of

long-term illness or delayed treatment. These were voluptuous young women who bore little resemblance to the frail, disproportioned and frequently-scarred bodies of perinatally-infected adolescents in the study. My assumptions about how these participants contracted HIV would later unravel. It was in reflecting on this unseating of my own knowledge, and in some ways of the established literature, that I was prompted to explore how each of these adolescent girls made or unmade her HIV narrative.

Each of the adolescent girls under discussion here was involved in a precarious practice of information management. Of course they were becoming accustomed to us as researchers, deciding what to tell and what not to tell us in the process. But in addition to obscuring things from us, these participants were involved in intricate manoeuvres to conceal things from others, including their relatives, healthworkers, partners and neighbours. Concealment did not always entail silence. Sometimes respondents gave voluminous amounts of irrelevant or incorrect detail to appear cooperative without disclosing too much. Their performances varied in different contexts and for different audiences. More so, their bodies were often the vehicles through which knowledge about HIV was made or undone.

Reflecting on her own research with HIV-positive youth in Toronto, Sarah Flicker (2004) writes about how doubting participants' accounts poses a quandary for qualitative health researchers. She posits three possible attitudes researchers might adopt towards incongruent participant narratives: 1) they could exclude the respondent's case entirely, treating the data as untrustworthy; 2) they could tentatively include the inconsistent data, but treat it with scepticism; 3) or they could unreservedly include the respondent's case, premised on the fact that research does not seek truth, but representation. In this paper,

I adopt a fourth option, which is to situate the contradiction at the heart of the analysis. The analysis presented here is an attempt to make sense of layers of incongruity in the hopes of understanding how participants performed, masked, and digested their HIV illness narratives, as well as their purposes in doing so. I argue that for the young women who are the subject of this paper, these acts of telling and concealing might be interpreted as fragile negotiations of blame and care.

These four case studies are not representative of the wider experiences of HIV-positive adolescents. They nevertheless offer insight into the social stakes of young women's ART access. Mzantsi Wakho's extensive ethics protocol was approved by the Universities of Oxford and Cape Town, as well as the South African Department of Health.

GENDERED DISCLOSURE/EXPOSURE

On the day she found out Nokutula was pregnant, Nokutula's mother, Gugs, received a phone call from her eldest daughter who told her that Nokutula had been admitted to hospital. Gugs' eldest daughter lived in a neighbouring town, where Nokutula had been visiting for the weekend. Gugs rushed to the hospital to meet them. When she arrived, the doctor informed her that Nokutula was pregnant and had been admitted due to a complication with the positioning of the foetus (interview, 14 February 2014).

Nokutula recalled to us how embarrassed she had felt when her pregnancy was unveiled to her mother (field notes, 14 February 2014). She believed that, up until this point, her

mother had been totally ignorant of her sex life. To preserve the facade, she had often told her mother she was doing homework, when in fact she was visiting her boyfriend.

In her interview (14 February 2014), Gugs confirmed that she had been shocked at the news of Nokutula's pregnancy. She said Nokutula had later conceded to her that she had known she was pregnant before visiting her sister, but had not told anyone. Gugs recalled Nokutula explaining to her that it was only when she (Nokutula) fell ill, and was taken to the doctor, that her pregnancy was unmasked.

Later, Nokutula gave us a different account to the one she had given her mother (interview, 14 February 2014). She told us that she had taken a pregnancy test at home. Upon discovering she was pregnant, she sent a text message to her boyfriend to tell him the news. Together, they decided that she would get an abortion. This was the real reason she had travelled to see her sister. Nokutula had hoped that her sister would finance the procedure, and that by having it in the neighbouring town, she would be able to keep both the pregnancy and the abortion a secret from her mother.

However, when she visited the doctor, Nokutula was informed that she was already four months pregnant. It was therefore too late to terminate the pregnancy. To keep her sexuality and the pregnancy quiet, Nokutula would have required a compliant body – one that was healthy and operable. Because she could no longer silence her body, she could no longer keep its secrets from her mother.

For all the talk of preventative medicine, it remains the case that when patients present in health facilities, it is most often because their physical symptoms have brought them

there. It is women's pregnant bodies that bring them in disproportionate numbers to South African clinics. While Nokutula had suspected and diagnosed her own pregnancy, in two of the other cases under discussion here, it was mothers who screened their daughters' physical symptoms and sent them for pregnancy tests. Lindiwe's mother noticed that Lindiwe was gaining weight (field notes, 20 August 2013), while Koketso's mother considered Koketso's tooth problems and stomach aches to be signs of pregnancy (field notes, 9 November 2013). Young women's bodies also came under scrutiny from neighbours. Koketso's mother, for example, had heard rumours in the village that her daughter might be pregnant (field notes, 9 November 2013).

Pregnant bodies provoked a particular reading in the context of HIV care. Gurevich and colleagues (2007, p.15) argue that antenatal HIV screening brings the status of women as "containers of wombs" to bear. Yoliswa was told that "the [PPTCT] pills" were "very good" and would "protect her baby" (field notes, 18 February 2014). So, in securing treatment, Yoliswa also came under a particular form of risk surveillance, in which she was held culpable for her baby's protection.

In each of these cases, unwanted physical symptoms surfaced, pulling young women into the clinic, where nurses read their internal bodies and further excavated their confidences. In the process, distinctions between surveillance and care were often opaque, as were the respective roles of mothers, nurses, and neighbours.

Pregnancy and the Uncovering of HIV

When Nokutula was released from hospital, she and Gugs returned to Ridgetown, where Gugs accompanied Nokutula to the clinic for some "stomach checks".

> While they were busy with those [check-ups], they took some blood tests. The sister [nurse] called me in and said, 'Nokutula has something to tell you.' And Nokutula said she was HIV-positive. It was the most painful news ever (interview, 14 February 2014).

Nokutula's story is illustrative in terms of how HIV diagnoses are generated. The stories presented here are not idyllic narratives of empowered health citizenship. Like many others, these young women came to the knowledge of their HIV status incidentally rather than voluntarily. Nokutula's nurse said that, "for the sake of the baby", HIV testing was compulsory (field notes, 14 February 2014). If it had not been for the fact that all four young women underwent a pregnancy test, they were unlikely to have tested for HIV at all. They were dragged into the clinic by their pregnant bodies, which exposed the secrets of their sexuality and took away the option of 'not knowing' their HIV status.

Both Nokutula and Lindiwe's mothers were called into nurses' consultation rooms to receive the news of their daughters' HIV diagnoses (interview, 21 August 2013). The disclosure of these young women to their mothers is therefore more aptly described as exposure, since they had no control over when or how the information escaped. Nurses played an important role in bringing the sexuality of these young women under maternal authority. Calling in mothers was simultaneously an act of concern and discipline, both protective and punitive.

Pregnancy, Exposure and Recrimination

While Gugs had been deliberate in telling us that she had encouraged Nokutula to use contraception long before her pregnancy, Nokutula denied that she had ever talked with her mother about sex until her pregnancy was exposed. If Nokutula's account was true, this would have been interesting in terms of the body's affect: as the surface of the body gives way to latent secrets, so too might previously-silenced, and potentially blaming, conversations be brought into the open.

Similarly, Yoliswa said she had never discussed sex with anyone until her pregnancy. While some of her friends had told her about the contraceptive injection, this had been presented as a way to protect herself from rape (field notes, 18 February 2014). Ironically, it was only after she fell pregnant that neighbours would call out to her in the street, saying that she should have used a condom. When Yoliswa described being pregnant she said: "It was not nice […] I was shy to walk on the street […] I was scared of people […] I thought they would laugh at me" (interview, 8 February 2014). Pregnancy denied Yoliswa the ability to keep her sexuality secret and thereby control how others saw her. In public, she could never forget her body, which made her feel under constant scrutiny. In the presence of a pregnant body — one that lacked discretion — previously hushed conversations were therefore made public, attended by recrimination.

The feeling of exposure, which Nokutula recalled experiencing the moment her pregnancy was unmasked, also characterised more mundane clinic encounters. In mid-March 2013, we accompanied Nokutula on a visit to her local clinic. While sitting in the queue, a counsellor stood up and began to instruct the rows of patients about the importance of HIV testing and how to use a female condom. Two older women, seated

a few places down from us, commented that they did not appreciate these things being spoken about in the clinic. They felt the openness of "this generation" had led to pregnancy and disease. It was the publicity of sex talk then, over and above its content, which was deemed dangerous. And as I have shown, it was occasionally pregnant bodies that provoked public, and shaming, conversations about sex.

In trying to unravel a paradox in South African sexual culture, Jonny Steinberg (2013) investigates the relationship between easy public talk about sex and persistent sexual opprobrium. Drawing on ethnographic vignettes, he explores a world in which sexual intimacies become everyday public topics while being simultaneously shrouded in shame. The publicity of sex likens it to a staged event, but one in which the performer's primary task is to protect her/himself from audience taunting. When Mildred reflected on the sexual education that occurred that day, she described Nokutula as having been visibly uncomfortable, "as though someone was talking about her" (field notes, 13 March 2014). While public health activists have often used frank conversations about sex to tackle HIV stigma (Hardon & Posel 2012), I, like Steinberg (2013), observed another phenomenon at work in HIV clinics. Here, "easy public talk about sex" seemed "tailor made for accusation".

By (involuntarily) enrolling in HIV testing, the four young women under discussion here were offered much-needed access to treatment and care. Yet they also entered a healthcare system animated by blame and humiliating exposure. Becoming visible to state healthcare was to be simultaneously regulated and recognised with impacts for ART enrolment and retention.

BLAME AND THE TERMS OF CARE

To explore this nexus of care and blame further, we might turn to Lindiwe's story. Soon after we first met, I asked Lindiwe's mother Tina how she thought Lindiwe felt about ART. "She doesn't even want to see them [the pills]", she told me. "If you tell her about taking her medicine, she just disappears [from the house]" (interview, 21 August 2013). When I asked how long Lindiwe had not been taking her treatment, Tina's answer stunned me. "It's a year now", she said.

Lindiwe was the only adolescent in our study who appeared to have removed herself entirely from ART care. Healthworkers would traditionally classify her as 'lost to follow up'. Except that Lindiwe was not 'lost'. Her local clinic knew very well where she was and that she was not taking her prescribed medicine.

The Sister in Charge at Lindiwe's clinic once boasted to us about her facility's "clean record": there were reportedly no adolescent defaulters in their system (field notes, 25 October 2013). It was convenient, I thought, that Lindiwe was evidently no longer classified as part of "the system". Less convenient for the clinic's doctrine of treatment adherence was the fact that Lindiwe's decision to remove herself from ART was not having any bodily effects. She had not fallen ill. It seemed that, like patients, clinics were involved in delicate processes of obfuscation to keep uncomfortable knowledge quiet. Lindiwe was a threat both to the clinic's "clean record" and to the diagnoses and recommendations they were generating. The ability of health staff to discipline

Lindiwe's body into treatment-taking and validate their knowledge-making now relied on her illness manifesting physically (field notes 21 October 2013). "Leave her", they told Lindiwe's mother, "she will get sick and realise" (field notes, 2 October 2013).

When I asked Tina why she thought Lindiwe had abandoned her treatment, her response was that her daughter was "in denial". It was familiar terminology, regularly applied to patients that defied medical prescription. The term carries particular valence in South Africa. Dubbed 'AIDS denialists', Thabo Mbeki's government was notorious for questioning the causal link between HIV and AIDS, prevaricating over the efficacy of ART, and delaying the rollout of essential medicines. Embedded in the attribution of 'denialism' is an assertion of irrationality — a failure to accept an uncomfortable truth. But 'denial' also regularly follows accusation. Indeed, Mbeki's 'denial' sought to rebuff what he perceived as an attack on African dignity: an account of AIDS in which Africans were cast as "natural-born, promiscuous germ carriers" (Mbali 2002, p.10). Might Lindiwe's 'denial' also be read as an attempt to shirk blame?

Lindiwe had tested for HIV after a positive pregnancy test at her local clinic. While the pregnancy turned out to be a false alarm, her HIV-positive diagnosis stuck and she was soon initiated onto ART. Initially, Lindiwe had repeatedly assured us of her diligent pill-taking. Months into fieldwork, however, she conceded her disillusionment with her medication. Lindiwe explained that although she "knew" she was HIV-positive, she did not "believe" it (field notes, 20 October 2013). She cited her misdiagnosed pregnancy as indication that the nurses made up lies about her. In Lindiwe's mind, the clinic had not simply made a diagnostic error. They were responsible for a deliberate fabrication. Her misdiagnosed pregnancy, rather than being a faulty scientific reading, was a

personal indictment — a form of malicious gossip. This "HIV thing", she thought, was also a lie.

Neither her pregnancy nor her purported HIV illness had taken physical effect, creating room for Lindiwe to contest the clinic's 'accusatory' knowledge-making. As with the misdiagnosed pregnancy, Lindiwe treated her HIV-positive diagnosis as a hateful rumour, which she said the nurses had spread throughout the village. To re-initiate ART would therefore entail a form of admission — terms that Lindiwe seemed to consider unacceptable.

Lindiwe had not been sick with an AIDS-related illness nor did she need to protect an unborn baby from HIV infection. She had therefore never been in immediate need of ART. For those whose bodies were less forgiving, entry into ART care was a necessity — one coupled with the task of dodging blame.

Telling Men

Because it is often women's reproductive bodies that are brought into clinics for HIV testing, it is also largely women who, after receiving an HIV-positive diagnosis, are faced with the complexities of telling, or not telling, their families and partners. South African research suggests that women are often reluctant to disclose to male partners for fear of abandonment, blame and abuse (Denis 2014). These dilemmas played out in the lives of young women under discussion here. Lindiwe, for example, worried that her boyfriends would leave her if they knew her HIV status (field notes, 14 October 2013).

Because she had not been a virgin when they met, Nokutula believed her boyfriend would blame her for bringing HIV into their relationship (field notes, 11 March 2014). In reflecting on her decision not to disclose to her boyfriend, Nokutula recounted a conversation they had had some time prior. Nokutula's boyfriend had asked whether she would tell him if she knew she was HIV-positive. When Nokutula replied that she would, he laughed. Nokutula recalled feeling uneasy. Her response was to suggest that they both test, but her boyfriend had refused.

Nokutula believed her boyfriend had long suspected that both he, and Nokutula, were HIV-positive. Koketso said the same about her boyfriend. Nevertheless, the burden of broaching this conversation was shifted onto these two young women, placing them at increased risk of blame. "He [my boyfriend] has too much pride", Nokutula told us. "He is expecting me to do all the talking […]" (field notes, 6 April 2014). While the knowledge of their shared HIV status may have been tacitly understood, it was in speaking it that it would become a potential site of blame. Nokutula's proposal that she and her boyfriend test together suggested that the HIV diagnosis itself had power in how blame was apportioned. A shared diagnosis might amount to a more equal attribution of responsibility. Women's reproductive bodies make them more likely to test for HIV and receive care, but also more likely to face recrimination. By having "too much pride", many men avoid the blame that animates testing and treatment. Yet, they also remain undiagnosed and unsupported. Some end up dead.

STIGMA AND TRANSMISSION

As Nokutula's story illustrates, the gendered apportioning of HIV stigma has often blamed women both for the source and the spread of HIV (Denis 2014, p.284). HIV/AIDS has long since gripped the public imagination with theories about its origins and mode of transmission, often infused with the rhetoric of blame (Stadler 2003, p.357). The positioning of women as vectors of disease is one such example. To add to this, the coupling of South Africa's newfound democracy with a deadly virus that killed black people in their numbers provoked distrust of biomedical accounts of HIV. Anti-colonial sentiments positioned HIV/AIDS as a Western invention, used to cast black bodies as perpetually diseased, over-sexed and in need of salvation.

Perhaps the most prevalent non-medical account of HIV in Africa, however, is witchcraft. Witchcraft offers a response to the question, "Why are we suffering?" by transferring blame away from the (potentially immoral) behaviour of victims and onto indeterminate perpetrators. Wholly subscribing to scientific accounts of transmission locates blame more precisely, with the victim themselves, their partner, or their mother. Some suggest that ignorance and misapprehension about HIV transmission perpetuate stigma. Yet the increasing acceptance of biomedical accounts of HIV transmission, which is often demanded in ART enrolment, can also be acutely blaming. In a Ugandan study by Roura and colleagues (2009), the interpretation of HIV as a modern, sexually transmitted disease subjected those living with the virus to greater social sanction than supernaturally-caused ailments.

Among HIV-positive youth in this study, the circulation of blame was similarly propelled by the question, 'How was this virus contracted?' with the answer being either sexually or parent-to-child. As such, medical categories that delineated HIV-positive adolescents by mode of infection became difficult to distinguish from those of blame. More so, ascribing adolescent mode of infection was often determined by how HIV did, or did not, manifest physically, with implications for the relationship between blame and bodies. Lindiwe's relationship with perinatally-infected adolescents in her support group is illustrative here.

Perinatally-infected adolescents in Lindiwe's support group were small and skinny — almost androgynous. Those her age had often suffered severe opportunistic infections, including multi-drug resistant TB, and were left with residual scarring. Others experienced visible lipodystrophy as a side effect of ART. In contrast, Lindiwe's HIV illness could not be readily fixed on her healthy body. While many in her support group had infantile bodies, Lindiwe once celebrated that her thighs and hips made her appear older than her age (field notes 20 October 2013).

Lindiwe was a contentious figure among adolescents in her support group. One of them, Thembakazi, said Lindiwe had "at least 10 boyfriends" (field notes, 16 September 2013). Siya, a young man in the group, told me that when they were both younger, he had a crush on Lindiwe. But after discovering that she was not a virgin, and therefore "not a real girl anymore", his feelings dissipated.

I was struck by how vehemently some perinatally-infected youth seemed to propagate these misogynist norms, stigmatising young women's sexuality. Doing this seemed

particularly important for a young man like Siya, whose frail, scarred and stunted body unsettled his performance of masculinity. Unlike Lindiwe, Siya could not escape external readings of his body as a site of 'physical decay'. In order to maintain dignity, he sought to delineate his own physical 'degeneration' from the 'moral degradation' of adolescents like Lindiwe. In contrast, Lindiwe seemed concerned with preserving her bodily integrity. She expressed that she did not want "people to look down on her" by "treating her like a sick person" (field notes, 14 October 2013). Thus, each of these categories — peri and postnatally-infected — seemed to attract its own stigmas. Blame was tossed back and forth between the two poles of HIV stigma: 'bad sex' and 'bad death/decay'.

A conversation we had with Khaya (age 18), also a perinatally-infected young man in the support group, is another useful example. Reflecting a moralising attitude towards youth sexuality, Khaya remarked that many in his community were having sex "too young", and that consequently, teenage girls were falling pregnant. Khaya worried about how public perception might draw links between HIV and forms of 'deviant' behaviour. "People think HIV is for those who drink and have sexual activity", he said. He was concerned with showing others that he, and people like him, were different: that HIV "doesn't choose" (field notes, 31 January 2014).

Lindiwe said those who teased her for "having boyfriends" were just jealous that "she was in love" (field notes, 4–6 September 2013). This was certainly plausible. While policing the sexuality of others, some perinatally-infected participants expressed a strong desire for sexual partners. But their bodies made them feel unattractive and therefore

sexually limited. Lindiwe's asymptomatic body seemed to defy her illness, allowing her to signify and sexualise her body in ways unavailable to others in her support group. Some nurses were sensitive to how talk of viral transmission could incite blame and thereby dis-incentivise service access. One such nurse, in rural Mtembu, recounted how she counselled patients before an HIV test in attempt to create a non-blaming environment.

> We have to make them relax […] I educate them more about HIV. I tell them how it is transmitted. I tell them that you can get it from birth, from a boyfriend, from using the same needle. So I give examples: I say your brother at home is in a fight, he is stabbed by a knife, and you run to help him and you get covered in his blood, not knowing his status, and you get HIV that way. I give them these examples […] to let them know they can get HIV from anywhere – *not just through sexual activity* [emphasis added] (interview, 15 November 2013).

Here, the nurse implicitly acknowledges that HIV testing is saturated with possibilities for blame. Indeed, to take an HIV test might be read as a form of confession, in which one concedes to the unsafe sexual practices that place one 'at risk' of infection. By listing the many 'innocent' ways in which people might contract HIV, this nurse defuses the shame or accusation that might be associated with a positive result. In the remainder of this article, I consider how these tactics for negotiating and distributing blame manifested in relationships between mothers and daughters.

MOTHERS, DAUGHTERS AND THE TACTICAL DISTRIBUTION OF BLAME

For some HIV-positive mothers, the discovery of their daughter's HIV status seemed to prompt a worry that they might be held culpable. When I asked Lindiwe's mother, Tina,

how she felt upon hearing her daughter's HIV diagnosis, she said: "I felt so bad because I always took her for [HIV] tests. Because I knew that she was born [HIV] negative. So I was quite disappointed in her" (interview, 21 August 2013). Tina thus deemed it important to clarify to us that she was not complicit in Lindiwe's diagnosis. I had no way of knowing whether or not Lindiwe had contracted HIV sexually, but unwittingly, I had taken her body as confirming evidence. Lindiwe looked nothing like the perinatally-infected adolescents in our study, not even those "slow progressors"[19] who had started treatment in primary school. The physicality of Lindiwe's body played an important role in affirming Tina's account of her mode of infection, and thereby absolving Tina of blame.

As a virus transmitted through blood and sex, HIV is invariably relational. It implicates others. Disclosure of HIV is often accompanied by other related disclosures: of sexuality, sexual partners, and in some cases, of a parents' HIV status. Managing information about HIV is often a shared project. In this case, this project is shared between mothers and daughters. And both are involved in its secrets and disclosures. For those young women whose mothers were also living with HIV, the ambiguity of adolescents' mode of transmission prompted delicate negotiations of blame. This is best illustrated in Yoliswa's narrations of her HIV diagnosis.

When Yoliswa first shared the story of her HIV diagnosis, it was during a conversation alongside her mother, aunt and cousin, only a few days after the birth of her baby girl.

[19] This refers to children who survive beyond their first five years without antiretroviral treatment or AIDS symptoms. Thirty-six percent of HIV-positive infants in Southern Africa are estimated to be slow progressors (Ferrand et al., 2009). See Lowenthal et al.'s (2014) research from Zimbabwe and Ferrand et al.'s (2009) Southern African study.

Every member of her household was on ART, including Yoliswa's new-born baby who was receiving Nevirapine to prevent vertical transmission. Yoliswa explained that she had first tested for HIV soon after discovering her pregnancy. Although she disclosed the pregnancy to her mother immediately, she delayed HIV disclosure for months, afraid of her mother's reaction (field notes, 8 February 2014). Later, Yoliswa told us that although she had been receiving the contraceptive injection prior to her pregnancy, she had missed a few appointments (18 February 2013). She further conceded that she had not used condoms prior to her HIV diagnosis. In her narration, then, Yoliswa seemed to suggest that she had contracted HIV sexually. Meanwhile, she also sought to diminish potential blame, professing that no one had ever educated her about sexual risks, and thereby emphasising her naivety.

A month or so later (field notes, 24 March 2014), we accompanied Yoliswa and her baby to a clinic appointment. During the consultation, Yoliswa's nurse reviewed her medical folder. Scanning its pages, she announced that Yoliswa had defaulted on HIV treatment in 2011. This surprised me, since, as far as I knew, Yoliswa had only started HIV treatment in the past year, soon after she fell pregnant. Reading the folder aloud, the nurse narrated that Yoliswa had presented at the clinic three years prior with scabies, shingles and a persistent cough. She was subsequently tested for HIV and initiated onto ART. It was only recently that Yoliswa had re-started treatment. Yoliswa was reportedly re-initiated onto ART at the hospital's antenatal site, where she had tested for HIV, despite already knowing her status.

Yoliswa had therefore represented herself at the antenatal site as an untested and untreated pregnant teenager. She appeared to have done this deliberately as a way to write over her past non-adherence. Recall how Yoliswa had been treated as a newly diagnosed pregnant woman: her body had been approached as an important vessel and treatment was given to her as a means to "protect her baby".

Yoliswa's recorded medical history had since unravelled her secret. After discovering that Yoliswa had been restarted on treatment after defaulting, the nurse's response to her changed to one of mistrust. The knowledge that Yoliswa had previously defaulted became doubly potent in light of her pregnancy. Yoliswa was given a long and stern talk about the importance of taking the pills on time. She was told that if she did not take the pills, the virus would "go high" and she would "be sick", which would "increase her chance of infecting the baby".

The nurse then proceeded to tell the story of another 'deviant' mother who travelled a lot and did not have a stable set of medical records. This was significant since Yoliswa's records were similarly disorganised: her hospital file had evidently not been corroborated with her clinic records until now. In the story of the deviant mother, the patient's multiple medical records provoked suspicion. The nurse insisted on testing the patient, only to find out that "she was positive, breastfeeding, and had also passed the virus to her baby" (field notes, 24 March 2014). Like the mother in the story, Yoliswa's indiscretions were ultimately uncovered.

But what was perhaps more interesting was that Yoliswa was initially successful in her representation, and therefore initially able to escape clinic discipline. In a system of

seemingly omniscient data collection, the separation of tasks between different units of the healthcare system can nevertheless keep certain facts inert. Yoliswa took advantage of this rupture in her records in the hopes of escaping a punitive response to her past non-adherence. The fact that she appeared well, despite having defaulted on treatment almost two years prior, would also have made it possible for Yoliswa to write over this indiscretion.

Indeed, Yoliswa's healthy-looking, pregnant body had confounded my own attempts at knowledge-making. Up until this point, I had believed Yoliswa was sexually-infected. Knowing that she had suffered AIDS-related illnesses years before her pregnancy muddied my assumptions.

During our next visit with Yoliswa, I asked again about the first time she tested for HIV. Revising her story, Yoliswa told me that she had tested for HIV when considering having sex for the first time. She went on to explain that her mother had been HIV-positive while pregnant with her. As a result, Yoliswa had suspected that she herself might have HIV.

Having interviewed Yoliswa's mother about her own pregnancy, it was evident that this had been concealed from us. Since Yoliswa had been born years before HIV treatment became publically available in Ridgetown, it was now apparent that she had most likely been perinatally-infected. Having been born with HIV, I was surprised that Yoliswa had not tested for HIV earlier. There had evidently been a deliberate delay in finding out for

certain whether she had contracted HIV from her mother. The slow onset of Yoliswa's illness, and relatedly her asymptomatic body, made this possible.[20]

As she expanded on this revised story, Yoliswa implicitly refuted the nurse's accusations of recklessness. Contrary to her previous account, Yoliswa said she had tested for HIV before ever having had sex (field notes, 3 April 2014). While the nurse reported that Yoliswa's AIDS symptoms had mandated her first HIV test, Yoliswa claimed to have tested as a responsible precaution. It is significant that, when Yoliswa told this narrative of events, neither her mother, nor any other member of her family, was present. More so, she was telling the story to defend herself against the nurse's accusations and my additional probing. Yoliswa was therefore involved in a delicate and contextually dependent negotiation of blame. In retrospect, she must have been working concertedly, during our initial meeting with her family, to position herself as sexually-infected and thereby protect her mother from potential accusation.

The uncovering of Yoliswa's perinatal infection recalled a conversation with Nokutula a few weeks prior. While sitting together in a clinic queue, Nokutula told us that she and her mother used to collect their medication on the same monthly date. "My mom is also taking pills", she said, "for the same thing that I am taking" (field notes, 7 March 2014). Up until this point, we had not known that Nokutula's mother, Gugs, was HIV-positive. One of the reasons Gugs might have withheld her HIV status from us may have been that this revelation would make it plausible that Nokutula had contracted HIV at birth.

[20] For an expanded discussion of the long-term survival of vertically-infected adolescents in Southern Africa with slow disease progression, see Ferrand et al. 2009.

Nokutula's story gave rise to questions of timing — that is, when particular pieces of information are revealed. Because Nokutula's HIV diagnosis was made through her pregnant body, her mother was able to take a position of compassion, rather than risk indictment herself. After learning Nokutula's HIV status, Nokutula's mother told her that her boyfriend would be the person she "got this [HIV] from" (interview, 14 February 2014). While Nokutula's mode of infection might have remained unknown, Nokutula's physicality allowed her and her mother to appropriate the story of sexual transmission.

These young women's stories complicate a foundational epistemological assumption in adolescent HIV, which has treated categories of vertically and horizontally-infected as knowable and meaningful. Given that systems of HIV care revolve around information, in the form of hard scientific data, delineating adolescent mode of infection (as it turned out) was a surprisingly murky and unstable business. Categorisation often depended on what was or was not disclosed in the stories and bodies of HIV-positive mothers and adolescents. What I, along with the scientific community, was expressing through these categories was not in fact a claim about mode of infection. This often remained unknowable. Instead, what we were referring to was when, and in what state, bodies presented in the clinic.

The way Nokutula disclosed her mother's status might be revealing. That her mother was taking "the same pills" as her could have been Nokutula's only clue to her mother's HIV status. Perhaps she and her mother had never spoken of their shared diagnosis directly, although I suspect there was at least tacit knowledge of this, given that they used to share the same pill collection date (field notes, 7 March 2014). "She takes the same pills I am taking" may also have been a euphemistic way for Nokutula to refer to

her mother's HIV status, while still protecting her mother's reputation through discreet speech.

BLAME AND CARE

Why might young women like Yoliswa and Nokutula have worked so hard to protect their mothers' standing, particularly when it meant putting themselves at increased risk of opprobrium? Nduna and Jewkes' (2011) research among Eastern Cape youth who did not know their fathers suggests that many young people choose silence as a means to contain volatile situations in their home. Discretion demonstrated deference to elders, showed gratitude for care, and protected mothers (in particular) from upset. Similarly, in Lambert and Wood's (2008) Eastern Cape study, knowledge about AIDS was kept tacit to circumvent disrespect. Preserving intergenerational mutuality may have been especially important for Nokutula and Yoliswa, whose children were being cared for by their mothers. By assuming blame, and thereby protecting their mothers from accusation, Yoliswa and Nokutula may have been guarding their mothers' status as household caregivers and moral authorities.

To explore this further, one might look to the story of a grandmother in our study, who was taking ART alongside her orphaned grandchildren. To account for her HIV, she explained that before she had known how HIV transmission worked, she had done her grandchildren's laundry despite having cuts on her hands (field notes, 13 September 2013). This is how she said she contracted HIV. It was a very unlikely story, which would have been refuted in the many HIV education workshops she had attended.

Nevertheless, the narrative preserved her moral integrity and, relatedly, her credibility as a caregiver.

Lindiwe's schoolteacher once commented that Lindiwe "gave her mother a hard time" by disappearing to "visit her boyfriends" (field notes, 16 September 2013). While Lindiwe's disappearances would certainly have worried her mother, there seemed to be more to the teacher's comment: that Lindiwe's actions were inadvertently directed at her mother. More strongly stated, the perceived shame of Lindiwe's sexuality was rooted in how it contaminated the mother-daughter relationship. "People think I love a man and don't love my mother […] People think I don't respect other people", Lindiwe lamented (field notes, 20 October 2013). Respect and deference, it seemed, could nurture mother-daughter care, just as strong relationships between mothers and daughters might bolster young women's respectability.

When Lindiwe's mother found out she was pregnant and HIV-positive, she was reportedly "very rude", threatening to no longer buy things for Lindiwe. But she had also comforted Lindiwe, saying she could "live a long life" (field notes, 4 September 2013). Koketso had been afraid to disclose to her mother and recalled her being "very disappointed" at the news. But, she also described her mother as having been "supportive" (field notes, 9 November 2013). These simultaneous articulations of blame and care are significant. By exonerating themselves from blame, subtly shifting blame to their daughters, mothers might also (paradoxically) be augmenting their ability to care for them.

As in the clinic, 'caring' for young women seemed to be wrapped up with bringing their sexuality to order, and encouraging appropriate respect for elders. Lindiwe's mother, for example, described her 'out of control' sexuality as symptomatic of Lindiwe's generation (field notes, 20 August 2013). Uncomfortably then, boundaries between blame and stigma might blur and merge: AIDS stigma has been characterised as a form of "psychological policing", in which "those who are seen to breach power relations of gender and generation are disciplined and punished" (Campbell et al. 2006). Hence, the apparently opposing orientations of stigma and care become interlaced with a similar social project — one of maintaining the social hierarchies in which many people's relatedness is encompassed.

In a previous paper (Vale 2016b), I explored circulations of blame and care in the households of some perinatally-infected adolescents living without their mothers. Older female relatives invoked moral narratives that discouraged them from repeating the mistakes of their missing mothers, who were demonised for their failed care and reckless sexuality. Adolescents were encouraged to rewrite their mothers' transgressions through good behaviour and deference to elders. Hence, through the demonisation of young women's sexuality, older female relatives sought to re-assert adult authority and enact proper care. Similarly, mothers and daughters in this paper might have been re-instating submission to adult guardians as a means of restoring care. In both cases, guardians worked to preserve their children's innocent victimhood in so far as this did not affect their own standing.

It is worth re-iterating here that these were matrifocal households, in which women were compelled to lead for men who were not on the scene. Blame, it seemed, could not be

erased. It could only be distributed. Among the families narrated here, the tendency was seemingly to distribute blame away from those who had to lead, in order that they could indeed lead.

CONCLUSION

The four young women under discussion here drew comfort from the availability of life-preserving ART, which made it easier for them to accept their HIV status. After she tested positive, Yoliswa said she felt okay "because she knew there was something she could take". But she also worried about broaching the news to her family (interview, 8 February 2014). Enrolling in ART care entailed not only that these young women received much-needed treatment. The terms of this recognition also meant entering into seemingly-inescapable circuits of blame. Blame was shifted precariously between mothers, daughters, lovers and HIV-positive adolescents themselves, animated by imaginings of how the virus was transmitted. Because bodies, clinic data and medical categories were often saturated with stigma, they became key sites to manage or evade recrimination. Yoliswa, for example, used lapses in medical data, as well as her asymptomatic body, to craft a temporary reprieve from health workers' repudiation.

What seemed primarily at stake in these tactical negotiations of blame was the preservation of care between mothers and daughters. Despite the absence of men, familial care appeared nevertheless to be defined in patriarchal terms — enmeshed with the preservation of adult virtue and the censure of young women's sexuality. Consequently, some young women enacted embodied sacrifices, shouldering blame on their mothers' behalf so as to preserve adult respectability and intergenerational

mutuality. Similarly, by protecting their own virtue, and subtly diverting blame to their daughters, some mothers also bolstered their ability to care for them. The censure of young women by older, female authorities also reflected in the relationships between patients and nurses in the ART clinic, where the lines between punishment and protection were sometimes ambivalent. Where blame is enmeshed in the terms of care, young women's ability to access it will remain costly, precarious and highly ambivalent.

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Discussion

The articles in this thesis have elucidated adolescent antiretroviral treatment (ART) as a process of social incorporation. To be a young ART user was not simply to consume medication once or twice daily. It also meant enrolling in, and belonging to, ART clinics, integrating ART into the rituals of home, and, for many in this study, participating in non-state care networks. For these young people, practicing ART meant entering into a set of social relationships with HIV institutions and care providers, learning new ways of imagining, controlling and using their bodies, and appropriating a series of bureaucratic and pharmaceutical technologies into their everyday lives.

Beyond its biomedical properties, ART had real social potency. Just as social relationships had bearing on how ART was practised, so too did ART manufacture sociality in the form of dependencies, obligations, and practices of reciprocity. Indeed, adolescents' ART practice was embedded in relationships of care — implicated in intimate ties within households, in young people's sense of neighbourliness, and in the ways that adolescents imagined their connections to state patrons.

More so, the articles in this thesis locate young people's ART practice amid wider pursuits for survival, recognition and connection in contemporary South Africa. Through ART and its associated programmes, adolescents and their families attempted to strengthen familial ties, connect to powerful patrons, appeal for care, and access basic resources. Yet these pursuits were often volatile, entailing that young people submit to discipline, shoulder blame, confront maternal loss, and contend with resentment. If the

articles in this thesis were to make one unified claim, it would be this: for adolescents in this study, ART was more than an endeavour of empowered self-reliance. It primarily entailed a pursuit of connection and (frequently hierarchical) belonging. It was a route to being recognised, cared for, protected, and included in social institutions, which subordinated adolescents while also taking them under their wing.

Social incorporation, through a lifelong and stigmatised illness, can only be precarious and double-edged. Enrolling in and belonging to ART programmes entailed significant social possibilities as well as dangerous social stakes for youth. At the crux of each article is an attempt to understand how adolescents, often alongside their families, negotiated ART given its ambivalent social consequences. In understanding these negotiations, we might better be able to grasp the fragility and complexities of adolescents' retention in ART programmes.

YOUNG ART USERS AS INSTITUTIONAL ACTORS

Throughout the thesis, institutions were an important analytical focus. Adolescents' ART practice was institutionally nested, often at the interface between household, NGO support group, and clinic. As the first article, *Mobilising AID(S)*, demonstrated, being positioned at the intersection between multiple institutions of care was, for some HIV-positive youth, socially fraught. Adolescents' receipt of care, whether as social grant beneficiaries or support group members, could unsettle established patterns of resource allocation within households, prompting conflicts across generations and among siblings. Guardians and NGO workers occasionally tussled over authority with respect to the adolescents in their care. Further, conspicuous connections to well-resourced HIV

organisations made some young people feel vulnerable to neighbourhood gossip, jealousy, and resentment. Suspecting they had been bewitched, two youths had to contend with profound spiritual insecurity as the moral economies of their HIV/AIDS-related benefactors and their local neighbourhoods collided. For some adolescents in this study, then, mediating between multiple, and sometimes conflicting, care institutions was central to life on ART.

Being a young ART user also implicated symbolic institutions, including those of gender and generation. Mothers and motherhood had significant symbolic force in signifying adolescent ART. *Negotiations of Blame* explored the experiences of the few adolescents in this study who initiated ART through antenatal care. As future mothers, they received mandatory HIV tests and were soon initiated onto treatment to prevent HIV transmission to their babies. In the homes of some adolescents who inherited HIV at birth, ART was narrated through stories of their dead and missing mothers, demanding that adolescents confront and even atone their mothers' transgressions. Youth in this study also pursued and practised care within the confines of their generational positioning. To receive care from elders (whether healthworkers, mothers, guardians or caregivers) often meant respecting, affirming, and even protecting, their authority.

While there were occasionally tensions between young people's support groups, families and clinics, the thesis also highlighted areas of convergence in the institutional cultures that governed adolescent ART. Across NGOs, clinics and homes, older women were primary care providers, acting as moral authorities and regulators of adolescent behaviour. For the most part, the institutions involved in adolescent ART were matrifocal spaces in which young women in particular were censured, and in which

relationships of care were often hierarchical and disciplining.

In line with foundational principles of institutional ethnography, I sought to look up at this complex of institutional relations from the standpoints of HIV-positive adolescents and their families. The aim was to discover how these institutional relations worked such that participants engaged with them as they did. How did young people's ART practice reflect their ways of encountering, working with, or manoeuvring within care institutions?

ADOLESCENT ART, IN CONTEXT

For young people in this study, ART presented a plethora of uncertainties. With much of their lives still ahead of them, these youth had to contemplate lifelong dedication to an arduous treatment regimen on which their health depended. The uncertainties of life on ART were complicated by a fraught and shifting social context. In this study, adolescents and their families signified, mobilised, and practised ART in response to profound social and economic insecurities.

In *Mobilising AID(S)* and *Bureaucracies of Blood*, in particular, I reflected on a national, local, and household context of exceptionally high poverty rates and worsening unemployment. More than a quarter of South Africa's working-age population (15–64 years) is jobless (Statistics South Africa 2015b). Over the last decade, the radical expansion in government social spending has buffered the depth and reach of the country's poverty. Despite this, more than half the population (53.8%) survive on less than R779 per month (Statistics South Africa 2015a). Twenty-one percent of people live

in extreme poverty, unable to pay for their basic nutritional needs (Statistics South Africa 2015a). While the poor are heavily dependent on social grants, most people are not eligible for them. As a result, social-grant income is used to support many beyond its intended beneficiaries.

Those trying to understand life and livelihoods in contemporary South Africa are confronted with the vexing question: 'How do the poor survive?' In her book, *Eating from One Pot*, Sarah Mosoeta (2011) attempts to answer this question, drawing on intensive fieldwork from KwaZulu-Natal. She argues that household survival among the country's poor is desperately fragile, with many homes teetering on the edge of collapse. The articles in this thesis have explored how HIV status, and membership to ART programmes, factor in this politics of survival, given a growing AIDS economy and HIV-targeted social welfare. For some adolescents, enrolling in an ART programme meant connecting to a host of HIV-related resources and networks. Having an 'AIDS orphan' in the family carried particular weight in the local care economy, both among NGO care organisations and state providers. *Mobilising AID(S)* explored the tactical and precarious appropriation of these categories in families' pursuit of social and material resources.

For many people in Mosoeta's study, survival hinged on the ability to share the meagre resources of their families. Yet poverty also eroded solidarity within households, creating fractures along gender and generational lines. Mosoeta observed that it was often the elderly who risked violence and abuse by virtue of their status as pension recipients. In this study, those youth who benefitted from HIV or orphan-targeted care felt vulnerable to resentment and gossip. Their status as grant beneficiaries could also

fuel family contestations, both within and between households. This meant that being incorporated into HIV support programmes was attended by new vulnerabilities.

As in Mosoeta's ethnography, the homes in this study were largely matrifocal. Older women were often the fulcrums on which care and survival turned. Through health facilities, NGO networks and social welfare programmes, women, in their disproportionate numbers, maneuvered for basic medicines, material resources and social membership. But this thesis also highlighted the significant role of HIV-positive youth in negotiating household survival. By mobilising their categorisation as 'orphan', 'HIV-positive' or 'vulnerable youth', some adolescents facilitated and imagined linkages between their own households and centres of power, connecting to support groups, social welfare, and global development programmes.

In addition to gruelling poverty, households in this study had experienced significant societal and familial rupture. AIDS deaths compounded a longer history of loss and separation: for years, young adults in these families had migrated to work in urban centres, while others had been killed in violent crime. Older women played pivotal roles in families' attempts to suture social wounds and inscribe sociality. As *Redeeming Lost Mothers* illustrated, this sometimes involved invocations of an imagined 'traditional' past — one of gerontocracy, restraint, and mutual obligation. Yet, HIV-positive youth were also playing significant roles in negotiating the fragility of their social worlds. Adolescents were working to repair and strengthen sociality in their homes, affirming obligations to their elders and occasionally shouldering blame.

Thus, for many in this study, ART was taken up as part of a volatile struggle for life and livelihoods. In addition to offering a biomedical treatment for HIV, ART was a process of social inclusion through which adolescents enacted precarious bids for attachment, care, and survival.

STIGMA

The articles in this thesis speak to several established tropes in the South African literature on HIV/AIDS, exploring questions of stigma, biosociality, witchcraft, orphanhood, and gender. In each case, I hope to have offered a novel 'generational' lens to these debates — first by investigating how 'old' issues take new form within a contemporary and shifting socio-historical terrain, and second, by exploring their implications for a generation of youth.

Perhaps most strikingly, the articles in this thesis contribute to understandings of stigma in the post-ART era. While many commentators expected stigma to decline with the mass rollout of ART, a growing literature has illustrated the stubborn continuity of stigma and indeed the new stigmas that have attached to HIV treatment itself (Niehaus 2007; Roura et al. 2009). Each of the articles included in this thesis has illustrated the dogged persistence of stigma, which, in the lives of families in this study, never seemed to dissipate. It could only ever be redistributed, redefined and redirected. This was part of the work entailed in living with ART. More so, stigma was often encased in the terms of care.

In the article, *Bureaucracies of Blood*, I illustrated the entanglements of care, recognition

and agency, on the one hand, with scrutiny, policing and submission on the other. To be surveyed by, and hierarchically dependent on the state entailed important forms of recognition, care and agency. Yet these also rested on subordination, punitive discipline, exposure, and sometimes (paradoxical) indifference.

The uncomfortable dialectic between care and blame was also highlighted in the second article, *Redeeming Lost Mothers*, in which the blaming of dead and absent mothers served as a pretext for nurturing intergenerational mutuality, respect and obligation. By holding up the stories of missing mothers as moral lessons or threats, some guardians sought to promote ART as a practice of care and deference.

In the fourth article of this thesis, I showed that some HIV-positive young women were susceptible to stigma in the very process of accessing care. It was because they were disproportionately drawn into ART programmes that these young women were also especially burdened with the task of *Negotiating Blame*. As a consequence of their HIV status being disclosed or exposed, these young women received much needed care. Yet, as their HIV status was revealed, some were also impugned for bringing HIV into their romantic relationships, censured by their mothers, or humiliated by their nurses. Opprobrium was often shifted to, and shouldered by, young women. The appearance of adolescents' bodies, whether pregnant or sickly, could attract recrimination and blame. Conversely, an asymptomatic body could hide potentially shameful secrets, related to adolescents' mode of infection, their past non-adherence, their sexuality, or their HIV status.

In both of the above articles, the shape and experience of stigma was linked to

adolescents' generational position within families. The redirection of opprobrium served to bolster the authority of living, adult caregivers and thereby strengthen intergenerational care, defined in terms of respect and deference. In *Negotiations of Blame*, the shouldering of stigma by young women served to protect gender and generational authority. But it could also (paradoxically) augment the ability of older women to care for young girls. In *Redeeming Lost Mothers*, shifting stigma onto adolescents' missing mothers served to signify ART as a project of social suture, and position living adult guardians as comparatively praiseworthy.

Old Tropes, New Context

While HIV/AIDS stigma remains persistent, its shape and form are also in flux as the epidemic changes. The economy of AIDS stigma is attuned to the HIV/AIDS response itself. As *Negotiations of Blame* and *Mobilising AID(S)* suggest, skewed access to the pharmaceutical, social and economic resources of AIDS interventions can attract blame and resentment to beneficiaries — young women and HIV-positive youth in particular. In the context of a mushrooming HIV/AIDS industry and grave poverty, the ability of some HIV-positive youth to access HIV-targeted resources provoked tension in their families and neighbourhoods. Here, stigma attached not to the virus itself, but rather to the disproportionate attention HIV status attracted from potential patrons and providers.

But while the widespread provision of HIV services, particularly to women and youth, can have unintended consequences for stigma, so too does an era of inevitable AIDS death continue to haunt the present. In *Mobilising AIDS*, I showed how deceased parents could continue to 'provide' for their descendants through foster child grants. Some families had ongoing linkages to the NGO support networks that had cared for

adolescents' now-deceased parents. As *Redeeming Lost Mothers* illustrated, the deceased could also pervade the present in more symbolic ways. By weaving narratives to promote ART with moral lessons about deceased mothers, some families imbued ART as a way to remember, confront and make amends for the dead. In some homes, ART targeted two aspects of the deceased mother's legacy — the inherited HIV illness of her child and the social ruptures purportedly caused by maternal loss. The very new technologies of the present were signified to grapple with the inherited misfortunes of the past. In this respect, the association between HIV/AIDS and death persisted despite, and even through, ART. This association is particularly potent for HIV-positive youth in this study, many of whom live with a virus inherited from their deceased parents. In more ways than one, these adolescents become extensions — in time — of their parents' legacy.

The enduring association between HIV/AIDS and death is one example of how old thematic tropes in the epidemic continue to have salience, if new form, in the post-ART era. Similarly, *Mobilising AID(S)* discussed some adolescents' worries about bewitchment while making a life with HIV. From the early years of the South African epidemic, witchcraft discourses have been appropriated as a way to make 'social sense' of HIV/AIDS (Ashforth 2002). In *Mobilising AID(S)*, I explored the narratives of two HIV-positive youth who felt vulnerable to witchcraft. Their summation that they had been bewitched was not due to their HIV status per se. Instead, they perceived themselves to be particularly vulnerable to jealousy, given their ability to survive and thrive in spite of (and occasionally using) their HIV status. In Africa, anxieties about witchcraft have long been associated with distributions of power and resources, in

contexts of dire poverty and inequality. The resources that circulate around HIV add new complexity to this social milieu, with the potential to fuel politics of resentment.

The dynamism of witchcraft discourses is now widely acknowledged. Notions of witchcraft are constantly being reformulated and recreated — responsive to modernity's shifting social tensions. In this study, young people's narratives about witchcraft were located in a very recent social circumstance: while poverty has remained critical and widespread, the HIV care industry has flourished, creating new avenues for those living with the virus to access much-needed social and material resources. In this context, established associations between witchcraft, HIV and 'jealousy among neighbours' might take new form. Anthropologists documenting witchcraft in Africa have referred to the "modernity of witchcraft" (Geschiere & Roitman 1997). In doing so, they affirm that this so-called 'traditional' practice, rather than being an anachronism, is in fact reflective and productive of contemporary and highly modern meanings.

BIOSOCIALITY

From early on in the HIV/AIDS epidemic, researchers have sought to explore the socialities and identities attached to HIV, and later, their implications for life on ART. Much has been written about the new biosocialities attached to HIV treatment — whether conceived as rights-driven citizenship or submissive clientship. Furthering this work, the articles in this thesis have reflected on the forms of sociality associated with adolescent ART. They have shown that social relations are fundamental to the achievement of everyday ART. These have involved proximity, reciprocity, expectation and obligation. The biosociality literature has explored how ART users negotiate their

rights, responsibilities and relationships *vis-à-vis* state and donor programmes. Many document how ART users have mobilised their bio-status to make material and political claims. Similarly, in their efforts to *Mobilise AID(S)*, some adolescents in this study utilised their categorisation as 'orphan' or 'HIV-positive' or 'vulnerable youth' to garner resources.

Yet, for the most part, adolescents in this study were not in pursuit of 'responsibilised' autonomy. Instead, they were in search of connection and belonging. For many adolescents, to belong meant to be encompassed into social hierarchies (whether familial, institutional or imagined) that protected, cared for, and recognised their members. So, in contrast to the valorisation of self-reliance and independence, which characterises so many health and development interventions,[21] youth in this study were involved in creating and using networks (which were often hierarchical) to secure both moral and material support.

Sometimes establishing these connections entailed performances of the 'empowered' health citizen. Yet, the purpose was not to foster solidarity among ART users in order to lobby powerful patrons. The biosociality of adolescents in this study often reached for dependence and paternalism. In *Mobilising AID(S)*, for example, adolescents' pursuit of survival, as well as their imagined connection to democratic modernity, entailed connecting to well-resourced outsiders. This was sometimes at the expense of social solidarity within their families and neighbours. Rather than subverting authority, these youth were frequently appealing to it. Even in their homes, some adolescents in this

[21] For a fuller discussion on how this 'ethics of hierarchical interdependence' differs from the prioritisation of self-sufficiency, as typified by so many development programmes, see the first chapter of China Scherze's (2014) book, 'Having People, Having Heart'.

study worked to protect a form of sociality that rested on obedience, discipline and intergenerational respect.

Because the biosociality literature has been largely disparaging of hierarchical and patrimonial relationships within HIV/AIDS institutions, these relationships are rarely interrogated. The forms of moral connection, agency, or care embedded in them remain largely un-investigated. In this study, the 'biosociality' entailed in adolescents' ART participation was often submissive and disciplined. Young people's connection to state patrons, as well as their receipt of health and social care, was sometimes interlaced with surveillance, blame and submission to older, female caregivers. But these relationships were also consensual, wilful, and embedded with subtle power.

Indeed, across the articles in this study, adolescents and their families exhibited a tactical mastery, appropriating institutional technologies for their own ends. In order to *Mobilise AID(S)*, some young people and their families became adept at performing their need in a way that resonated with prospective patrons, playing up their dependence. Achieving care under volatile circumstances meant leveraging personal connections, learning institutional terminology, appropriating documents, enacting performances of need, and using or suppressing one's body. Dependence was a "mode of action" (Ferguson 2013, p.226) — a form of submission that paradoxically required putting oneself forward as a subject.

As with witchcraft, there is a risk in treating these social practices as instances of 'tradition'. These "aspirations to dependence" might appear to many liberal thinkers as worrying resonances of a paternalist colonial history (Ferguson 2013). But, as

Bureaucracies of Blood showed, these relationships were in fact historically novel. As wage labour has declined in South Africa, social membership through personalistic and dependent relations with employers has also eroded. In a context of joblessness and social exclusion, the pursuit of hierarchical affiliations uncovers families' pressing and very contemporary needs for moral connection, care and obligation (Ferguson 2013, p.237). More so, the incorporation of women and children into these hierarchical systems is historically novel and has been propelled by grand-scale social welfare.

In many ART clinics, values of discipline and obedience have been propagated in an effort to produce the 'self-reliant' ART user. The article, *Redeeming Lost Mothers*, explored how these institutional discourses were re-appropriated in some adolescents' homes — not for the purposes of 'responsiblised' independence, but precisely for building connection. Young people's disciplined ART-taking was imbued as a practice of relatedness, affirming mutual obligation and deference to adult authorities. Here, adolescent ART was signified not simply as a process of self-making, but also for the purposes of home-making. The bio-social potential of ART in homes and families is rarely examined, despite the home being a primary site for ART.

Biosociality and Visibility

The literature on biosociality has explored how people living with HIV make themselves visible to powerful actors as entitled recipients of care. In *Mobilising AID(S)*, adolescents, often as a consequence of their parents' death, became visible to HIV/AIDS NGOs and support networks. Similarly, as people enrol in public HIV services, they also become visible for state care. In *Negotiations of Blame*, I discussed how women were often especially visible to state HIV programmes, owing to their pregnant bodies. The

widespread provision of ART to prevent parent to child transmission has brought pregnant women under ART surveillance and contributed to their disproportionate presence in institutions of HIV care.

To be visible was not only to secure care, but also to be recognised and valued. As *Bureaucracies of Blood* showed, there was dignity in being seen, written and archived. But young people's visibility in state and NGO care was also deeply ambivalent. In presenting themselves for recognition and resources, adolescents also became visible for discipline, resentment and accusation.

ART brings new possibilities and limitations for what is revealed and concealed. Many more people can live asymptomatically, and therefore more discreetly, with HIV. Yet despite ART, young people in this study have not been able to escape their bodily-ness. Some carry the physical manifestations of delayed treatment and long-term HIV illness, while others have their once-secret sexuality exposed through their pregnant bodies. The body remains an important site of stigma and accusation, and as such, it was also through the body that some sought to rebuff blame.

In this study, it was most often young women who were blamed. They faced recrimination not only for the spread of HIV/AIDS, but also the social damages from which the epidemic was perceived to stem. In addition to lingering witchcraft discourses and associations between HIV/AIDS and death, this study therefore highlights another continuity in the distribution of stigma in the post-ART era — its inherent misogyny.

PATRIARCHY

The forms of patriarchy under operation in these articles were by no means 'traditional', even when they called upon imaginings of the past. This was not an old patriarchy on repeat, but instead, situated and contemporary forms of patriarchy, enacted by women, often in the absence of men.

Bozzoli (2015) has traced the history of South African patriarchies from powerful pre-industrial masculinities to the violence of present-day masculinities, which she describes as "fragile" and "under siege". Through a rendering of political economy, Bozzoli describes the forms of male power that have been lost, the marginal gains made by women, the resulting insecurities of men, and how these insecurities manifest in regimes of violence. It is worth recounting some of this history here in order to situate, and offer some preliminary thoughts about, the forms of gendered recrimination and discipline at work in this thesis.

Pre-colonial South African societies underpinned the power of senior men. This was premised on economic systems of cattle-keeping, chiefly modes of governance, and the payment of bride price ('lobola'). These buttressed the position of 'big men' in homes, clans and tribes (Bozzoli 2015, p.10). Colonial intervention brought Christianisation, land alienation, a system of migrant labour, and the growth of towns. As Bozzoli (2015, p.10) describes, these "transforming influences of modernity, capitalism and the state impinged upon the preceding systems in harsh, uneven and unfinished ways". Along with mission-driven Christianity, sexuality became increasingly 'privatised' and was more often associated with shame and embarrassment (Mayer 1961). This eroded

previous forms of sexual socialisation (Delius & Glaser 2005) and, ironically, entailed a loosening of sexual controls.

Colonial migrant labour meant that chiefs had less control over young men, and mothers less authority over their sons. Young men were increasingly disconnected from the domestic and the female, "trapped in the weirdly nowhere worlds of mines, compounds, prisons or townships" (Bozzoli 2015, p.12). Yet re-imagined modes of 'traditional masculinity' also persisted among migrant men. In an era of industrialisation, masculine respect was underpinned by male economic provision. This refashioned older conceptions of manhood, locating them in urban-based labour. A home, for which a man provided, became a measure of masculinity (Gibbs et al. 2014; Ferguson 2013).

In the late apartheid period, as well as the years since then, South Africa's economic growth has been accompanied by rising unemployment. Many of these unemployed have been excluded from the labour market more or less permanently (Ferguson 2013, p.230). The delinking of men from wage labour has further contributed to a radical decline in marriage (Ferguson 2013, p.231). These social circumstances have had severe ramifications for male personhood, once premised on wage remittances and social membership through labour (Ferguson 2013, p.230). Male elders have become increasingly delinked from the family and from younger men, children are raised in matrifocal homes, and the 'absent father' has taken on a paradoxically pervasive 'presence' in family life. Meanwhile, women have had greater access to cities, labour markets, and sexual partners.

"Between the rootlessness and re-subordination of men and the opening of slivers of

opportunity for women", there arose a new set of possibilities for remaking, and propping up, masculinity, femininity, patriarchy and power (Bozzoli 2015, p.13). A number of South African studies (Gibbs et al. 2014; Hunter 2005; Reihling 2013) have explored the volatile and multifarious ways in which young men have sought to foster masculinity and respect in this new context. But "of what did the reconfigured so-called 'patriarchy' consist? For certainly there was a distinct absence of actual patriarchs" (Bozzoli 2015, p.13).

Despite the marginal social strength gained by women, and the economic and domestic exclusion suffered by men, this has not given way to a sort of 'matriarchy'. Instead, Bozzoli argues, what persists is a dysfunctional, volatile and violent patriarchy, often driven by youth. The centrality of women in households has not resulted in a role reversal or the end of patriarchy. Arguably, this is not surprising. Shifts in the position and power of South African men and women are likely to be uneven, contradictory, and incremental.

Much of the literature has suggested that it is men, anxious and insecure about their own masculinity, who castigate women. In the context of HIV, this has meant that women are frequently cast as the source of contaminating pollution (Leclerc-Madlala 2001; Skhosana 2001). Whether accepted or problematised, the common assumption is that women are on the receiving end of patriarchal power and more or less defenceless in negotiating it (Jewkes & Morrell 2012). But, as *Redeeming Lost Mothers* and *Negotiations of Blame* show, patriarchal practices have remained the norm, even in female-headed households where men were largely absent. I have suggested that one way of trying to make sense of this might be to consider how patriarchal values are

uncomfortably re-signified in order to make a newer matrifocal order workable. In this study, some women seemed to appropriate forms of patriarchy in their everyday pursuits of care and connection. In particular, older women apportion blame to their younger counterparts. In *Redeeming Lost Mothers*, blame was attributed to young mothers in their absence. *Negotiations of Blame* explored how blame was shifted to, or shouldered by, adolescent girls (many of whom were also mothers).

Among some families in this study, the tendency seemed to be to apportion blame away from those who had to lead (usually older women), precisely so that they were able to do so. For a few adolescent girls, this meant carrying blame for their older female carers in a way that would preserve their authority, and relatedly, their ability to care.

Patriarchal tropes were not underpinned by the economic position of men as breadwinners. Indeed, in the few homes where young men were present, they were rarely the primary earners. The perpetuation of patriarchal values also did not rest on the circulation of bride wealth. Marriage has drastically declined in these areas. Almost none of the grandmothers, mothers and daughters I met were wives, although some were widows. Articles in this thesis therefore begin to ask a severely under-explored question: 'What happens to femininity in the context of a volatile, dysfunctional and reconfigured patriarchy?' How are women fashioning the moral and social orders of increasingly female-centred family institutions?

Gender, Care and Respectability

This thesis has offered some tentative thoughts on the contemporary forms of gendered recrimination that are perpetuated in some female-centred homes. This is in a context in which patriarchy is insecure and gendered power is perpetually morphing. It is certainly beyond the realms of this thesis to fully deconstruct or account for this phenomenon. However, some insights might be drawn from a smaller literature on shifting femininities since the late apartheid period (Bozzoli 1991; James 2015; Phillips 2011; Phillips & James 2014), during which time the grounds of masculinity have been radically shaken.

During the latter period of the 1980s, unattached female migrants, particularly those working in urban informal economies, risked being demonised as 'loose' and 'notorious', both by white administrators and rural black patriarchs (Phillips & James 2014). Asserting respectability, while removed from the 'traditional' patriarchal home, was of immense importance. Christianity, along with Christian affiliations, had significant influence on constructions of female respectability in this context. Domestic work was also strongly associated with 'decent', 'maternal' qualities (Ally 2010; Phillips 2011). Establishing a sense of order, respectability, and domestic responsibility have purportedly been central to recent practices of South African femininity.

In this study, HIV/AIDS stigma regularly took the form of women blaming and censuring other women. Yet, this gendered recrimination was bound up, in paradoxical ways, with care and respectability. Both are severely threatened by HIV/AIDS. Gendered blame functioned as an appeal for, at times even a mode of, care that came encased in reproach. On occasions, its aims were paradoxically beneficent. In *Negotiations of Blame*, I suggested that, in shifting blame to their daughters, some

mothers might have sought to protect their own respectability, and relatedly, their capacity to care. *Redeeming Lost Mothers* showed that, in some homes, bolstering communality was entangled with the demonisation of dead and absent mothers.

Among families in this study, care had important moral dimensions. The preservation of care, which was tied to respectability and dignity in important ways, shaped how adolescents and their families related to others, both within the home and outside its boundaries. To give and receive care showed others that one was a virtuous relative. One could be recognised and admired for good care as much as one could be criticised for stinginess and neglect. This was perhaps most evident in the ways that some guardians in *Redeeming Lost Mothers* sought to present their own caregiving in comparison to the 'failed' care of adolescents' dead and absent mothers. Domesticity, in the sense of nurturing, maintaining order, and preserving harmony, seemed central to the configuration of older women's respectability and subjectivity. To be cared for — by the state, by one's family, by NGO patrons — was to be bestowed important forms of dignity and recognition, however precarious. As illustrated in *Bureaucracies of Blood*, documents could serve as important tokens of acknowledgement, care and membership. To archive someone's documents was to give testimony to their lives in a caring way.

In this thesis, reflections on persistent misogyny add to a wider analysis of the shape of AIDS stigma in the post-ART era. The stigmas explored in this study are a reflection of how HIV-positive adolescents and their families have wrestled with very contemporary uncertainties. These are messy, everyday stigmas in which the boundaries between victims and victimisers are frequently opaque: perinatally-infected adolescents hurl accusation at those infected sexually, HIV-positive mothers shift blame to their HIV-

positive daughters, the poor resent other poor for the little resources they can hustle, and bereaved families regenerate sociality by blaming their deceased.

UNDERSTANDING YOUNG PEOPLE'S ART RETENTION

Given the small size of my research cohort as well as the bias towards perinatally-infected youth in support groups, my ability to make public health recommendations is limited. Nevertheless, I am able to raise challenges, pose questions, and complicate assumptions, in the hopes that these will inform further research and nuance policy and programming. In order to improve ART enrolment and retention, we must understand how HIV treatment is received and reinvented by those who use it. This is a primary contribution of qualitative health research, which can elucidate how public health programmes are remade in local contexts. The success of health interventions depends not only on carefully designed policy and effective medicine, but also on the messy achievement of the programme by those who deliver and use it.

For the young people in this study, ART was a process of volatile social incorporation. Being an ART user was not simply a medical matter, but an inherently social achievement, intertwined with adolescents' negotiation of survival, social mobility and recognition in present-day South Africa. There were often significant social and moral stakes entailed in the process of ART participation, as much as there were important benefits.

Social Possibilities

Redeeming Lost Mothers and *Bureaucracies of Blood* explored how adolescents' daily pill consumption, as well as their participation in ART programmes, was accomplished in the context of their local moral worlds. The articles explored how youth and their families imbued ART with social meaning, and how in so doing, they also bolstered their own participation. Both articles expounded the emotional, discursive, and disciplined work that went into the everyday accomplishment of ART for adolescents.

Redeeming Lost Mothers drew attention to the work of ART in young people's home lives, exploring how HIV treatment was weaved into mutual obligations between adolescents and their guardians. It affirmed that adolescent ART was most often achieved and signified in collaboration with others. The everyday consumption of ART is fundamentally a home-based practice and yet our understandings of the socialities of HIV treatment are almost always imagined vis-à-vis state and donor programmes. In our efforts to promote and narrate ART, we might pay attention to its place in young people's family histories, authority structures, and routines.

Redeeming Lost Mothers also highlighted an underexplored convergence between two major concerns for adolescent HIV. Researchers and interventionists have been deeply concerned both with adolescents' adherence to ART (Nachega et al. 2009; Nglazi et al. 2012) and their ability to manage the distress of parental loss (Cluver et al. 2007; Rotheram-Borus et al. 2005; Wood et al. 2006). Failure to support adolescents in either of these areas could have severe consequences for youth wellbeing, including psychosocial distress in the case of bereavement (Cluver et al. 2007; Wood et al. 2006) and illness or loss of life in the case of adherence. Yet improving ART adherence and

supporting adjustment after parental loss have always been treated as distinct projects. The findings of *Redeeming Lost Mothers* suggest that these projects may be fundamentally related, and that bridging these areas of research and intervention could produce life-altering innovations for youth on ART.

Redeeming Lost Mothers showed that the tasks of strengthening household sociality and promoting adolescent ART could be reciprocally intertwined. Arguably, linking these projects was one of the ways in which families made ART 'work'. Relatedly, in *Bureaucracies of Blood*, ART surveillance technologies were made to 'work', primarily through families recognising their social potential. The bureaucracies of ART, so often depicted as disciplining and disempowering, were also shown to facilitate care and recognition in some adolescents' lives. By exploring the social and moral possibilities of a hierarchical, disciplining and bureaucratic relationship with the state, I elucidated why some adolescents might wilfully participate in it. The 'success' of bureaucratic surveillance rested on the consent of those who came under it.

In the health system, technologies of surveillance and monitoring are often evaluated based on their ability to improve patient outcomes, including levels of retention, adherence or compliance. We are often concerned with their efficacy as tools of governance that assist healthworkers in tracking and controlling large patient numbers. It is worth paying attention to how surveillance technologies — whether documents or blood tests — might serve as tools for patients. Beyond assisting their own self-monitoring, these disciplinary instruments might demonstrate membership and entitlement, bestow recognition, or grant subtle power. By exploring how surveillance technologies become assets for ART users, we might better understand how, why, and under what conditions, ART governance is made to work.

Social Stakes

Redeeming Lost Mothers and *Bureaucracies of Blood* attempt to complicate our understanding of 'success' on ART. They do so by exploring the unexpected ways in which adolescents and their families achieve ART, often by mobilising its social possibilities. When it worked, ART formed part of wider pursuits for care and connection. The remaining articles in this thesis were primarily concerned with the social stakes of ART — the ambivalence of ART participation and the threats to its success.

Mobilising AID(S) joins other literature which has sought to problematise constructions of the 'deserving poor' in South Africa's social welfare economy (Bundy 2015; Ferguson 2007; Hölscher 2008). Despite generalised poverty, and the widespread appropriation of social grants as a poverty alleviation mechanism, state welfare in South Africa continues to be delivered under certain pretences. It rests on the farce that most working-age adults will be able to find work, insure themselves against short-term unemployment, and contribute to their own pensions (Bundy 2015). Social grants are distributed only to those considered unable to work, either because they are too old, too ill, or caring for young children. Non-state and global development programmes have also championed particular constructions of the 'deserving' care recipient. *Mobilising AID(S)* illustrated how constructions of the 'AIDS orphan', 'foster child' or 'HIV-positive youth' could be appropriated in order to 'work' this system. Many have pointed to the millions of poor South Africans who, despite chronic joblessness, remain excluded from this configuration of the 'deserving poor'. But, as *Mobilising AID(S)* suggests, narrowly targeted care economies can also have unintended social consequences for their beneficiaries. In this case, access to HIV-targeted care made adolescents feel vulnerable

to resentment from neighbours and sparked familial conflicts. These were the social stakes of care.

Similarly, *Negotiations of Blame* worried at the stigma faced by young people in the very process of accessing HIV services. In some respects, it was also about how targeted care — in this case for pregnant women — could produce new stigmas. Young women were more likely to test, and therefore be blamed for, HIV than their male partners. Their HIV tests were mandatory and the disclosure of their HIV status was similarly coerced. Receiving the care they needed, whether from mothers or nurses, meant submitting to accusation. Not all were willing to accept these terms. Those that did became involved in precarious tactics for managing and distributing blame.

At the centre of these *Negotiations of Blame* was the body. It was because these young women could fall pregnant — a fact of their bodies — that they were brought under clinic surveillance and became susceptible to accusation. But it was also through their relatively asymptomatic bodies that some were able to shirk other forms of recrimination. One young woman denied her HIV status altogether. Another was able to hide her months of evading HIV treatment. And finally there were those that could protect their mothers from accusation by obscuring the possibility that they had inherited HIV at birth.

It is worth considering how clinic categories and technologies can themselves become instruments of blame with the risk of keeping people from services. The articles in this thesis have discussed how ART folders might unwittingly identify HIV-positive patients, how terminology like “mother-to-child-transmission” might contribute to

maternal blaming, and how categories of "perinatally" and "sexually-infected" are appropriated as tools of shame and accusation.

CONCLUSION

This thesis has suggested that, if we are to understand young people's ART retention, we ought to also pay attention to its rich social potential. Families in this study have imbued ART as a vehicle to repair familial rupture, to connect to social and material resources, and as a site of care and recognition. ART was not only a "technology of the self" (Foucault 1988), but also of the social — strung into relationships of expectation, obligation, dependency and reciprocity. Young people in this study were embedded in clinic, home and NGO institutions and, through ART, were often navigating the continuities and fissures between them. More so, adolescents achieved ART with the help of others and were not simply caught up as individuals in the net thrown out by public health. But along with its social potential, ART also had significant social stakes. Participating in ART necessitated precarious tactics in order to redistribute blame, appeal for care, and negotiate resentment.

If drawing attention to ART's social character is one contribution of this thesis, the other is its specific generational focus. I have sought to elucidate adolescent ART amid contemporary shifts in South African political economy, domesticity and social welfare. The question of youth ART emerges from a changing epidemic, in which more children are reaching adolescence alive and more young people have access to ART. As the HIV/AIDS epidemic, its response, and socio-political life in South Africa continue to change, so too will the nature of life on HIV treatment. But more than a historical or

epidemiological generation, young people in this study belonged to an age cohort. As such, the thesis has paid particular attention to the ways in which adolescents — as children, grandchildren, and categories of vulnerable youth — experienced and appropriated ART. By locating adolescents' ART amid families' broader struggles for recognition, sociality and survival, I hope to have illustrated the precarious and unexpected conditions under which successful HIV treatment is achieved, while also signalling important considerations for social support.

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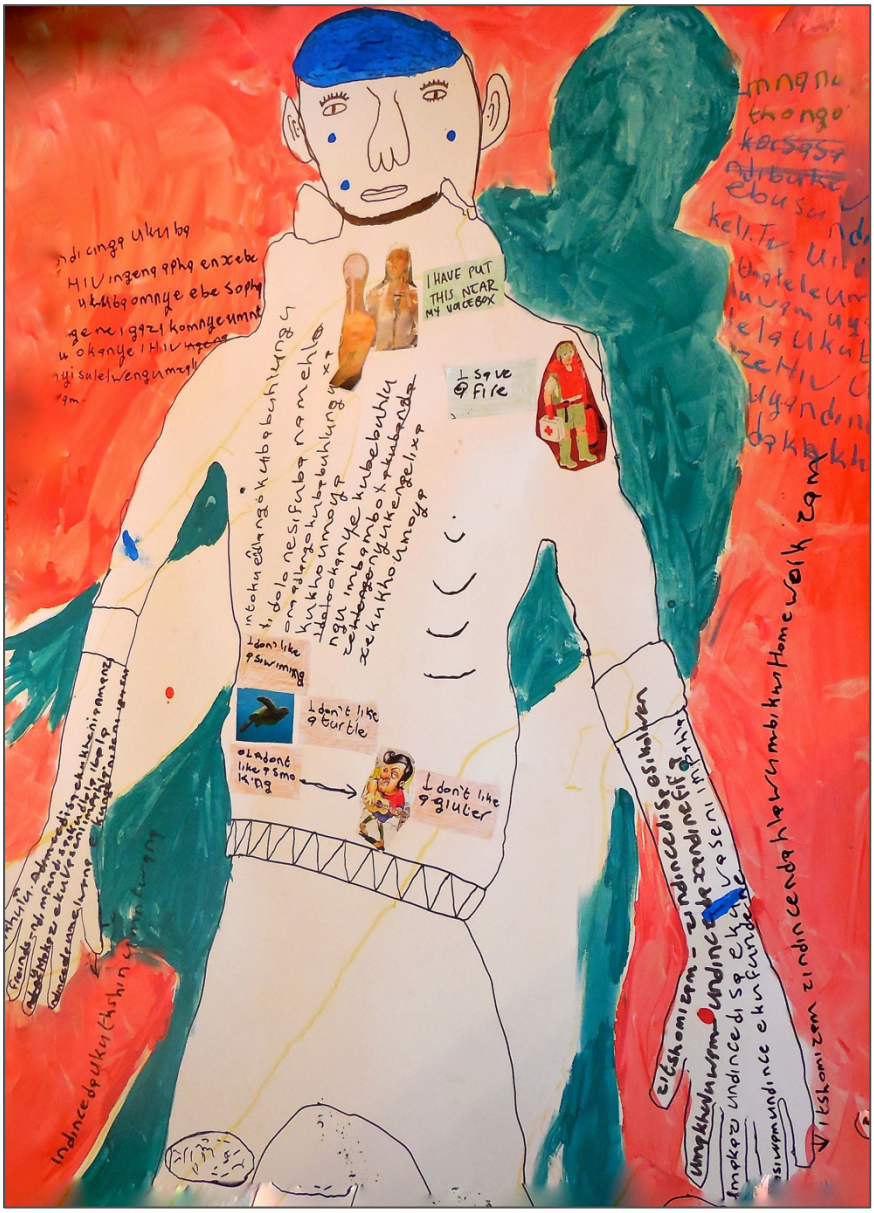
Appendices


I HAVE PUT THIS NEAR MY VACCBOX
I don't like swimming
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DPhil Presentations

1. 'Negotiations of Blame and Care among HIV-positive Mothers and Daughters in South Africa', *Family Troubles Symposium* (University of Reading, September 2015).

2. 'Bureaucracies of Blood and Belonging: what documents tell us about how HIV-positive youth's relationship with the state', *South African AIDS Conference* (Durban, June 2015).

3. 'Deception, Distraction and Disinterest: The challenges of participatory research with HIV-positive teenagers and their families', *South African AIDS Conference* (Durban, June 2015).

4. 'Youth ART-taking as a practice of maternal atonement: tracing the methodological journey of a qualitative research finding', *EBSI Research Group* (Oxford, November 2014).

5. B. Vale, 'Bureaucracies of Blood and Belonging: what documents tell us about HIV-positive youth's relationship to state welfare', *South African Discussion Group* (Oxford, November 2014).

6. B. Vale, 'Redeeming the Dead: reflections on the medication-taking practices of HIV-positive adolescents in the Eastern Cape province of South Africa', *Linacre College Seminar* (Oxford, May, 2014).

7. B. Vale and M. Thabeng, 'Exploring the Medication-Taking Practices of HIV-positive Adolescents in the Eastern Cape: preliminary findings after 8-months of ethnographic fieldwork'

Presented to:

- *Raphael Centre Termly Talk* (Grahamstown, April, 2014). Audience included medical doctors, members of the Settlers Hospital board, Rhodes Community Engagement officers, NGO workers
- *Hospice* (Grahamstown, April, 2014). Audience included NGO and community healthworkers
- *DG Murray Trust* (Cape Town, March 2014). Audience also included representatives from Kheth'Impilo and Pediatric AIDS Treatment for Africa.
- *Section27* (Johannesburg, April, 2014)

8. R. Hodes and B. Vale, 'Exploring Medication-taking Practices and Sexual and Reproductive Health among HIV-Positive Adolescents in the Eastern Cape: preliminary findings', *IYDSA* (East London, February 2014).

9. B.Vale, M. Thabeng and Y. Dunkley, 'Exploring the HAART-taking Practices of HIV-positive Adolescents in the Eastern Cape: feedback from a multi-method ethnographic study in four rural villages' (Eastern Cape, November 2013). Audience included NGO workers, medical practitioners and community healthworkers.

10. D. Mark and B. Vale, 'Born free with HIV: HIV-Positive youth in South Africa: future leaders in ART adherence and sexual health', *Adolescent Research Meeting*, *Desmond Tutu Foundation* (Cape Town, August 2013).

11. B. Vale, 'Vulnerable victims, reckless risk-takers and self-regulating citizens: locating HIV-positive teenagers in public health constructions of youth', *Graduate Seminar on the History of Childhood* (Oxford, July 2013).

12. B. Vale, 'Building theoretical frameworks in research on adolescent HAART adherence', *MSc Class in Social Intervention* (Oxford, January 2013).

SOCIAL SCIENCES & HUMANITIES
INTER-DIVISIONAL RESEARCH ETHICS COMMITTEE

Hayes House, 75 George Street, Oxford. OX1 2BQ
Tel: +44(0)1865 614871 Fax: +44(0)1865 614855
ethics@socsci.ox.ac.uk www.socsci.ox.ac.uk

Co-ordinator of the IDREC
Social Sciences Divisional Office

20 December 2012

Dr Lucie Cluver
Department of Social Policy and Intervention

Dear Dr Cluver,

Research Ethics Approval

Ref No: SSD/CUREC2/12-21

Title: Youth Pulse: Identifying risk and protective factors for adherence to long-term medication amongst adolescents in South Africa

The above application has been considered on behalf of the Social Sciences and Humanities Inter-divisional Research Ethics Committee (IDREC) in accordance with the procedures laid down by the University for ethical approval of all research involving human participants.

I am pleased to inform you that, on the basis of the information provided to the IDREC, the proposed research has been judged as meeting appropriate ethical standards, and accordingly approval has been granted.

Should there be any subsequent changes to the project, which raise ethical issues not covered in the original application, you should submit details to the IDREC for consideration.

Yours sincerely,

Dr Liesl Osman

cc: Dr Mark Boyes
Professor Mark Orkin
Tintswalo Mercy Hlungwani
Rebecca Hodes
Beth Vale
Elona Toska

LO/CK

CENTRE FOR SOCIAL SCIENCE RESEARCH
University of Cape Town ▪ Private Bag Rondebosch 7701 ▪ South Africa
Tel: 021 650 4656 ▪ Fax: 021 650 4657 ▪ Web: www.cssr.uct.ac.za

TO: Dr Rebecca Hodes

FROM: Jeremy Seekings
Professor and Director, Centre for Social Science Research, UCT

SUBJECT: Ethics Review CSSR 2013/4.

RESEARCH: Promoting Adolescent Antiretroviral Adherence …

DATE: 17th April 2013

Dr Hodes, a Research Associate in the Centre for Social Science Research, submitted for review relevant documents relating to research that she intends doing, with colleagues from the UCT and Oxford University, on adherence to antiretroviral treatment among adolescent men and women in the Eastern Cape. The documents were scrutinised by the CSSR Research Ethics Review Committee, which included (by invitation) a member of UCT's Health Sciences Faculty Research Ethics Committee.

The Review Committee raised a number of concerns, primarily with respect to the issue of involuntary disclosure of personal information by other participants in discussion groups. The relevant documentation has been reworded, and the researchers have made a clear commitment to pay close attention to this issue. With these changes, the review panel is satisfied that the research will be conducted in a manner that meets the standards of the University of Cape Town.

The proposed research is therefore approved.

Jeremy Seekings.

Jeremy Seekings
Professor and Director, Centre for Social Science Research

Eastern Cape Department of Health

Enquiries:	Zonwabele Merile	Tel No:	040 608 0830
Date:	29th August 2013	Fax No:	043 642 1409
e-mail address:	zonwabele.merile@impilo.ecprov.gov.za		

Dear Ms Elona Toska

Re: Promoting antiretroviral adherence and sexual and reproductive health service access amongst HIV positive teenagers

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.
3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

DEPUTY DIRECTOR: EPIDEMIOLOGICAL RESEARCH & SURVEILLANCE MANAGEMENT

EASTERN CAPE

MZANTSI WAKHO RESEARCH PROTOCOL

1. Purpose of the Study

Southern Africa is home to 1.2 million HIV-infected adolescents (1) , whose long-term health outcomes depend on strict adherence to antiretroviral therapy (ART). The limited research conducted with adolescent ART-users in Africa reflects low adherence rates (2) and poor access to sexual and reproductive health (SRH) services (3). As adolescence is a time of increased risk-taking and experimentation, HIV-positive teenagers represent an especially vulnerable and challenging group for HIV service providers. However, their retention in ART programmes and use of SRH services remain under-investigated, and HIV-positive adolescents have rarely been included as partners in the design and operationalization of their own HIV and SRH services.

This research applies innovative investigative strategies to study the health needs of HIV-positive young people growing up in contexts of extreme risk, investigating their potential for resilience, and exploring how to support their adherence to ART and uptake of SRH services. It fills a pressing research gap by investigating areas of intersection between adolescent ART adherence and SRH, while also offering methodological and programmatic innovation through the development of youth-driven tools to support ART adherence and SRH service uptake.

This study uses both qualitative and quantitative methods to achieve two aims:

(1) To identify and investigate risk and resilience-promoting factors for ART adherence and access to SRH services amongst HIV-positive teenagers, through linked qualitative and quantitative studies.
(2) To collaborate with HIV-positive adolescents, healthcare and social service providers to design support tools to improve adolescent ART adherence and SRH service uptake.

In line with these aims, this mixed-methods research project will have four components:
1. In-depth **qualitative** research with 50 adolescents and 70 key informants (caregivers, health and social workers) to explore: 1) how HIV-positive adolescents use, adopt and resist HIV care and treatment, and SRH services, and 2) how those caring for HIV-positive adolescents experience and perceive challenges and facilitators of ART adherence and SRH uptake.

2. Participatory **qualitative** workshops to involve adolescents as key stakeholders in the collaborative design of youth-driven support tools to:
a) Support ART adherence and SRH service uptake,
b) Assist youth in negotiating the barriers and challenges that impede their desired retention in care, and
c) Customize ART and SRH interventions for optimized adolescent outcomes.

3. A linked **3-year longitudinal quantitative** study of 600 HIV-positive adolescents will assess risk and resilience-promoting factors for ART adherence and SRH utilization. This quantitative study will be directly informed by the ongoing qualitative research, and will be conducted in collaboration with a clinical research team coordinated by Dr. Craig Carty.

4. Finally, the linked **quantitative** study will test the acceptability of the support tools developed in participatory workshops with a in the larger-scale quantitative sample.

The aims and methods for this study were developed through collaborative planning between HIV-positive adolescents, researchers from health and social sciences, UNICEF and South African National Departments of Health, Social Development, Basic Education and Women, Children and Disabilities, alongside clinical researchers at the Eastern Cape Department of Health, Frere and Cecilia Makiwane hospitals, NGO Pediatric AIDS Treatment for Africa (PATA), and CBOs (Raphael Centre, Small Projects Foundation and Keiskamma Trust). Ongoing consultations with these and other partners, including the Treatment Action Campaign and Kidzpositive, have underlined the importance of combining three information sources: in-depth qualitative research on the experiences of HIV-positive adolescents, particularly as these relate to ART and SRH; active collaboration with teens to develop

relevant support tools; and quantitative survey methods to identify causal mechanisms and test acceptability of tools on a wider scale.

The interdisciplinary and collaborative nature of this study, and its inclusion of a range of partners, aims to inform a broad-based, inclusive approach to HIV policy and programming. Since the study is planned in collaboration with HIV-positive adolescents, as well as state and non-state partners at local, national and global levels, it provides an opportunity to bring the experiences of youth into the policy arena. Policy and programming impact are integral aims of this research, and will be combined with ongoing results dissemination to NGOs, CBOs, government and health sectors, as well as to participating communities.

This study has a direct capacity-building aim, and includes a South African Principal Investigator (RH) who will gain further research skills through mentorship, two South African PhD students and a further two students (one PhD, one Master's) from within the South African government. Additionally, all staff take part in capacity-building programmes within the project (see section 13 for details).

2. Background

90% of adolescents living with HIV reside in Southern Africa, including those infected perinatally, in childhood, and in youth (4). South Africa has the world's largest population of HIV-positive adolescents: 292,000 in 2011 (1). ART provides an opportunity for long-term survival and wellbeing (5,6), but requires diligent lifetime adherence of 87-95% (7) to attain viral suppression and prevent viral resistance (8,9). Non-adherence is particularly hazardous in most low- and middle-income countries, where there are commonly only two drug regimens available in the public health sector (10). Non-adherence also presents a wider public health threat: transmission of drug-resistant HIV (11).

Adolescence is often a time of initiating sexual relationships, characterized by low levels of communication and openness (12). Many health programs use models of 'therapeutic citizenship' (13,14), proscribing disclosure of sero-status to romantic partners and others, the use of condoms during sex, and adherence to both ART and contraception. However, fear of rejection and internalized stigma result in low rates of disclosure to partners (15). In contrast, research has found low levels of adherence among HIV-positive youth (2), and demonstrated that AIDS-affected youth are more sexually vulnerable than other adolescents, with high levels of unprotected sex (2,3). Adherence and SRH service uptake are closely linked for HIV-positive adolescents, but their specific needs present challenges to resource-constrained health services (16). In order to develop effective interventions to support HIV-positive adolescents and improve their health outcomes, this research seeks to understand risk and resilience-promoting factors for adherence and SRH service utilization.

Despite the crucial role played by HIV-positive adolescents in their own retention in care and in preventing HIV transmission, few programming approaches have been led by youth themselves. Advocacy groups of people living with HIV (PLHIV) have repeatedly called for increased community participation in health service delivery and greater involvement of PLHIV in research (17). By leveraging the participation of HIV-positive adolescents in the design of youth-friendly support tools, the study will aim to further programmatic collaboration between service-users and service-providers and to enable adolescent-focused approaches to ART adherence and the uptake of SRH services.

2.1. State of the evidence

Limited research and interventions exist for adolescents living with HIV (ALHIV) outside of the United States (US) (18). The available, largely qualitative, work identifies challenges with romantic relationships, education, gender and family roles (often within homes disrupted by parental death), illness and depression (19,20). Preliminary reviews have identified one published qualitative (21) and two quantitative studies (2,22) on adolescent ART adherence in sub-Saharan Africa. Nachega et al. reported adherence rates, but not risk or protective factors, in 154 adolescents in a private sector clinic programme in nine countries. Adolescent adherence was 21% at 6 months and 7% at two years, lower than that of adults. Evans et al. used clinic records in 7 NGO-supported clinics in Mpumalanga and Gauteng provinces. Older adolescents (15-19 years old) showed greater levels of unsuppressed viral load, virological failure and loss to follow-up. Two further adolescent studies in the region investigate linked outcomes: in a US-run specialist clinic in Botswana, psychological distress was associated with virologic

failure amongst 692 adolescents (23); and in Uganda, 575 adolescents on publicly-funded treatment showed 2-year mortality of 8.5% (24).

The limited research on HIV-positive adolescents in sub-Saharan Africa reveals the complex challenges that arise from disclosure of HIV status, ART adherence and the uptake of SRH services. These challenges include individual-level ones (mental health, self-perception), family-level (parental death, parenting), community-level (norms about sexual activity, stigma), and structural ones (transition to care, poverty). ALHIV are confronted by difficulties associated with transition from paediatric to adult HIV care (25), HIV status disclosure to peers (26), the taboos associated with young people's sexuality (27), parental AIDS illness and death (28,29), and the resultant poverty, stigma and bullying victimization (30). Longitudinal evidence also suggests that adolescents who have lost a parent due to AIDS are at heightened risk of psychological distress due to stigma-by-association (31). Teenagers must grapple with these challenges within caregiving arrangements that may include parental death and sickness (19,21). Beliefs regarding pollution and uncleanliness – related to HIV and to medication side-effects – may create ambiguity in adolescents' understandings of their own bodies and medical rituals, and this is complicated further by the experiential overlays of peer interactions, romantic relationships, the negotiation of gender and family roles, and the transition into and out of school.

Although research has been conducted on reproductive intentions and services for HIV-positive adult women in South Africa (32,33) there are significant evidence gaps on access to SRH and retention in HIV care for HIV-positive adolescents, both in relation to ART and SRH programmes. The available studies have found that access to ART has accelerated pubertal and sexual maturation (34), with 88% of HIV-positive 15-19 year old girls reporting sexual activity in Kenya (3). Research has also demonstrated inconsistent condom use, poor uptake of SRH services and repeated unintended pregnancies and terminations among HIV-positive adolescents (3). While access to prevention of mother to child transmission (PMTCT) services has reduced rates of vertical transmission in South Africa (35), research on whether female HIV-positive adolescent are accessing these services and outcomes is limited (36).

Gender, age, environment (urban/rural) and route of transmission may all play a role in determining ART adherence and SRH service uptake, but further research is needed. HIV-positive adolescents differ in clinical and social markers, such as disease stage, neurological impact of ART, and disclosure to and by families. For example, perinatally-infected adolescents have more resistant virus mutations, while those infected in adolescence are more likely to have been diagnosed through pregnancy, and almost nothing is known about those infected through South Africa's high rates of childhood sexual abuse[1].

This study of HIV-positive adolescents hypothesizes an interactive model of individual, family, school, structural and service-level factors influencing ART adherence and SRH service uptake, potentially mediated by HIV-disclosure, stigma associated with ART and with adolescent sexual activity, and the potential side-effects of both ART and contraception. This model also presents an opportunity for research to inform policy and practice. Even when some risk factors may be unalterable (such as orphanhood), the identification of *modifiable* risk and resilience factors provides valuable evidence to inform interventions. This study will be the first to investigate risk and protective factors for ART adherence and its connections to SRH service uptake amongst HIV-positive adolescents in South Africa. Using both qualitative and quantitative methodologies, it aims to unpack the complex interplay between these health services and to use participatory and youth-driven methods to develop a tool to promote ART adherence and SRH service uptake.

3. Methodology

This study combines research and programmatic development, and asks the crucial questions: what are the lived experiences of HIV-positive adolescents in relation to ART and SRH, and what obstructs or promotes their ART adherence and uptake of SRH services? It uses participatory methods to ensure that adolescents are active agents in the conceptualization and design of a tool to facilitate ART adherence and SRH service utilisation.

[1] Amongst those perinatally-infected, some have been on treatment from an early age, and new research suggests that around a third are 'slow progressors': surviving without diagnosis or care, but becoming ill around puberty (4).

This study uses mixed qualitative and quantitative methods to achieve two aims:
(1) To identify and investigate risk and resilience-promoting factors for ART adherence and access to SRH services amongst HIV-positive teenagers, through linked qualitative and quantitative studies.
(2) To collaborate with HIV-positive adolescents, healthcare and social service providers to design support tools to improve adolescent ART adherence and SRH service uptake.

This study will use:

i) Systematic reviews of risk and protective factors in ART adherence, SRH service uptake and internalised stigma for HIV-positive adolescents (underway); and reviews of best practice in support tools and programmes for HIV-positive adolescents (based on the UNICEF Lessons Learned report on strengthening health services and outcomes for adolescents living with HIV, 2013);

ii) Qualitative and participatory methods with 50 adolescents and 70 key informants (caregivers and service providers), followed by

iii) Participatory workshops with five groups of adolescents. These workshops are conducted in collaboration with the South African National Department of Health and UNICEF, and explore adolescent views of the Draft National Youth Health Policy and the UNICEF lessons learned report. They take an adolescent-led approach to intervention consultation, adaptation and design.

iv) Semi-structured interviews, ethnographic research and clinic observations with social and health service providers working in ART, SRH, PMTCT and Out Patient Department clinics. Methods iii) and iv) will be integrated with:

v) Quantitative longitudinal survey (n=600, 3 years) to test risk and resilience-promoting factors for adherence and SRH service uptake, and to measure acceptability of the support tools developed in the participatory stage. Data collected during this survey will include: biomarkers (i.e. viral load, CD4-cell count), clinic-level data (i.e. resources, such as counseling, staff/ patient ratio in the clinic) and individual-level panel survey data (i.e. potential individual, family, school and community-level factors) through tablet-administered questionnaires. Survey items were informed by extensive literature reviews as well as the qualitative component of Mzantsi Wakho. Where possible, standardized validated measurements were used. Cognitive interview methods ensured cultural relevance and understandability (37) of key measurements that had not been validated among teens in sub-Saharan Africa. Prior to data collection, the survey was translated, back translated and piloted with 17 HIV-positive teens. More than 20 leading academic and research experts on adolescent health research were consulted on approaches to interviewing HIV-positive adolescents, scales used in interviews and overall study design.

The three-year study combines qualitative, participatory and quantitative approaches. In 2013, research preparation comprised systematic literature reviews of risk and resilience-promoting factors for adolescent adherence and SRH use. It also included extensive consultation with government, NGOs, CBOs and our longstanding AIDS-affected Teen Advisory Group.

Year 1. 2014-15 (underway) will combine qualitative and quantitative approaches. Eighteen months of qualitative research will identify adolescents' medication-taking practices and engagement with HIV and SRH services, and apply participatory methods to develop teen-led support tools. This data directly informs the quantitative survey stage which will interview 600 adolescents to examine risk and resilience-promoting factors in a more generalizable sample. In addition, sampling will allow acceptability-testing of the teen-developed support tool.

South Africa has ART coverage of 52% (38), close to sub-Saharan Africa's median of 49% (39). The study will be conducted in the Eastern Cape, South Africa's poorest province, with 30% antenatal HIV-prevalence (40). The study will be conducted predominantly in the Amathole and Cacadu Districts, as well as Buffalo City Sub-District.

3.1. Preliminary consultations

The study design is based on both a literature review and extensive consultation with government and NGOs. Consultations have taken place with: UNICEF, UNAIDS, SA National Action Committee for

Children Infected and Affected by AIDS, National Departments of Health, Social Development and Basic Education, Health Systems Trust, Keiskamma Trust, Kheth'Impilo, Desmond Tutu HIV foundation, Kidzpositive, and the Treatment Action Campaign, as well as clinics and youth groups, and our Teen Advisory Group of AIDS-affected adolescents, who helped to guide previous qualitative and quantitative research on the previous Orphan Resilience study and Young Carers studies (www.youngcarers.org.za). The TAG group was established in 2008 and includes children and adolescents living in AIDS-affected families as well as HIV+ adolescents aged between 12 and 19, with whom we have conducted collaborative research since 2008 (approved by Oxford IDREC in 2008 and 2012 and included in UCT REC applications in 2009).

3.2. Avoiding stigma

A primary concern of this study is to avoid the potential for the research to stigmatise participants or their families. In light of high levels of HIV-related stigma in South Africa, the quantitative study will be presented within communities and organisations as investigating service access for teenagers who have had any extended contact with the health system. This ethically necessary methodological approach provides an opportunity to identify differences in risk and resilience factors between HIV-positive and HIV-negative adolescents, and to explore the need for targeted support. Recruitment processes and documentation will not mention HIV or AIDS, but will mention adolescent health and access to health services in general. This approach was emphasised as essential in community consultations prior to our past two research studies (Young Carers) in order to avoid unintentional disclosure and stigma, and has been approved for both studies by UCT's Health Sciences REC. In each community or location, both adolescents with HIV and those with other chronic illnesses or disabilities (such as asthma or epilepsy) or those accessing other types of health services such as home-based care will be included in the study, with purposive oversampling of HIV-positive adolescents. This will allow a non-stigmatising research process, as well as 'matching' of participants.

For the qualitative study, participants will be sampled through women's health clinics, trauma clinics, ART clinics, ART support groups and programmes for AIDS-affected and HIV-positive youth. While ART clinics and support groups will necessarily target HIV-positive youth, programmes for AIDS-affected teenagers may also include those not living with HIV. In these instances, all youth in the programme will be eligible to participate in the research, but engaging HIV-negative youth will only serve a comparative and ethical function – allowing researchers to observe similar and different experiences between HIV-positive and HIV-negative youth, and preventing participation-associated stigma.

3.3. Community partners: sampling beyond the clinic

All other known studies of HIV-positive adolescents to date have been based on ART clinic samples, which are necessarily biased towards participants more engaged in the HIV health system. If we are to effectively identify barriers to SRH uptake and ART retention, it is essential that sampling includes adolescents who have never accessed SRH or have ceased ART. Clinic-based samples will include a combination of state and NGO-run clinics (both primary health and antenatal facilities), as well as a variety of types of clinics: primary, ANC, OPD and women's health clinics. Key partners in accessing health facilities are facility managers and senior healthcare workers in 31 clinics, Keiskamma Trust (Hamburg), Small Projects Foundation, Paediatric AIDS Treatment for Africa (PATA) and provincial government departments. Sampling will therefore take place in both clinic and community settings. Adolescents who have been lost to follow-up will be identified from clinic-specific defaulter lists, ensuring that the sample has an "intention to treat" approach to sampling by including all those that have initiated ART and then stopped. Non-clinic settings will include schools, children's homes, home-based care organisations and community-based sampling through youth programmes in villages or cities. Similar to qualitative research, the researchers will also be engaging (in a non-research capacity) with broader categories of youth in the community through programme facilitation and workshops. This is to ensure that the researcher team does not become associated only with HIV/AIDS, which could amount to participants incurring stigma through their association with the researchers. The CBO and NGO advisors, and healthcare workers (both clinic and community-based) participating in this research collaboration will guide researchers in selecting, approaching and accessing these community forums.

3.4. Qualitative methods

Why qualitative research?

Public health research and practice has cast the challenge of adolescent ART adherence and SRH service use in predominantly clinical terms, informed by a set of assumptions about youth, risk and compliance (5,18) with medical prescription. Yet the meaning and relevance of these constructs for adolescents on ART and using SRH services remains poorly understood and only superficially accounted for in many HIV treatment, care and support programmes. Exploring young people's practices of ART-adherence and SRH uptake as expressions of agency will deepen understandings of youth risk-behaviour, providing a potential opportunity to design, implement and integrate health programmes that are more responsive and ultimately more effective approaches to adolescent healthcare.

Public health programmes often position HIV-positive youth both as 'vulnerable victims' and 'reckless risk-takers'. While the former suggests helplessness, positioning youth as ill-equipped for self-care and independence (12), the latter invokes a powerful public health threat. Both assumptions necessitate ongoing, but paternalistic, intervention with the aim of encouraging, even policing, youth compliance (14,41). Constructions of youth irresponsibility and recklessness are in stark contrast to ideals of 'therapeutic citizenship' (13,14), now prevalent in HIV and SRH programmes. Here, high demands are placed on teenagers to practice 'responsible lifestyles'. This includes strict adherence to complex treatment regimens, disclosing to intimate partners, negotiating safer sex and accessing and adhering to family planning (often shorthand for avoiding parenthood) - all of which are complicated by context. Public health constructions of the behaviours, needs and desires of young people have powerful effects on the design, implementation, and ultimate efficacy of interventions. Despite the crucial role played by HIV-positive adolescents in their own retention in care and in preventing transmission of HIV, very few of the programmatic responses to improve their health-seeking behaviours incorporate adolescent participation in their design.

In the field of HIV programming, a growing body of anthropological and sociological research has demonstrated that individuals and societies may have entirely different perceptions and priorities to those assumed by public health models (42–45). The standard public health framework often positions human beings as isolated decision-makers, unencumbered by social circumstances. Little attention has been given to the social structures, obligations or uncertainties that shape health behaviours in ways that thwart or contradict medical prescription.

For example, it is possible that considerations of enjoyment, peer acceptance and dignity may supersede those of long-term survival for some adolescents. We need to consider that secrecy may be an 'embodied practice' (46) for these teens – in other words, tactically withholding information regarding sexual practices and HIV status may be integral to negotiating the social world, in which norms of culture, gender, authority and sexuality may mitigate against strict compliance with prescribed health-seeking behaviours such as adherence to ART and contraception. The lived realities of these adolescents may be strikingly different from the adult disclosures necessitated by HIV support groups and ART adherence programmes. This study will consider the hierarchies of power within which adolescents live – of culture, generation and the healthcare system. Without in-depth engagement with the deeply held beliefs and understanding of young people regarding the meanings of SRH, chronic illness and bodily integrity, and their relation to different conceptions of an adult future – including fertility desires – we risk developing ineffective or irrelevant interventions based on inaccurate assumptions that do not account for the centrality of agency and locality in health-seeking behaviours, and that thus have little effect on improving adolescents' adherence to ART and SRH services.

While urgent, evidence-based solutions are required to support ART adherence and improve reproductive health outcomes among adolescents, this research also recognizes the experiential and cultural complexities of living as a teenager in South Africa. This research therefore aims to generate high-quality data on adolescent ART adherence and understandings of SRH through beginning the first phase of the study with in-depth, multi-methods qualitative research.

Qualitative Research Methodology

Qualitative research will take place in two stages: Stage I will consist of a year-long multi-methods qualitative study with 50 adolescents and 70 caregivers, healthcare and social care workers, and will explore the web of contextual and interpersonal factors that inform adolescent ART-adherence and utilisation of SRH services. Data collection methods will include in-depth thematic and narrative

interviews, clinic observations, and body-mapping workshops linked with other art-based group work.

Second in Stage II, adolescents will design youth-friendly support tools to promote ART adherence and SRH service uptake, and contribute to planning the National Department of Health's Youth Health Policy through review and activities. Researchers will work with HIV-positive adolescents, as well as with NGOs, CBOs and clinics, to develop adolescent-led programming recommendations for supporting ART adherence and promoting SRH service uptake. While it is difficult to anticipate what form these adolescent-led strategies may take, existing tools and best practice approaches outlined in the UNICEF Lessons Learned (2013) report will be explored with teen research participants. This stage will use a set of participatory workshops, and will be guided by adolescents' decisions on whether to include other stakeholders, for example clinic staff or local leaders, in this process.

Programmatic interventions that include adolescent participation in youth-friendly health promotion tools are starting to be explored in Southern Africa with promising results (47–49). This is in line with global policy trends, which advocate for increased community participation in health service delivery, shifting of health promotion tasks to lay workers in order to address human resource shortages (50), and greater involvement of people living with HIV (PLHIV) (17). By leveraging the participation of HIV-positive adolescents in the design of youth-friendly support tools, the study will aim to further programmatic collaboration between service users and service providers towards a more holistic approach to youth health-seeking behavior.

This qualitative research will inform the development and interpretation of the quantitative survey, and the qualitative and quantitative research team members have planned a set of integrated qualitative and quantitative dissemination activities.

3.5. Quantitative methods

The findings of the qualitative research, for instance relating to the nature and significance of socio-cultural barriers that potentially impede ART adherence and SRH service utilisation, have informed the content of the quantitative survey, which is underway in 2014. Data collection includes both participant self-report and assessment of clinic records. The quantitative study will take place in collaboration with a clinical research study led by Dr Craig Carty and Prof. Gerry Boon at Cecilia Makiwane and Frere hospitals

The first stage of the quantitative survey will interview 600 HIV-positive adolescents. The second and third stages of the quantitative survey will include a one-year and two-year follow-up, and a survey with a sub-sample to test the feasibility of the tool developed through the qualitative participatory workshops.

The annual quantitative surveys will include 1) biomarkers of adherence; 2) a self-report questionnaire that is completed in the supportive presence of an interviewer due to potential low levels of literacy. This questionnaire will collect information about socio-demographics, health service access and potential risk and resilience-promoting factors for ART adherence and SRH service uptake. Questionnaires will be administered using audio mobile-assisted self-interviewing, with language and structures suggested by the Teen Advisory Group and adolescents living with HIV. In addition, 3) clinic-level data will be collected from hospitals and clinics.

The quantitative study will focus on identifying risk and resilience-promoting factors for ART adherence (in comparison to other long-term medication) and understandings and uses of SRH services among adolescents in South Africa. It hypothesises an interactive model of multiple interlinking influences on adolescent adherence, with potential risk and protective factors including neurocognitive, health service-related, financial, psychological, familial, cultural, nutritional and peer-related ones, but will also include factors arising from the qualitative stage. By identifying potentially modifiable intervening factors, this study will aim to inform evidence-based interventions to promote ART adherence and SRH service uptake. Please contact the research team for copies of questionnaire items at mzantsiwakho@gmail.com. A follow-up quantitative survey will assess the feasibility of the adolescent-developed support tool in terms of fidelity, adherence, exposure, and participant satisfaction. The methodology for feasibility testing will follow guidelines for pilot feasibility testing of the Complex Interventions Framework by the MRC (51).

3.6. Characteristics of the Study Population

Sampling

The full mixed-methods study will sample 720 participants (650 adolescents and 70 key informants). The proposed qualitative research will include 50 adolescent respondents on ART, and 50 key informants, including caregivers, social workers and healthcare workers. The quantitative research will include 600 adolescents. Sampling for both the qualitative and the quantitative study will use the WHO definition of adolescents: aged 10-19 (1,52).

Qualitative sampling

The qualitative sample will be comprised of adolescents on ART and HIV-positive adolescents who are using SRH services, recruited from sites that provide health and social support services for teenagers living with HIV. These include women's health clinics, trauma clinics, ART clinics, youth programmes for AIDS-affected and infected teens and ART support groups. These recruitment sites are likely to produce a biased sample given that all adolescents will be currently accessing services. However, engaging participants over a year-long period will allow for the inclusion of adolescents who are both retained and lost in systems of care.

While the study will be presented to youth as being about 'your life and your engagement with health services', recruitment that is based in ART clinics or programmes for HIV-positive youth implies that the researcher is aware of the HIV-status of prospective participants. Presenting the study as being about 'your life and health' will make room for those who are not particularly open about their HIV-status to participate. Whether or not participants choose to openly disclose their HIV status to the researcher will be left up to them. Presenting the study as being broadly about 'health' will also allow a non-stigmatizing way to present the research to youth groups that include both AIDS-affected and infected teens. To ensure that participants feel comfortable and safe at all times, they will choose the time and place for research-related activities and un-structured engagements. Additional participants in the qualitative study include healthcare workers, social workers, doctors, counsellors, teachers and caregivers. Adult participants linked to adolescent participants (i.e. their caregivers, health workers or social workers) will only be interviewed with permission from the adolescent.

Quantitative sampling

Due to a lack of data on the population of HIV-positive adolescents and low disclosure rates, identifying the composition of a representative sample of HIV-positive teenagers presents numerous methodological challenges. Extensive review and consultations with the Department of Health and UNICEF have identified poor availability of data. National-level data either excludes under-15 year olds (Statistics South Africa, 2011) or groups by 0-14 and 15-49 years (HSRC, 2009), thus precluding identification of adolescents. The 2012 UNAIDS Country Report for South Africa, using clinic-level data, is unable to distinguish between adults and children – and certainly not adolescents – receiving ART. In addition, there is a lack of data on proportions of adolescents infected postnatally, during childhood or adolescence, and of perinatally-infected adolescents who have been informed of their status (39).

In summary, the 3-stage sampling strategy is as follows: 1) Probability-proportional-to-size selection of ART sites using the Department of Health register and initial clinic mapping results; 2a) Sampling of all adolescents on clinic registers that have initiated treatment including adolescents on treatment and in care, and adolescents who have defaulted or been lost to follow-up; 2b) Sampling of all perinatally-infected adolescents on clinic registers including those lost to follow-up and 3) One-year follow-up interview and 2-year tracking of clinic records.

Stage 1: Selection of ART sites using the DoH register. Using a clinic list from online databases of clinics and the Tier.net system recently established by the National Department of Health, (e.g. DoH, 2012) we consulted with healthcare providers in 84 clinics on the numbers of adolescents on treatment in each clinic. Probability-proportional-to-size random sampling from this list, stratified by area, was applied to reach the intended 600 cases. 32 facilities with more than 5 adolescents on treatment each were stratified in four groups by size: 10 facilities with 5-9 adolescents on treatment, 10 facilities with 10-19 adolescents on treatment and 10 facilities with 20-60 adolescents on treatment. The remaining 2 facilities, Frere and Cecilia Makiwane Hospitals, provide treatment for more than 300 adolescents each and were thus included in a fourth group.

Stage 2a: Sampling of all adolescents on clinic registers that have initiated treatment in the past three years. Using clinic records, all adolescents who have ever initiated treatment will be approached for voluntary participation in the study. These adolescents will include primarily adolescents infected through sexual transmission. Female participants recruited at ANC clinics will be eligible for the study if they are currently on ART as part of a PMTCT programme or if they initiated lifelong ART at pregnancy (based on current protocols in which pregnant women with CD4<350 must initiate lifelong ART). *Stage 2b:* Sampling of all perinatally-infected adolescents on clinic registers. Stage 2 sampling will include patients currently on treatment, as well as those who are lost to follow-up - no longer attending clinics – estimated 14% per year in a recent South African study (22). All other adolescent adherence studies include only clinic attendees (2,23,24), but equally important is the inclusion of adolescents who have started treatment but who are no longer or not currently accessing HIV services (often called 'defaulters' or 'lost to follow-up'). To date, no known adherence studies have included this group, and our sampling approach aims to do so in order to minimise potential bias towards adolescents more engaged in the HIV health system.

Stage 3: Annual follow-up interviews and tracking of clinic records including HI-viral load, pill count records, pharmacy refills, loss to follow-up and mortality for two years. All adolescents will be re-interviewed at one year and adherence will be measured through self-reports. In addition, our clinic-based research staff will work closely with health facilities over 2 years to record viral load measurement and pill counts, and will use clinic records to identify regularity of pharmacy refills, loss to follow-up and mortality. Quality of clinic records ranges from excellent to poor, and those clinics with poor record-keeping have requested assistance with building capacity from our research team to reach Department of Health standards. This capacity-building will have a dual benefit of ensuring adequate records for our research, and providing support to under-resourced health facilities. Refusal rates and socio-demographic characteristics of refusers will be recorded and analysed to estimate the extent of bias in the sample.

All of the very few other known studies to date of adherence amongst adolescents have used clinic-based samples. This is problematic as, by default, it excludes key groups of non-adherent adolescents who do not attend their clinic appointments (similar to examining truancy by using a sample of school-attending children and adolescents) or adolescents who do not actively engage with the healthcare system, for example by sending their caregiver to pick up their medication. In order to access both clinic-attending and other at-risk groups within HIV-positive adolescents, a range of targeted sampling strategies will be used, with recruitment in a range of locations, including antenatal clinics, ART clinics, testing sites and STI clinics, schools, prisons, children's homes, home-based care organisations and community-based sampling.

The research team is aware of the need for extreme sensitivity around disclosure – particularly time since disclosure, and context of disclosure – 20% of pregnant adolescents in South Africa are HIV-positive and most are diagnosed as part of a Prevention of Mother-to-Child Transmission (PMTCT) programme. There are also complexities around partial disclosure (for example adolescents told that they are taking medicine for an unspecified illness), and 'unspoken' disclosure (where adolescents have guessed that they are HIV-positive but have never been told). Some adolescents recruited through clinics will be unaware of their own status, and our research team has developed research protocols (see below) to negotiate this complex ethical issue.

3.7. Recruitment and Enrolment

Recruiting from health facilities: Qualitative and Quantitative Studies

Government approval will be sought to access state clinics and hospitals, while access to NGO-run clinics will be negotiated with NGO management. Healthcare workers at the facilities will be informed of the researchers' presence and purpose in the clinics and will be encouraged to ask questions or make recommendations. Access to potential adolescent participants will be negotiated with the help of doctors, nurses, community healthcare workers/expert patients. While there are clear power inequalities between community healthcare workers and their patients, qualitative research among community healthcare workers suggests that they are more trusted than nurses or doctors (53). Recruitment for the quantitative study in clinics will be conducted by research assistants who will be assigned to work in particular clinics, where they will build rapport with healthcare workers and clinic staff. In the first place, clinic cards and patient rosters, provided with the permission of site staff, the district, and the provincial Department of

Health, will provide information about eligible participants, including the numbers of eligible adolescents on treatment and their status (active, transferred or lost-to-follow-up). Adolescents who present for treatment at the ART, women's health, OPD and trauma clinics of healthcare facilities will be approached with information about the study, and a request to participate should they wish to. The process of obtaining assent and consent is clarified in detail in below.

Because teens may not have disclosed their HIV-status or sexual activity to their family, negotiating initial access through caregivers or guardians may risk violating their privacy. It is notable that the consent of a legal guardian is not required in order for a child older than 12 to initiate ART or access a range of SRH services. However, legal guardians will need to provide consent about their child participating in a research project about young people's experience of health services. Community health workers, who interact with families regularly, may also assist in negotiating legal guardian consent.

The question of consent is disputed terrain, especially given that adolescents are situated within the complex power structures of the clinic or hospital, communities and homes. Access and consent will need to be negotiated and re-negotiated on an ongoing basis, with continual re-enforcement that participation is voluntary and may be withdrawn at any time without repercussions. Importantly, researchers will ensure that any sign of discomfort or non-consent (whether verbal or not) will be interpreted as non-consent, following Psychological Society guidelines in working with children.

3.8. Inclusion and Exclusion Criteria

Qualitative study
Participants are eligible for one-on-one research engagements (individual interviews, unstructured participant observation, participatory group workshops) if:

a) They are between the ages of 10-19 years,
b) They are currently initiating/or have previously initiated ART or are accessing SRH services, or they are attending a youth programme for AIDS-affected teens, and
c) If they are below 18 years of age, they, and their legal guardian, have given written, informed and voluntary consent

Participants are eligible for group research activities (body mapping and associated focus groups, workshop-based support-tool development) if:

a) They are between the ages of 10-19 years,
b) They are currently initiating/have initiated ART,
c) If they are below 18, they, and their legal guardian, have given written, informed and voluntary consent,
d) They are part of a pre-existing group of openly-disclosed HIV-positive teenagers,
e) They are willing to discuss their experiences of HIV with the researcher and fellow participants, and
f) They sign a confidentiality agreement stipulating that they will not share what is discussed inside the group-space with others.

Quantitative study
Participants are eligible for the quantitative study if:

a) They are between the ages of 10-19 years old,
b) They have accessed/are accessing treatment for HIV (antiretrovirals), and
c) If they are below 18, they, and their legal guardian, have given written, informed and voluntary consent.

3.9. Qualitative Research Procedures
The qualitative study will engage adolescent participants over an eighteen month period, using multiple methods to explore their treatment decisions and retention in HIV and SRH programmes. A range of participatory and more structured data collection methods will complement observation and un-structured research. Group-based activities will form part of ongoing programme facilitation with HIV-positive youth, which researchers will conduct in collaboration with local HIV/AIDS organisations. In addition to working with youth participants, interviews will be conducted with caregivers and healthcare workers, who may or may not be those caring for or providing services to the teenage participants.

This study design aims towards a minimally invasive, participatory research methodology (54) that will

facilitate the collection of triangulated qualitative data. The research methodology, while systematized and well-substantiated, will also be adaptive and responsive to contextual, ethical or practical demands.

Existing qualitative research on adolescent adherence to ART has often been conducted with caregivers (55) producing research *about* children, but rarely *involving* children (56). The reasons for avoiding research with adolescents pertain to ethical considerations over their vulnerability and concerns that data obtained from children may be less reliable. However, there is a growing body of literature arguing that adults cannot serve as proxies of adolescent experience and that young people can be competent participants, as long as researchers facilitate their participation with caution and sensitivity (54).

In South Africa, seminal studies have facilitated focus groups with HIV-positive adolescents on ART (21,57) and conducted qualitative interviews with youth and their caregivers (57). Mixed methods approaches conducted within a more extensive time-frame will facilitate rapport between researchers and respondents, thereby improving the validity of data collected and allowing for triangulation of methods.

Qualitative data for this study will be collected through: ongoing participant observation, semi-structured in-depth interviews, clinic observation, body-mapping, and participatory group workshops. More detail on how, and at what stage, of the research process these methods will be implemented is provided below. The use of a variety of methods, both traditional and innovative, may help to address some of the ethical and methodological issues that arise in conducting research with adolescents (58). It may help sustain participants' interest, guard against the bias of using a single method, triangulate and crosscheck data, determine the efficacy of different methods (58), and negotiate a balance between non-invasive participation and guided interaction.

Rapport-building and participant observation

Identifying and recruiting participants for this study will require careful, creative and adaptive strategies, which give full consideration to the ethical and methodological challenges of working with teenagers, speaking about sensitive topics like sex, health and illness, and entering the research setting as an outsider. The research team has established partnerships with local HIV/AIDS organisations, primary healthcare clinics, and hospitals, all of which will advise on the most appropriate way to approach potential participants. The research design will also be informed by ongoing consultations with AIDS-affected and HIV-positive teenagers, both through activities with our long-standing Teen Advisory Group and our involvement as volunteer facilitators in a number of programmes for HIV-positive youth. These interactions will provide an opportunity to learn how young people prefer to be engaged, what their interests and concerns are, and what discursive strategies they use to understand and to describe sexuality and health.

Research will begin with an 8-week period of rapport-building, during which researchers will build relationships with HIV-positive adolescents through ongoing participation in NGO programme activities, observation in primary healthcare clinics, and shadowing community health workers. As researchers build relationships with adolescent patients, they may also participate in aspects of their daily life by walking them home, attending extra-curricular activities, meeting friends and family etc. Researchers will also be facilitating a range of extra-curricular programmes, including art-making, health-related workshops and skills-building with HIV-positive young people over this period. The numerous interactions with HIV-positive youth, both inside and outside of health facilities, will allow opportunities to start negotiating future, more structured research participation. During the rapport-building phase, both health-facility and programme-based youth will be aware of the researchers' position as a participant observer. Participating health facilities and NGOs will sign a memorandum of understanding (MOU) with the researcher, when relevant and appropriate. Permission to access state health facilities was obtained from the South African government. Researchers will always introduce themselves as researchers to those who enter the 'scene' of study.

During the period of initial rapport-building and observation, adolescents will decide if they would like to participate in more ongoing (one-on-one un-structured time with the researcher) and/or structured (workshops,, body-mapping or interviews) components of the research, and offer suggestions of how, when and where they would like to engage with researchers. In cases in which participants indicate an interest in participating, the researcher will begin negotiating legal guardian and/or other forms of adult consent in consultation with the adolescent (as explained in the section on consent below). Another key

aim of the rapport-building period will be to recruit Xhosa-speaking key informants to assist with access and translation. These may be teenagers or adults, depending on what is appropriate for the setting, and what participants are most comfortable with.

In light of low disclosure rates, the possibility that legal guardians may not know about adolescents' HIV-status or SRH service access, and the fact that some of the recruitment sites may also include HIV-negative teens, recruitment materials and consent forms will not make reference to HIV. One-on-one ethnographic engagements, which will lead from initial rapport-building and group activities, will be guided by participants, and may include walks, visits to the family home or attending the clinic together.

During the period of rapport-building, participants will be informed of a range of upcoming, more structured research activities in which they could choose to participate. Participation will be voluntary and may be withdrawn at any time without consequence. The order in which activities take place will be negotiated in field and may occur simultaneously for participants who choose to take part in more than one activity. Research activities will be introduced as ways for young people to tell stories about their lives, their bodies and their health, and will not make explicit mention of HIV. The extent to which teenagers reveal their HIV-related experiences will be left up to them, and may depend on the nature and context of the research activity.

Research activity 1: In-depth interviews

Adolescent participants may volunteer to participate in a series of (largely informal) interviews, some more lengthy than others. These interviews will be interspersed and sometimes merged with ethnographic activities, such as visits to adolescents' homes, playing, cooking or visiting the clinic. The participant will chose the interview location and, with their consent, some of these interviews may be recorded, although it is more likely the researchers will take notes. Initial interviews will ask about the *life histories* (59) of respondents, beginning with an open-ended question like, 'Can you tell me the story of your life?' and probing where necessary. These initial interviews will elicit information about respondents' upbringing, when they were diagnosed with HIV, how they discovered their status, their experiences of SRH services, their past experiences of sexuality and intimate relationships, and the current members of their household. Life histories provide a vital context through which to understand respondents' behaviour.

Follow-up interviews will explore participants' daily lives, engagement with HIV and SRH services, treatment practices, and perceptions and experiences of HIV, particularly as they pertain to major health events such as an opportunistic infection or pregnancy, adherence struggles and successes. Where respondents have also taken part in body-mapping, interviews will be informed by the themes and ideas that emerge through these media.

All interviews will explore a list of themes, but will be minimally-structured. Using open-ended questions is more likely to evoke a genuine, spontaneous and un-manipulated narrative as well as eliciting un-anticipated findings (60). Where necessary, gaps will be filled with more follow-up questions or prompts (61). Where feasible and consented to, we will also conduct interviews with respondents' guardians and healthcare workers to explore their perspectives on respondents' health-related practices. Separate interviews will also be conducted with 68 healthcare workers, social service providers and guardians about their experiences of caring for adolescents on ART.

Research activity 3: Body-mapping/focus group discussions

Body-maps are life-size body outlines, filled with visual representations of experiences, feelings and interactions as they relate to the body and the social world. They are useful for research relating to health and illness because they are able to visually represent the interactions between the physical self, perceptions of illness and wellbeing, personal identity and social context.

Body-maps have been used as a therapeutic tool among HIV-positive women in Khayelitsha (62,63) to convey experiences of living with HIV and taking ART. During the 'Mapping Our Lives' workshops, women engaged with medical knowledge, which included anatomical diagrams of organs and representations of the virus. But participants were also encouraged to create spaces for the social - to "think of the body as a museum of life" (62). The PI and other researchers on this project have previous

experience facilitating body-mapping workshops. Body-mapping and other research activities that use visual media to explore teenagers' experiences of ART and SRH may be conducted through weekend workshops or through two-hourly sessions connected to support group activities.

This activity will only be undertaken with HIV-positive adolescents who are willing to disclose both to the researcher and to other adolescents in the body-mapping group. Body-mapping workshops will be conducted with pre-existing groups of disclosed adolescents, such as support groups or programmes for HIV-positive youth. Where non-disclosed adolescents participate in these workshops, extreme care will be taken to uphold participant confidentiality. In our past research, this has taken the form of framing questions about illness and medicines in the more general sense of chronic illness and treatment, rather than with specific reference to HIV and ARVs. A confidentiality contract is discussed and signed by the group in the first session of the workshop.

The first hour of each body-mapping session will be spent in open-ended focus group discussions. These discussions will address relevant themes, including living with HIV, taking medication, adherence to medications, and sexual and reproductive decision-making. Respondents will reflect on their experiences in the home, at school and in the clinic, as well as their perceptions of HIV, ART, contraception and other SRH services (such as pregnancy testing and abortion). Reflections generated in these discussions will be mapped in and around the body outline; using symbols, words and pictures.

Given the effect of peer influence on adolescent behaviour, researchers will need to consider the extent to which focus group responses are shaped by peers in the group. Respondents may not be willing to share the intimacies of living with HIV with their peers, in which case body-mapping strategies will be adjusted to accommodate one-on-one as opposed to group reflections.

In this study, the processes of creating body-maps, eliciting the reflection and expression of participants, will be more important than their final product. The maps will be used to elicit discussion in follow-up interviews, as well as to verify and develop emerging themes in this study. Importantly, respondents should provide their own interpretations of their artwork (56). Data will also be collected through the focus group discussions that serve as part of the body-mapping process. As with in-depth interviews, adolescents who participate in body-mapping and diary activities may choose to engage with researchers on more casual terms beyond these semi-structured methods of data collection.

Research Activity 4: Clinic observation and shadowing of healthcare workers

Healthcare workers constitute a vital vanguard in the provision of HIV and SRH care and treatment services to HIV-positive adolescents. Through close and respectful observation of the experiences and practices of healthcare workers, this research will explore the challenges that they experience in their clinical encounters with HIV-positive teens. Permission to 'work-shadow' healthcare workers who encounter HIV-positive adolescents through their work at ART, Women's Health, OPD and Trauma clinics, will be sought from both hospital management, nurse managers, and the healthcare workers themselves. If this permission is granted, researchers will shadow healthcare workers, with a particular focus on nurses, the front-line care providers in most of these clinical contexts. Through clinic observation, supplemented with in-depth interviews, researchers will aim to learn about how nurses experience consulting, treating and supporting the teens in their patient cohorts. It will explore their understandings of the greatest facilitators of, and barriers to, ART adherence and the uptake of SRH services, as well as their intimate and direct knowledge of how the services which they provide may potentially be improved to support better health outcomes among teenagers.

Tool Development 1: Working with adolescents to collaboratively design support tools for adherence and access to sexual and reproductive health services

Through participant observation, interviews, and body-mapping, researchers will identify adolescents who experience challenges in accessing and adhering to ART and SRH, and who may be interested in exploring ways to circumvent or face these challenges. Researchers will work with these adolescents, as well as with NGOs and clinics, to develop adolescent-led guidance for ART and SRH programming. This part of the study will be focused on adolescent-led strategies and approaches, and it is difficult to anticipate in advance what form these may take. This stage will build on the previous ethnographic and qualitative processes, including a small number of additional adolescents if desirable, and will take place

through a set of participatory workshops. Study design will be guided by adolescent's decisions on whether to include other stakeholders – for example clinic staff, or local leaders – in this process. A primary goal of this stage is to allow the direct input of adolescents into the design and programming that is usually undertaken on their behalf. In addition to tool development, the workshops will focus on assessing feasibility in terms of: (i) acceptability of intervention, (ii) barriers to implementation and participation (64) and local contextual issues.

Integrating and linking with quantitative methods

To date, research on ART adherence and SRH decision-making among HIV-positive children and adolescents has been minimal, and what is available has been characterized by a sharp divide between qualitative and quantitative studies. Clinic-based quantitative research has been unable to account for the subtlety and complexity of influences on adolescent ART adherence and SRH decision-making, nor has any known research included adolescent participation in the design of surveys and support tool.

This study has the further aim of directly informing the design of a linked quantitative study of barriers and facilitators for HIV-positive and -negative adolescents, and to utilize this larger sample to test for acceptability the adolescent-designed support tool described above. Sequencing of research has allowed data collected and analysed in the qualitative study to contribute directly to the quantitative study – not only in what questions are asked, but also in how they are asked and in what order. By exploring the cultural, generational and gendered structures of authority in which adolescents are embedded, and by eliciting important information about the way in which adolescents understand, live and speak about key concepts such as HIV testing, ART medication, contraception and fertility desires, the quantitative study design has been guided by its findings in study design, and sensitised to the context in which this data is gathered.

By working as a team with both qualitative and quantitative researchers, projects will be integrated not only in design, but also in the development of inter-disciplinary understandings of the experiences of HIV-positive adolescents, particularly as these relate to and influence their uptake of, and adherence to, ART and SRH. This cooperation has been key during the design of this research protocol and will continue throughout analysis and dissemination.

3.10. Quantitative Research Procedures

The quantitative data collection process will include: (1) participant interviews, (2) secondary data from patient records, and (3) facility-level information.

Quantitative Measures – Questionnaire

The questionnaire has been drafted after consultations with over 20 experts in the field of adolescent health and piloted with HIV-positive youth in South Africa and the region. Measures use (where available) tools validated in Southern Africa (65–67). All measures have been piloted prior to use.

Digital devices – 7-inch tablets – will be provided to participants for completing the questionnaire. Trained research assistants will sit with adolescents to demonstrate how to use the tablet and to guide the participant where necessary. The participant will then be offered the opportunity to complete the questionnaire autonomously. The name or contact details of the participant will not be included in the questionnaire – each individual will only be identified through a unique participant ID. Data will later be collated, but the confidentiality of the participant will be upheld. The use of mobile devices – 7-inch tablets – will increase the accuracy of the answers given by participants. Adolescent participants of multiple studies using mobile devices have reported that this method allows for more truthful answers and greater confidentiality (68–71). A study among students in South Africa concluded that most students perceived the electronic questionnaire to be a more confidential method of answering questions about sex: 77% of those using electronic questionnaires and 51% of those using paper questionnaires (72). The cellphone number made available in recruiting material will only be accessible to the research team. If participants leave a 'please call me' message (a free text message), only the research team will contact them. Should participants share additional contact details with researchers (Facebook, Mxit, etc.), this information will be kept confidential.

(i) *Outcome measures: Adherence.* For adolescents who report having been prescribed any

chronic medication, a triangulated approach to measuring ART adherence, found to be the most reliable method amongst youth (73,74) will be used. It is important to measure adherence across a sufficient but feasible time period. Our systematic reviews of ART adherence amongst adolescents, adults and children (in preparation) found either cross-sectional surveys using retrospective reporting of general adherence (75), or of past 3 days (76,77) with a small number of studies using pharmacy refills up to 24 months (2). Although pharmacy refills are only a moderately reliable indicator of ART adherence, it is important to measure adherence over a longer-term period by identifying change over time. This study therefore proposes the use of three methods for assessment of adherence. 1) each participating adolescent will receive visits, including a questionnaire completed with the help of an interviewer. These will collect information about ART adherence, socio-demographics, service access and potential risk and resilience-promoting factors, using standardised instruments and triangulating measures of adherence (78,79) and used in South Africa (80–82); 2) viral load and CD4 cell-count (where available) measures; 3) medication refill rates (83). Viral load, CD4 and medication refill rates will be recorded from patient files at each facility where they are receiving care.

Sexual and reproductive health outcomes will be measured using standardized tools from similar Southern African studies and studies among HIV-positive adolescents in the region and globally. Sexual health outcomes will include measures of: (i) sexual activity: debut, current levels, (ii) types and number of partners (84) condom use by partner type, (iv) forced sexual experiences/ sexual abuse, (v) transactional sex, and (vi) HIV knowledge and attitudes. Reproductive health outcomes will include (i) parenthood ideations and plans, (ii) pregnancy – past and current, and use of contraception (hormonal, condom, termination of pregnancy, etc.). Through open-ended questions, the survey will explore experiences of adolescents in accessing SRH services and potential reasons for dropping out or defaulting.

Potential risk & resilience factors: (Figure 1) Individual factors include mental health issues (85), HIV-related neurocognitive impairment (23), physical and learning disability (86), level of treatment understanding, and beliefs in myths or fears around HIV or medication (87). *Gender, sexuality and sexual health factors* are highlighted as important by HIV-positive adolescents (88). Potential factors include transactional sexual relationships and challenges around disclosure to sexual partners, particularly unintended disclosure via taking medication (21). Teenage pregnancy and enrolment into a PMTCT programme may positively or negatively impact adherence. Studies of PMTCT programmes report low adherence, and a qualitative study of teenage mothers reported overwhelming fears of confidentiality breaches by obstetrics staff (89). In addition, contraceptive and sexual health services use may impact adherence, with reports of healthcare staff strongly critical of adolescents wishing to have sexual relationships and plan families.

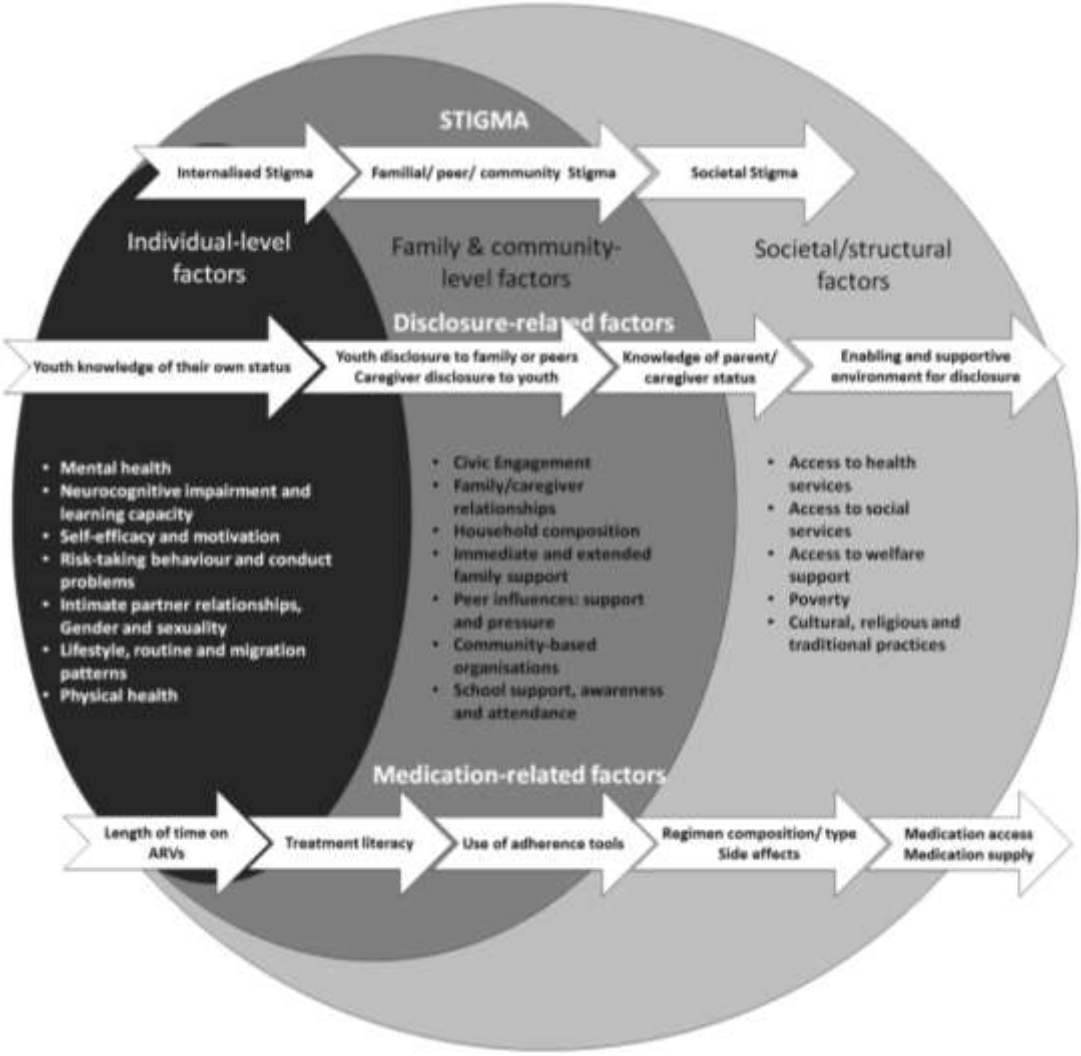
Family and community factors: Qualitative studies suggest that *family relationships* and extent and nature of primary caregiver involvement may be crucial (90). Potential factors will include HIV disclosure by and to families (and timing and nature of disclosure) (91), migration, changes of primary caregiver due to death and illness, physical, emotional and sexual abuse and domestic violence (92).

School, peer & community factors may be particularly important as adolescents develop social identities (93). Potential factors include bullying, stigma and support inside and outside school (94), school attendance and achievement, drug and alcohol use, gang membership and incarceration.

Structural factors: *Social protection and economic factors* include socio-economic status, food security (95) and access to services such as state grants and social services. Distance and transport to clinics have been shown to impact adult adherence (96), and may present even greater difficulties for adolescents with fewer financial resources. *Antiretroviral, HIV treatment, care and support service factors* include use of traditional healers, the social position of those who may recommend alternatives ART (97), complexity of regimens and palatability of medication. Side-effects of medication (such as fat redistribution – lipodystrophy) may be especially embarrassing for adolescents in their peer environment. Prior research indicates that experiencing lipodystrophy and other side effects of HIV medication can affect people's self-esteem, sense of control, social and sexual relations, and can contribute to demoralization, forced disclosure, and the decision to stop treatment (98,99). Access to HIV support services such as support groups, youth clubs and adherence monitors, may be an important predictive factor. In addition, adolescent experiences in health services may be relevant, as qualitative studies report adolescents treated with disapproval and contempt by healthcare staff (100).

Based on the initial findings of the qualitative research and participatory workshops on tool development, the final step of quantitative research will involve testing the feasibility of a tool for young people developed by adolescent participants. A quantitative appraisal of the tool's accessibility, potential for reach and exposure will be conducted with a sub-sample of the expected 600 youth. Based on the main content of the tool, short-term outcome measures shall be selected and measured during the initial data collection and feasibility step. These outcomes will most likely include adherence to ART (past-month recall) and utilization of SRH services (primarily pregnancy, contraceptive use and TOP services).

Figure 1: Hypothesised risk and protective factors for adolescent ART and SRH use



Quantitative Measures – Retrospective Patient Records

In light of potential poor treatment and health literacy rates among patients on ART, the questionnaire information on CD4, viral loads and medication refills (2) will be complemented with data recorded from patient files. This data will be recorded using a protocol previously applied in other studies among adolescents on ART (94) adapted to patient files in the facilities that participate in the study. Participant self-reports through the questionnaire and data extracted from patient files will be linked through an anonymous unique identifyer. Data will be extracted from patient files at baseline and on an annual basis for two years (2015-2017).

Quantitative Measures – Clinic-level information

An extensive literature review on factors affecting adherence and access to SRH points to a series of clinic-level factors that affect both. Factors including clinics-based nutrition programmes, staff/patient ratio, provision of counselling, and ease of access to patient records are associated with improved adherence or access to SRH services (literature review is in process). To that end, the research team will develop a clinic-level "profile" of literature-informed indicators, which will be linked to each patient who receives care in that clinic during data analysis. Clinics will not be uniquely identified, but dummy variables will be computed based on the clinic-level factors for participants who receive care in that facility.

3.11. Data entry, safety, monitoring and storage

Data quality will be ensured through rigorous training, spot-checking during data collection and during data entry, which will happen in parallel with data collection. All data collected will be automatically uploaded into a secure server through an open-source software platform – Open Data Kit (www.opendatakit.org), which will be anonymized prior to data analysis to ensure confidentiality of participants. Regular backups of all data will ensure that the database is safe.

Every effort will be made to maintain participants' confidentiality. All data will be identified by a unique participant number and kept in confidential files. Identifiers will be removed from interview transcripts, questionnaires and original recordings, and coded so that only the researchers can access identifiable information. No individual identifying information will be collected or disclosed in reports, publications, or presentations.

Participants will be notified, both verbally and in consent forms, that confidentiality may be breached if the participant is considered to be at significant risk of harm. This includes abuse, neglect or family violence (further details below).

Electronic versions of transcripts, recordings, questionnaires and field notes will be kept in a password-controlled electronic file, accessible only to the researchers. All study documentation including questionnaires and informed consents will be kept in locked cupboards or password protected hard-drives/ computers. Consent documents will be kept separately from questionnaires. Hard-copy data (transcripts, field notes and questionnaires) will be coded – removing identifiers so that only the researchers are able to link it to individuals using a study master list available only to the project investigators and fieldwork project managers.

Data will be stored within the secure offices of the AIDS and Society Research Unit at UCT.

3.12. Data Analysis

Qualitative Study
Qualitative data analysis will adopt key procedural principles from Grounded Theory (101). Data collection and analysis will occur simultaneously, 2.) Analytic codes and categories will be developed from the data and not from preconceived hypotheses, 3.) The analysis will use constant comparison to compare similarities and differences across and within themes, thereby limiting bias, 4) Theoretical memo-making will occur alongside analysis and during the write-up, and 5) The sample will be selected for the purpose of theory construction as opposed to the representativeness of the given population, following theoretical sampling, common to grounded theory (102). Multiple researchers will review the coded data in order to verify findings. The characteristics of the sample recruited will be thoroughly and clearly presented to ensure that others may assess the credibility and transferability of findings (103). Although safeguarding the confidentiality and anonymity of the participants is paramount, analysis will document the overall pool of available teenagers, caregivers and healthcare and social support workers that were deemed eligible for participation, how many refused to participate and their reasons for refusal.

Quantitative Study
Data analysis will be undertaken in SPSS and AMOS (with MPlus if needed). Where relevant, mixed-method data will be used. All analyses will control for socio-demographic co-factors and potential confounders.

Research aim 1: To examine differences in rates of adolescent adherence and access to SRH amongst key subgroups will use descriptive statistics, multivariate regression and ANCOVA.

Research aim 2: to identify which risk and resilience factors predict ART adherence and SRH uptake amongst adolescents, to investigate interactive pathways, interactions and cumulative effects between factors will use multivariate regression, and a set of statistical techniques previously utilised in our longitudinal studies of AIDS-orphaned children. These include log-linear modelling (104), testing of interaction effects in regression models, mediator and moderator analyses in path analysis, and structural equation modelling – which allows simultaneous analysis of multiple predictors, intervening variables

and outcomes(105).

Research Aim 3: To examine whether risk and resilience factors and pathways differ among subgroups of HIV-positive adolescents will use ANOVA, SEM and log-linear modelling to compare subgroups;

Research Aim 4: To determine whether HIV-positive and HIV-negative adolescents have different exposure to risk and resilience-promoting factors, and to health services will use multivariate regression and ANCOVA.

Finally, the quantitative study will analyze the feasibility of the tool developed through participatory workshops, focusing on participant satisfaction and potential for adherence/exposure to the tool by HIV-positive adolescents. Descriptive statistics and regression will be used to identify which tool features are most appropriate for HIV-positive adolescents.

4. Risks and Benefits for Participants

This study aims to investigate risk and protective factors for ART adherence and SRH service uptake among adolescents in South Africa. We will be interviewing adolescents as young as 10 years old, and because the interviewers are adults, this presents a significant power inequality. This power differential is further complicated by class and language distinctions between researchers and study participants. These inequalities will be sensitively and carefully considered. Building trust and rapport with participants, and explicit reflexivity during data collection, data analysis and reporting of the study will all be essential in generating high-quality data and research findings in a non-coercive setting. When fieldworkers are employed and trained for the study, training will focus on building social sensitivity towards unequal power relations. By explicitly encouraging social sensitivity and awareness of our team's roles as researchers and social positions, we will reduce feelings of inequality and prevent coercive work with participants. It is also important to recognise that in a positive and youth-centred research environment, adolescents may benefit from the opportunity to interact with adult facilitators. Adolescents may appreciate a trusted adult to confide in and an opportunity to access information in a confidential setting. We do not anticipate that the interviews will cause any additional distress either to adolescent participants or their caregivers. However, in order to reduce any risk of respondents becoming distressed, guidelines have been developed (see below).

We note that – in all our previous studies – a range of complex cases of children and youth in extreme need have arisen from our research (partly because this is often the first opportunity a child has to discuss in detail their lives, we have very high levels of disclosure regarding rape, abuse and other traumatic life events and conditions). All cases where a child or adolescent may be at risk or is experiencing significant harm are discussed in detail with the qualified South African child protection social worker on the team. Given the very low availability and variable quality of social services in some low-income areas of South Africa, close supervision by the social worker is provided of all cases, referrals and any supportive action taken by the team.

1) Qualitative data collection tools will be participant-driven and youth-oriented. Quantitative interview materials administered through tablets include teen-friendly images and language designed to engage youth in a comfortable and open style.
2) The majority of adolescents in this study will be HIV-positive and will have disclosed their HIV-status to the researcher in confidence. This study recognises the duty of researchers to uphold participants' constitutional right to privacy and dignity, particularly in a context where HIV remains highly stigmatised. Therefore, in line with the National Health Act (2004) and legal guidelines released by the Open Society Foundation (106) as well as the former AIDS Law Project (2003), researchers will not disclose the status of adolescent participants without their explicit consent. All researchers involved in the project have been trained on strict confidentiality and disclosure guidelines and have signed a fieldwork agreement that includes this information. In cases where HIV-positive participants report having unprotected sex with their partners, resulting in a tension between the participant's right to confidentiality and the public health impetus to protect at-risk partners, researchers will adopt the following procedure as per recent guidelines: 1) advise the adolescent about the risks of unprotected sex for both their own health and the health of their partner, 2) encourage voluntary disclosure and safer sex

and provide support to the participant, 3) suggest a joint session with a trained HIV/AIDS counsellor who can assist the adolescent in disclosing or negotiating safer sex, 4) if these approaches are not successful, the researcher will inform the participant that they will be informing a doctor or healthcare worker familiar with the adolescent, explaining the ethical obligation to do so. This is in line with section 14 (80) of the National Health Act, which makes provisions for disclosure if non-disclosure amounts to a serious threat to public health. When consent for participation is sought, participants will be made aware that their confidentiality will be breached only to prevent grave harm and never before consulting with them. If researchers have to resort to informing a healthcare worker of a participant's unsafe sex practices and non-disclosure, it will be recommended that the relevant healthcare worker follow established best practice for HIV disclosure outlined in published legal guidelines (106).

3) Given the complex nature of adhering to long-term medication, this study will identify a number of adolescents who have defaulted or not yet initiated life-saving medication, including ART or TB medication. In cases when participants report non-adherence, the researchers will highlight the importance of adherence to medication and encourage the participant to consult their healthcare workers and adherence buddies. Specific information obtained on the dosage, adherence patterns and other influencing factors for each individual will not be shared with their healthcare worker or legal guardian in order to maintain participant confidentiality. However, adolescents experiencing symptoms of TB, pneumonia or any other opportunistic infection will be referred to a healthcare professional. Given the risk of significant harm, this constitutes a legitimate breach of confidentiality. Participants will be told at the consent stage and in information forms that there are limits to confidentiality when someone is deemed to be at risk of significant harm.

4) In order to protect confidentiality of the participants and protect them from the stigma associated with HIV/AIDS, each interview will be conducted with as much privacy as possible in a space chosen by the participant. In addition the study will be presented within communities as investigating health and social services experiences generally, rather than being an HIV-specific study.

5) As in all research with children and adolescents, there is a possibility that participants will take the opportunity to disclose difficult living circumstances or abuse. This study recognises that researchers have a responsibility towards children who may disclose information showing them to be at risk of severe harm. Recent research in South Africa has carefully considered these issues. Guidelines are set out by the HSRC/UNICEF study on children's psychological adjustment in South Africa (107) and in the South African Children's Institute/ACESS Child Participatory Poverty Research (108). These promise confidentiality except when a child is shown through the research to be at risk. In cases of risk, and with the consent of the child, they will either be referred to organisations that can provide assistance (ACESS study), or their caregivers will be told (UNICEF study). The choice of these options will be made in consultation with the social worker and psychologist on the research team, and on the basis of best outcomes for the child. Most research with vulnerable children in South Africa considers it an ethical principle to provide help for children whom the research identifies as in need. For example, research undertaken by the Medical Research Council Unit for Anxiety and Stress Disorders routinely refers children to child psychiatric services or to the University of the Western Cape Child Psychology clinic in cases in which there is need for these services (109,110). A University of Cape Town study on child mental health referred children in need to social services, as does research in the Africa Centre on HIV-positive caregivers and infants (111). Researchers on this team have been investigators on three previous studies with AIDS-affected children in South Africa. Based on these studies and on protocols devised from research studies with similarly vulnerable groups (112), the following protocol is proposed:

a) Informing all participants at the consent stage that everything said will be confidential unless it becomes clear that they are at risk of significant harm.

b) If information is disclosed that suggests that the participant, their sexual partner, or a member of the household is at risk of significant harm, the researcher will discuss concerns with the child at the end of the interview before any further action is taken.

c) If the participant or a member of their close network is at risk of severe harm, the researcher will discuss the possibilities for referral with the child participant. If the child does not consent to sharing

of information, and the harm is not considered to be significant, the child will be given information about self-referral agencies such as ChildLine SA.

d) However, if the harm is considered to be significant the researcher, assisted by employed fieldwork volunteers, will consult with social services or other organisations. If the decision is made to take action, the participant(s) will be informed (*Please see attached draft referral form*). If referral requires disclosing the child's HIV-status, then the procedure described in 2) above should be followed.

6) This study has an obligation to plan for the possibility of participants, child or adult caregiver, becoming distressed. All interviews will be trained and experienced in working with affected children and families. The research team includes a social worker, a psychologist and HIV counsellors who will be available to supervise researchers and help them to discuss issues with the families and children following the interviews. As discussed above, if there is a need for a participant to access more extensive support (such as consulting a counsellor or attending a clinic) referrals will be made (Please see sample referral letters in the appendices).

The research team is obligated to any participant who may feel distressed following the study or who may reports behaviours that require follow-up counselling. All interviewers are trained and experienced in working with affected children and their families. If a participant becomes distressed, interviewers will be available to discuss any issues he or she may have, and make referrals if required. Interviewers will also contact the project manager by cell phone when they have a particular concern, or when a participant requires more information or their case requires further discussion. Furthermore, in cases laid out in question 13.a (i), additional sessions might be needed to ensure that risks identified are addressed by participants.

Risks to Researchers

There are general risks in doing fieldwork and we ensure that all research assistants and fieldwork staff are trained in awareness and safety measures. We provide all staff with panic alarms. Staff will not undertake interviews in any situation in which they feel uncomfortable or unsafe. Where there is concern about safety of an area, staff travel in pairs. Where needed, a 'community guide' with strong knowledge of risks will be hired to assist with staff safety. Consulting community organisations about the methods and purpose of the research in each area will also help to ensure that researchers do not face suspicion and mistrust from non-participants in the community. University counselling services will be made available to researchers should they need psychological support. All staff cars are properly equipped and regularly serviced.

Benefits to participants

Participants will have an opportunity to share their experiences and concerns with trusted and sympathetic adults and access referrals where necessary. Fieldworkers and volunteers on the project will assist adolescents in accessing health and social services. Given the network of partners and collaborators and the objectives of this study, the intention if for participants' responses to be used to inform health policy and programming for youth at local, national and regional levels. Health facilities and organisations participating in the study will receive highly specific feedback about the experiences of their youth patients, the aim of which is to have a positive impact on service provision. Finally, this project hopes to develop and test for acceptability an adolescent-driven support tool to benefit youth accessing ART and SRH.

5. Process of Obtaining Informed Consent and Consent

General Principles
All information sheets and consent forms will be given to potential participants and their legal guardians by the researcher or members of the fieldwork team. All information sheets and consent forms will be read to participants in their preferred language to prevent illiteracy from hindering a participant's understanding of the methods and purpose of the study. All participants will be told they have the right to decline to participate, drop out at any time, and that all the results will remain confidential. Any avoidance of study participation will be understood as a lack or withdrawal of consent.

Participants may consent to participate only after having the information sheet been read to them and been given an opportunity for questions.

Participants will have the opportunity to consider consent for up to a week before interviewers return. However, when we have previously offered participants periods of 24 hours to 1 week to consider consent, the vast majority have requested to participate immediately. In light of this, we propose that participants are offered the choice of whether to consent or refuse immediately, or to have 1-7 days to consider whether they choose to consent.

All participants should be capable of giving their own consent, and we will not interview any adolescent or adults deemed incompetent. Special care will be taken to ensure that all participants are fully aware of and understand the research.

We will obtain written informed consent from each participant in this study.

1) Consent for adolescents to participate
In order to ensure fully informed, voluntary consent for adolescent participants, all adolescents will be provided with information sheets describing the study in their first chosen language, which interviewers will read aloud. If participants are illiterate, they will be able to give verbal consent and indicate with a cross on the signature line. Particular attention will be given to issues surrounding statutory requirements to break confidentiality (i.e. if the adolescent or a member of their household is at significant risk). Only after the purpose of the study and the format of the interview have been explained will the adolescent be asked for their consent to participate.

All attempts will be made to ensure that the research is a positive and participatory experience for all participants, and that consent is both voluntary and informed. All interviewers will have experience in working with vulnerable children affected or infected by HIV/AIDS. If the participants have sensory difficulties, the research team will ensure they can access the questions, for example, a signer will sign the questions to deaf adolescents. Reading the questions out loud will ensure that blind adolescents can participate.

To ensure that children and adolescents do not feel obliged to participate in the research, emphasis will be placed on their ability to refuse to participate, or to cease participation at any point during the research (*See attached Consent and Information Sheets*). Following British Psychological Society Guidelines (113), any avoidance by adolescents of the interview situation will be taken as evidence of failure to consent. Adolescents who refuse to participate, or who stop the interview, will still receive snacks and certificates. All research materials will be provided in English and Xhosa. Interviewers will explain all aspects of the project to adolescents and answer any questions they may have in adolescent's preferred language.

Perinatal HIV-infection can bring with it cognitive delays for children. These can be reflected in a wide range of difficulties, for example a lowered reading age or a lowered cognitive age. The effects and impacts of this for adolescents are still under-researched (52,114), and there are no clear guidelines on how to account for these difficulties in conducting research with children and adolescents who are perinatally-infected with HIV. Many perinatally-infected children look younger than their real age, may have developmental and educational delays (115) but feel and understand themselves to be teenagers. There is also an ethical imperative not to exclude adolescents based on an inappropriate understanding of their potential developmental delays. This study hopes to address this by careful training of research assistants to assess cases in which adolescents do not seem to understand the process or meaning of participation in research, and in these cases will refer to expert partners working within this research collaboration for guidance. We understand that this is a complex issue, and would welcome the advice of ethics committees in addressing this.

*2) Legal guardian consent for adolescent participation**
(**The following process and procedure is applicable to adolescents who have not yet turned 18. Adolescents who are 18-19 years old will be treated as adults with regards to informed consent issues, in compliance with all the of regulations cited in this protocol*.)

Each adolescent's legal caregiver will also provide consent for participation in this study, and will be provided with information describing the study in their first chosen language. Particular attention will be

given to issues surrounding statutory requirements to break confidentiality (i.e. where the adolescent or a member of their household is at significant risk).

In some exceptional circumstances related to HIV/AIDS vulnerability, the adolescent may wish to participate but the legal guardian is unavailable (through death, living elsewhere and being un-contactable, or being too sick to give consent). In these cases, the adolescents will be excluded from the study.

In our prior work with Young Carers and in our orphan resilience study, we identified a small but worrying group of orphaned children who wanted to participate in the study but who explained to us that they lived with a foster carer who was forcing them to undertake large amounts of domestic work against their will, and that the carer would not consent to their participation in the study because of the fear that this abuse would be revealed. When consent was requested from the caregiver, they did refuse. In cases in which children and adolescents experience abuse from caregivers or guardians, consent for the study would be difficult to obtain, as these caregivers would not want to be reported. In light of prior research findings regarding abuse experienced by HIV-affected children in the Young Carers project (116), we expect that similar difficult cases may arise in this study. These cases will be immediately reported to the appropriate authorities. Protocol about reporting the abuse and getting support for the participant will follow legal requirements and include reporting of the case to the social worker for the ward or local administrative unit. The team's co-PI is a trained South African social worker and will provide additional guidance on managing each specific case.

Research team members consulted colleagues at the University of Cape Town Health Sciences REC, the University of Witwatersrand, and Social Workers at Cape Town Child Welfare about this issue. We also consulted South African legislation, particularly the Department of Health Research Ethics Guidelines (2004). The ethics processes and procedures proposed in this research project were reviewed and approved by the following ethics committees and institutions:

(1) Health Sciences REC at University of Cape Town (REC REF 389/2009),
(2) Research Office at the University of KwaZulu-Natal: ethical clearance number HSS/0254/09),
(3) Department of Social Development, Republic of South Africa (date: 15/12/08),
(4) Department of Health, KwaZulu-Natal province (reference HRKM091/09),
(5) Department of Education, KwaZulu-Natal province (Ref. 0048/2009),
(6) Department of Education, Mpumalanga province (date: 13/05/2010),
(7) Department of Health, Mpumalanga province (date: 25/02/2010),
(8) Department of Education, Western Cape province (Ref. 20100225-0034), and
(9) Inter-Divisional Research Ethics Committee (I-DREC) of the Social Sciences and Humanities Division, University of Oxford for the Preventing Abuse of Children in PACCASA study (Ref. No.: SSD/CUREC2/11-40), Young Carers Round 2 study (Ref. No.: SSD/CUREC2/11-02 and SSD/CUREC2/09-52), and most recently
(10) I-DREC of the Social Sciences and Humanities Division, University of Oxford for the study protocol hereby presented (Ref No: SSD/CUREC2/12-21).
(11) Centre for Social Science Research, University of Cape Town (CSSR2013/4)
(12) Department of Health, Eastern Cape Province (29 August 2013)
(13) Department of Education, Eastern Cape Province (4 April 2014)

A growing South African literature (117–120) argues that Section 71 of South Africa's National Health Act, which requires active written consent from a legal guardian where research subjects are under 18, runs the risk of compromising adolescents' constitutional right to privacy, confidentiality and dignity. This is particularly the case with regards to research on stigmatised subjects such as HIV, ART and SRH (120). It also produces a recruitment bias in favour of respondents who communicate about sexual health with their guardians. Disclosing an HIV-positive status to family members may result in discrimination, violence and social ostracism (121). Hence additional parental or guardian consent may a) be logistically impossible, b) necessitate breaching of confidentiality, and c) place the participant at risk of harm (120). Therefore, adolescents who have not disclosed to their guardians will be excluded from the study.

The study will follow the ethical guidelines for conducting research among adolescents as outlined in the Child Care Act (2005) and the Department of Health Ethics in Health Research (2004). Where the adolescent states that their caregiver will not consent to their participation in the study due to the fear that their abuse of the adolescent will be revealed, or in exceptional cases where the adolescent is

unwilling to disclose their HIV-status to their caregiver (and is concerned that the research – whilst not focused only on HIV, will reveal this to the caregiver), the participant will be excluded from the study, but researchers will subsequently make social services referrals for all children and adolescents in abusive situations. Those eligible participants who have not disclosed to their legal guardian, parent or caregiver will be linked with disclosure counselling and support, where available at the local clinic.

Any adolescent who declines to participate before or after the interviewer has explained the project will not be interviewed, even if the legal guardian or nominated adult agrees to or encourages participation.

3) Informed consent for adult caregivers (qualitative study only)
For the qualitative study only, where adolescent participants assent, their caregivers will also be approached as potential interview respondents. This study will obtain informed consent for each adult caregiver. All adults will fill in 'opt-in' consent forms if they agree to participate. All information sheets, consent forms, and interview materials will be translated into participants' first language.

4) Informed consent for professional and community health and social workers (qualitative study only)
Healthcare workers will provide crucial information that will allow the research team to triangulate findings on factors affecting access to treatment (58) during the qualitative part of research. This study will obtain informed consent for each healthcare worker included. They will be given information sheets, consent forms, and interview materials in the participants' first language. Professional and lay health workers will be reminded not to mention their adolescent patients by name or to give any details that might identify patients. No real names (either of healthcare workers or patients they may accidentally mention) will be recorded in interview transcripts. Copies of all information sheets, consent forms and interview materials are attached in the Appendices.

6. Privacy and Confidentiality
Participants will choose the time, location and nature of their engagement with the research team. In the case of focus groups and other group-based research activities, participants will sign a confidentiality agreement, but will be warned that confidentiality cannot be guaranteed as group members may discuss what was said outside of the group despite having signed this contract. The cell phone number made available in recruiting material will only be accessible to the research team. If participants leave a 'please call me' message, only the research team will contact them. Should participants share their contact details with researchers, this information will be kept confidential.

7. Reimbursement for Participation
No financial incentives will be provided to participants, however all participants will be given snacks while participating in structured research activities. Participants will choose the site of their interviews to avoid unnecessary transport or child-minding costs, but if the participant chooses to travel for the purpose of maintaining privacy, they will be reimbursed for travel costs and, if necessary, a volunteer made available to assist with child minding. Participants involved in more ongoing research activities (particularly in the qualitative study) may also be offered assistance with homework, or other forms of non-monetary help based on the nature of the engagement. Following participation all participants will receive a Certificate of Participation regardless of completion. As in previous research conducted by members of this research team with HIV-affected communities, financial rewards will not be used. This is for two primary reasons: firstly, as financial incentives can in some cases lead to conflicts within the community or household, and secondly, in order to prevent adolescents agreeing to participate in the study in order to access money – which would reduce the voluntary nature of consent.

8. Emergency Care and Insurance for Research-related Injuries

Salaries for field staff who are not covered by University insurance include an additional sum to be paid towards medical insurance. In addition, the projects have extensive staff safety protocols, addressing issues from hazardous animals at research sites to road safety risks. All staff are trained in these protocols, which are available and attached.

9. What Happens at the End of the Study?

The study design, in partnership with government, NGOs and HIV-positive adolescents, has the specific aim of informing policy and programming. This collaborative approach to identifying the research focus

and in designing the study is central in ensuring that findings will have direct relevance for HIV programming in South Africa's public health sector and beyond.

Specific policy impacts will include direct input into USAID, UNICEF, UNAIDS and PATA programming (through our regular meetings with these organisations), and national policy commitments such as sub-Saharan African governmental 'National Strategic Plans', National Action Plans for AIDS-affected children and the Department for Social Development's Strategy for Adolescent Sexual and Reproductive Health Services. Research team members have experience in the dissemination of research findings for inclusion in national HIV policies for both academic and advocacy purposes.

Dissemination and outputs will take place throughout the study and will include both peer-reviewed publications and dissemination strategies targeted at policy-makers and programmers. With the research partners PATA, UNICEF, UNAIDS and the South African government, dissemination will include one-page policy briefs (see for example www.youngcarers.org.za/publications), presentations at key policy meetings such as the International AIDS Conference, the International Conference for AIDS and STI's in Africa, as well as smaller, high-level policy forms with government ministers in the Southern African region, funders such as UNAIDS/PEPFAR and the Global Fund. Dissemination of research findings will also take place at study sites, with health services, community meetings, and with local leaders.

Feedback to participants is a key part of a youth-focused research design (122). At each stage of review and data collection, the study will create 'brief reports': summaries of study findings in lay language. These will focus on findings relevant to NGOs, clinics and government in their work with adolescents. Researchers will also report back verbally to adolescent participants, encouraging their thoughts and feedback on emerging findings. For example, the later stages of the qualitative research will ask participants to respond to some of the quantitative findings, which will serve as a form of feedback. Presentations will be made to local NGOs, health services and community groups. No identifiable details will be given in any dissemination or feedback.

10. Research team

The UK and South Africa-based team builds on established strong working relationships between academics, government and civil society. Dr Cluver (Oxford University & University of Cape Town) has led two longitudinal surveys of 8500 AIDS-affected adolescents in South Africa and acts as an adviser to the SA Government, WHO, USAID, UNICEF and Save the Children; Dr Hodes (University of Cape Town) has conducted qualitative research on partnerships for ART provision and healthcare workers and patients experiences of SRH services with a focus on abortion; Dr Mark is Executive Director of Pediatric AIDS Treatment for Africa, an NGO working with 235 HIV clinics in 23 Sub-Saharan African countries, Dr Boyes (Curtin University) is a psychologist specialising in stress and coping; Dr Kaplan is a sociologist with experience in quantitative and qualitative research on HIV and modeling viral load and other biomarkers (University of Oxford), Professor Orkin (University of Witwatersrand) is the former Chief Statistician of South Africa and is an expert on community survey analysis. The team includes three Oxford University doctoral students (on Clarendon and Rhodes scholarships: E Toska, B Vale, M Pantelic) and a PhD and MSc student, both officials in the Department of Social Development (M Nxumalo and L Mokotedi), and based at Medunsa and University of Pretoria respectively.

The study includes a 'Methods Advisory Panel' of international experts in adherence research (Dr E Lowenthal, Children's Hospital of Philadelphia, Dr C Luo, Senior HIV Program Adviser, UNICEF and the UN Technical Advisory Group for Adolescents Living with HIV: Dr S Kassede, Dr C Suzuki, Dr D Chamla, Ms P Lim Ah Ken). In addition, the study includes a 'Policy Advisory Panel' (Dr R Yates, Senior Adviser, HIV/AIDS, UNICEF HQ,) UNAIDS (Dr R Jackson, UNAIDS Secretariat), UNICEF South Africa (Dr S Bhardwaj, Senior HIV/AIDS specialist, Dr S Crowley, Chief of Health), The South African Department of Social Development (Dr M Kganakga, Chief Director, HIV/AIDS), Department of Health (Dr L Madisha, Division of Pediatric HIV), Department of Basic Education (G Ndebele, Deputy Director-General of Social Inclusion). In addition, our Teen Advisory Group of AIDS-affected adolescents – with whom we have worked since 2008 – will be actively involved throughout the research in ensuring applicability and teen-friendly approaches.

11. Stakeholder Participation

Teenagers living with and affected by HIV/AIDS have been key contributors in designing, implementing and reviewing this study. The research team has a longstanding working relationship with a Teen Advisory Group (comprised of AIDS-affected teens and teens on ART, from the Western Cape and Eastern Cape). We will also be facilitating and working within existing programmes for a group of AIDS-affected teenagers linked to the Raphael Centre, Grahamstown, and a group of teenagers on ART linked to the Keiskamma Trust, Hamburg. Questionnaires and data collection tools will be piloted with these groups of young people who will be asked to give suggestions on how the design may be adapted to ensure it is teen-friendly. These groups will also highlight key issues and themes for exploration, suggest sensitive and exciting ways for engaging youth, and provide advice about the appropriate language and terminology to use in relation to sex, illness, medicine-taking and health. Where appropriate, some of these young people may be recruited as key informants or translators for the qualitative research.

The collaboration with adolescent participants will be a crucial aspect of the development of an adolescent-friendly support tool to promote ART adherence and SRH service uptake. Through participatory workshops, adolescent participants will lead the design of a programmatic tool to support their desired retention in care and to help make the healthcare setting more youth-friendly.

The following stakeholders have been involved in ongoing consultations with the research team, focusing our attention on the most relevant and useful questions for practitioners in the field: UNICEF, the South African government, Paediatric AIDS Treatment for Africa, Kidzpositive, the Treatment Action Campaign, Kheth'Impilo, Keiskamma Trust and Raphael Centre. These organisations have contributed to our research design and will be key partners in disseminating findings.

Finally, participants in both the qualitative and quantitative study will be briefed on emerging findings and asked to provide feedback.

12. Conflicts of Interest

No member of the research staff will receive incentives for recruiting participants or for any other purpose directly related to the study.

13. Capacity-building and authorship

All of our research studies include active capacity-building approaches, which have been discussed extensively with our Government partner the National Department of Social Development (DSD), and are monitored by the HIV and AIDS Division of DSD via bi-annual reports. We believe that effective capacity-building cannot take place without clear academic benefits of participation for stakeholders, although those benefits have to be tailored to different groups and individuals. The project will take place in collaboration with a research team at Frere & Cecilia Makiwane hospitals in Buffalo City Sub-District, and will work collaboratively with this research team on publications.

Capacity-building within this study occurs on several levels of expertise. Two senior government officials (Mr Lentswe Mokodeti and Ms Zanele Mercedes Nxumalo) will be undertaking MSc and PhD respectively through the research study, and are already being co-supervised by Dr Cluver. We also focus on capacity-building amongst local research assistants, data capturers and community health workers on the study. All fieldwork staff have regular 'training workshops' as part of their paid work time (we usually do them after our weekly team meetings) on a range of topics, including those designed to build their capacity in working with vulnerable families (such as play therapy, counselling skills, gender and sexuality sensitivity) and those designed to help them with future careers (such as CV-writing workshops, interview skills). In this, and all our previous projects, we have a system of a 'capacity-building fund' for every local staff member. This is a sum of money available to all staff but only usable for training or the gaining of qualifications. In the past, our staff have used this for a surprising range of purposes, including completing their Matric (High School certificate) in night school, training as an HIV counsellor, registering for diplomas in nursing and social work, and learning to drive. The provision of the fund worked well as an incentive to staff to find out about training courses and to think in a proactive and strategic way about their careers in their quarterly individual 'capacity-building' meetings with the Project Manager.

In terms of publications, use of data and distribution of results, our approach emphasises providing opportunities for the whole team, including the capacity-building students, local staff, NGOs and government bodies involved to publish from and distribute findings. In our experience, even the most

detailed advance-planning of who will first-author publications can require changes (as the study progresses and people's interests and expertise develop) but perhaps more important is the *ethos* of the research team regarding this important area. We believe that all publications should be multiple-authored, to reflect both the collaborative nature of the study but also the collaborative approach we have to the analysis and writing of publications. We also believe that all study members should be encouraged and supported to write first-authored publications using data from the study. However, we should note that this is not always simple – we have in the past had extremely long delays from students who have intended (and very much wanted) to write papers from the studies, but have not managed to do this. We reiterate that – beyond the core research team – other research members only have access to the anonymised version of the dataset, and only then after signing confidentiality agreements with the project investigators. In light of potential collaboration among this research team and other teams, such as the Adolescent Transition Model Project team based at Frere and Cecilia Makiwane Hospitals in Buffalo City Sub-District, all data sharing will be conducted based on data sharing agreements signed by all parties. These agreements, which will be reviewed and approved by the Principal Investigators and relevant institutions, will outline who can access the anonymised dataset, as well as shared analysis and publication rights and responsibilities.

14. Ethical and Regulatory Compliance

There is an extensive body of local and international literature on ethical concerns in conducting research with vulnerable children and young people. The ethical guidelines for this study are informed by a number of sources. These include the ongoing academic debate on informed consent and confidentiality (123), the ethical requirements of the universities and research institutions involved in research design, and ethical guidelines from psychological research bodies such as the British Psychological Society (113).

In planning study design and ethical protocols, key research guidelines and legislation in South Africa have been considered, including the Department of Health's Ethics in Health Research Guidelines (2004), the Department of Health, Guidelines for Good Clinical Practice in South Africa (2nd Edition 2006), the Open Society Foundation for South Africa's 'Best Practice Guide to HIV Disclosure' (2009), the AIDS Law Projects' 'HIV and the Law: A Resource Manual' (2003), 'Selected ethical-legal norms in child and adolescent HIV prevention research: Consent, confidentiality and mandatory reporting' (EDCTP 2011), the National Health Act 61 of 2003 (enforced starting 2012), the Children's Act (38 of 2005), the Children's Amendment Act (41 of 2007) and the Sexual Offences Act (32 of 2007). These South Africa specific documents have been supplemented by international guidelines, such as the WHO's Guidelines on HIV Disclosure and Counselling for Children up to 12 Years of Age (124), and the Helsinki Declaration (2008).

15. Appendices

Qualitative Documents

1. Information and consent form for adolescent participants (qualitative)
2. Guardian consent form for adolescent participation (qualitative)
3. Information and consent form for body-mapping workshop (qualitative)
4. Release form for body-mapping (qualitative)
5. Information and consent form for participatory workshop on support tools design (qualitative)
6. Information and consent forms for caregiver participation (qualitative)
7. Information and consent forms for healthcare and social worker participation (qualitative)
8. Information and consent forms for key informants (qualitative)
9. Interview guides: adolescent, caregiver, healthcare and social worker participation (qualitative)
10. Facility Information Sheet (qualitative)
11. Adolescent certificate of participation (qualitative)
12. Clinic/Facility certificate (qualitative)
13. Recruitment Pamphlet for Adolescents (qualitative)

Quantitative Documents

14. Information and consent form for adolescent quantitative questionnaire (quantitative)
15. Facility Information Sheet (quantitative)
16. Community and Schools information sheet (quantitative)
17. Adolescent screening sheet (quantitative)
18. Adolescent certificate of participation (quantitative)
19. Facility/ Clinic Certificate (quantitative)
20. Example referral forms for adolescents

Letters of approval/ support

21. Ethics approval from University of Oxford (SSD/CUREC2/12-21)
22. Ethics approval from University of Cape Town (CSSR
23. Letter of authorisation: Eastern Cape Department of Health
24. Letter of authorisation: Buffalo City Sub-District Department of Health
25. Letter of support: Prof. Gerry Boon
26. Letter of Authorisation: Eastern Cape Department of Basic Education
27. Letter of support: UNICEF

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Details on 'Referral' Cases

During fieldwork, it emerged that two adolescents in our study had serious and long-term problems adhering to their treatment. Siya's struggles with ART had severely compromised his immune system. Consequently, he had developed a TB-related brain tumour. During this time, Mildred and I assisted with referrals to the local hospital and transported Siya to his medical appointments. With his consent, we also liaised with his community healthworkers and adult guardians about his health status and tracked his recovery.

Although Lindiwe's mother told us that she had not taken ART for as long as a year, Lindiwe (age 15) appeared healthy, and often denied that she had any problems taking pills consistently. When we asked whether she was seeking support with her daughter's treatment, Lindiwe's mother explained that both Lindiwe's support group and her local clinic were already aware of her adherence struggles and were doing all they could to assist. We could not be sure whether this was true or not, but we chose not to breach participant confidentiality by notifying external parties. Instead, we prompted regular reflections, both from Lindiwe and her mother, about Lindiwe's treatment and affirmed the benefits of adherence. In the instances in which they chose to consult nurses or NGO caregivers further about Lindiwe's health and treatment, we helped facilitate this, providing transport or making phone calls.

Because most of our adolescent participants were registered to HIV support groups, they often had an already-established set of care networks from which to draw in

times of crisis. In a very complicated case, in which adult guardians and careworkers believed one of our adolescent participants to have been a recent victim of statutory rape, a social worker, psychologist, as well as the local police were quickly involved. We supported these existing referral systems where we could, accompanying the participant for a pregnancy test and health check-up, and creating a supportive space when she chose to share aspects of her troubling interactions with older men. This case is illustrative of the very unique care that many adolescents in our study had access to by virtue of their enrolment in NGO services.

MZANTSI WAKHO

This study is about young people in South Africa and how they think about their bodies, their health and their lives. The government wants to know more about how to improve health services and how to help young people and their families. Your story is important!

Make your voice heard

Tell me more

Please take time to read this sheet carefully and decide whether you do or don't want to take part. Ask the research team if there is anything that is not clear or if you have questions. Thank you for reading this.

Do I have to take part? Not at all. You can decide if you want to take part. If you don't want to, it won't affect any help you are getting and you won't get into trouble.

If you decide to take part, you are still free to stop at any time. You don't have to give a reason. Again, this will not affect any help or support you are getting from anyone.

What would I have to do? Over the next few months, you will choose places and times to meet with our researchers to talk about your experiences as a young person. If you agree, these meetings might include fun activities like drawing a timeline of your life, taking photographs together or role-playing. We want to get to get to know you better! You might want to introduce our researchers to your family, healthworker or friends. Share your life stories with us in whatever way you feel comfortable!

Why should I take part in this study?

This study will help us to learn more about how to help young people in Southern Africa.

You will be able to talk to our researchers in whatever language you choose. If you agree, some of the conversations that happen at weekly meetings will be recorded. All recordings will be kept confidential. If any of your words are used in our research, we will change your name so that nobody can recognise you.

What if the questions upset me? You can stop at any point, and you don't have to give a reason. You can also contact the research team at any point and say that you want your answers about certain questions to be destroyed, which we will do straight away. If you want to talk to someone about anything that has come up from this, you can tell one of the researchers or contact us on 071 040 9285.

Will what I say be kept confidential? Anything you tell us about yourself will be kept strictly confidential, and will not be told to anyone else. Any information about you would have your name and address changed so that you cannot be recognised from it.

But during this study it may become clear that you are suffering from serious challenges. If so, our researchers will explain to you, in private, possibilities for further help. If there is a safety issue, we might contact an organisation that can help you. But we will talk to you about it first.

What if I have a complaint? If there is anything to do with the research that you are unhappy with, you can contact Dr Lucie Cluver at Oxford University (lucie.cluver@spi.ox.ac.za) or Dr Rebecca Hodes (Rebecca.hodes@googleail.com) at the University of Cape Town.

What will happen to the results of the study? The results of this study will be used to help the government, and health and welfare organisations, to make better policies for young people and their families.

Who is organizing and reviewing the research? This research is being organized by the University of Oxford in England and the University of Cape Town.

Who can I contact for more information? Dr Lucie Cluver at Oxford University (lucie.cluver@spi.ox.ac.za)

Thank you for reading this sheet. If you feel comfortable with everything, you can fill

Do I want to take part?

1. I have read and understand the information sheet for this study and have had a chance to ask questions. ☐

2. I understand that I have chosen to take part and that I am free to stop at any time, without giving any reason. ☐
   This will not change any support or help I am getting.

3. I agree that any words I may say during the interview can be used, without giving my name, in presentation of the research. I agree to take part in the study. ☐

Name of participant Signature

…… ……

Name of researcher Date

…… ……

Thank you for participating in this study. Your story matters!

LETS GET STARTED!

Whatever you say is confidential. This means we will not report your real name.

Please write your name here

……

Now please think of a different name that we can use when we are writing about this research. You can pick any name you want.

……

Would you mind if we contacted you again?

Address:

.....

.....

Telephone number:

.....

contact me

health
Department:
Health
REPUBLIC OF SOUTH AFRICA

social development
Department:
Social Development
REPUBLIC OF SOUTH AFRICA

basic education
Department:
Basic Education
REPUBLIC OF SOUTH AFRICA

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SMALL PROJECTS FOUNDATION

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PATA
Paediatric AIDS

MZANTSI WAKHO

Dear Parents/Guardians,

We would like to invite your child to take part in research that is being run by a number of universities and by the South African government. The study is about the lives and health of young people. The government will use this research to plan services for youth and their caregivers. We will be hearing stories from youth, parents and healthworkers so that we can understand what it is like for young people to use health services, take medication, go to school and live in the Eastern Cape.

Your child has been invited to participate in the most interactive part of our research. If they chose to take part, they will spend time talking with our researchers and participating in group discussions and fun activities like art-making projects.

Young people can choose whether they want to take part or not, and they can stop interviews at any time. Everything we are told will be treated as entirely confidential, unless children are at risk of serious harm, in which case we will try to help. Your child's real name will not be used and no pictures of their face will be published. With their permission, your child's artwork will be used for research and education to teach others about the experiences of young people. Their real name will not appear with the artwork.

If you have any questions or worries about the research, please tell a member of our research team and they will be very happy to discuss or explain further to you.

Thank you,
Beth Nosizwe Vale, University of Oxford
Dr Lucie Cluver, Unversity of Oxford

If you have any questions or complaints about this study, please contact Dr Lucie Cluver at lucie.cluver@spi.ox.ac.uk.
Or call us on 071 040 9285

Please fill in the slip below and let us know whether you give permission.

Name of Participant .....

Child's grade .....

Can the child I care for take part in this study?
YES NO

Name of parent/guardian .....

Contact Phone Number .....

Date .....

health
Department:
Health
REPUBLIC OF SOUTH AFRICA

social development
Department:
Social Development
REPUBLIC OF SOUTH AFRICA

basic education
Department:
Basic Education
REPUBLIC OF SOUTH AFRICA

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SMALL PROJECTS FOUNDATION

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PATA
Paediatric AIDS

MZANTSI WAKHO

This study is about how to improve the lives of young people and their families.

The government wants to know more about how to improve health and social services to help young people and their caregivers. Your story is important!

Make your voice heard!

We want to hear your stories! Please take time to read this sheet carefully and decide whether you do or don't want to take part. Ask the research team if there is anything that is not clear or if you have questions. Thank you for reading this.

Do I have to take part? Not at all. You can decide if you want to take part. If you don't want to, it won't affect any help you are getting and you won't get into trouble.

What will I need to do if I take part in this research? If you decide to take part, you will first sign a consent form (on page 4), and then spend about an hour talking together with our researchers. You may decide that you would like to meet with our researchers again so that you can tell them more about your experiences as a caregiver.

Will what I say be kept confidential? Anything you tell us about yourself will be kept strictly confidential, and will not be told to anyone else. Any information about you would have your name and address changed so that you cannot be recognised from it.

Why should I take part in this study?

This study will help us to learn more about how to help families caring for young people in Southern Africa.

But during this study it may become clear that you are suffering from serious challenges. If so, our researchers will explain to you, in private, possibilities for further help. If there is a safety issue, we might contact an organisation that can help you. But we will talk to you first.

What will happen to the results of the study? The results of this study will be used to help the government, and health and welfare organisations, to make better policies for young people and their families.

What if I have a complaint? If there is anything to do with the research that you are unhappy with, you can contact Dr Lucie Cluver at Oxford University (lucie.cluver@spi.ox.ac.za) or Dr Rebecca Hodes (Rebecca.hodes@googlemail.com) at University of Cape Town.

Who is organizing and reviewing the research? This research is being organized by the University of Oxford in England and the University of Cape Town.

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PATA PATA PATA PATA PATA

Paediatric AIDS

Thank you for reading this sheet. If you feel comfortable with everything, you can fill in the box below

Do I want to take part?

1. I have read and understand the information sheet for this study and have had a chance to ask questions. ☐

2. I understand that I have chosen to take part and that I am free to stop at any time, without giving any reason. This will not change any support or help I am getting. ☐

3. I agree that any words I may say during the interview can be used, without giving my name, in presentation of the research. I agree to take part in the study. ☐

Name of participant Signature

…… ……

Name of researcher Date

…… ……

Beth.nosizwe.vale@gmail.com

071 040 9285

health
Department:
Health
REPUBLIC OF SOUTH AFRICA

social development
Department:
Social Development
REPUBLIC OF SOUTH AFRICA

basic education
Department:
Basic Education
REPUBLIC OF SOUTH AFRICA

MZANTSI WAKHO

This is a study about the well-being of young people in South Africa and their experiences in accessing health services. The government wants to know more about how to improve healthcare and social support for young people.

We can learn your experiences as a professional or community health worker.

Make your voice heard

We want to hear your stories! Please take time to read this sheet carefully and decide whether you do or don't want to take part. Ask the research team if there is anything that is not clear or if you have questions. Thank you for reading this.

Do I have to take part? Not at all. You can decide if you want to take part. If you don't want to, it won't affect any help you are getting and you won't get into trouble.

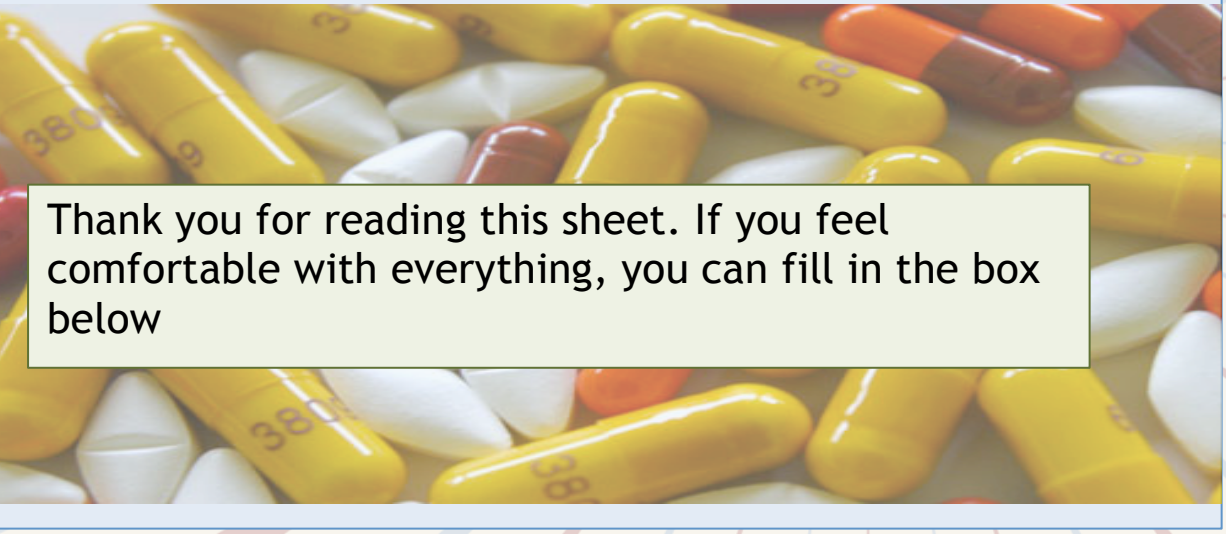
What will I need to do if I take part in this research? If you decide to take part, you will first sign a consent form (on page 4), and then spend about an hour talking together with our researchers. We will speak about your experiences with young patients, particularly those on long-term medication like antiretrovirals (ARVs). We will also speak to you about how you think we can make it easier for young people to take long-term treatment and access health services.

Will what I say be kept confidential? Anything you tell us about yourself will be kept strictly confidential, and will not be told to anyone else. Any information about you would have your name and address changed so that you cannot be recognised from it.

What will happen to the results of the study? The results of this study will be used to help the government, and health and welfare organisations, to make better policies for young people and their families

What if I have a complaint? If there is anything to do with the research that you are unhappy with, you can contact Dr Lucie Cluver at Oxford University (lucie.cluver@spi.ox.ac.za) or call us on 071 040 9285.

Who is organizing and reviewing the research? This research is being organized by the University of Oxford in England and the University of Cape Town



Thank you for reading this sheet. If you feel comfortable with everything, you can fill in the box below

Do I want to take part?

1. I have read and understand the information sheet for this study and have had a chance to ask questions. ☐
2. I understand that I have chosen to take part and that I am free to stop at any time, without giving any reason. This will not change any support or help I am getting. ☐
3. I agree that any words I may say during the interview can be used, without giving my name, in presentation of the research. I agree to take part in the study. ☐

Name of participant Signature

…… ……

Name of researcher Date

…… ……

health
Department:
Health
REPUBLIC OF SOUTH AFRICA

social development
Department:
Social Development
REPUBLIC OF SOUTH AFRICA

basic education
Department:
Basic Education
REPUBLIC OF SOUTH AFRICA

We want you!

Are you a young person interested in life, love, health and everything else?

Are you between the ages of 10 and 19 years old?

Are you taking any kind of medication?

If your answer to these questions is YES, we would love to invite you and your family to take part in our project!

Listen up teens!

If you take part in the research, you will meet with our fun, young researchers to share your life and your story. These meetings might include activities like playing ball games, drawing a timeline of your life, taking photographs together, making art or role-playing. We want to get to get to know you better!

You might want to introduce our researchers to your family, healthworkers or friends. Share your life stories with us in whatever way you feel comfortable!

MZANTSI WAKHO

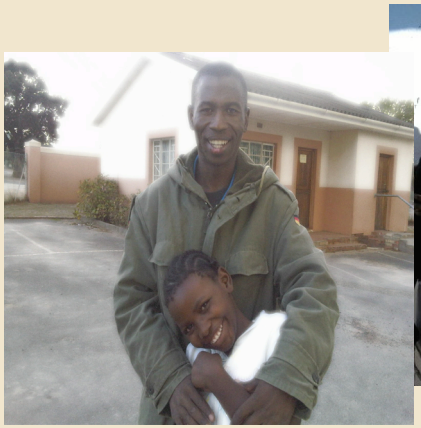
This study is about young people in the Eastern Cape and how they think about their bodies, their health and their lives. The government wants to know more about how to improve health services and how to help young people and their families. Your story is important!

Make your voice heard

Listen up parents and caregivers!

We want to know more about what it's like for caregivers like you to look after teenagers. Learning from your story, we can help improve health and social services for young people and their families!

If you take part, you will have an enjoyable meal with our caring and supportive researchers who will spend time talking with you about your life, your family and how you all work together to stay healthy.



Anything you tell us about yourself will be kept strictly confidential, and will not be told to anyone else. Any information about you would have your name and address changed so that

Want to take part or know more?

You can send a Please Call Me or SMS to Beth Nosizwe Vale and Mildred Thabeng at:

071 040 9285

Or let our nurse know

health
Department:
Health
REPUBLIC OF SOUTH AFRICA

social development
Department:
Social Development
REPUBLIC OF SOUTH AFRICA

UNIVERSITY OF OXFORD

basic education
Department:
Basic Education
REPUBLIC OF SOUTH AFRICA

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PATA
Paediatric AIDS

CIPHER
Children Matter

BODY-MAP RELEASE FORM

	YES	NO
1. I agree that the ownership of my body-map will be transferred to the Mzansi Wakho team.	☐	☐
2. I agree that my body map can be used, without giving my name, for research, education and public display amongst.	☐	☐

3. I agree that what I say in group discussions can be used, without giving my name, for presentation of the research:

In front of government and state officials	☐
In front of my community	☐
In front of my family	☐

4. I have agreed that my body-map will be stored the following way:

_____