
Bureaucracies of Blood and Belonging: Documents, HIV-positive Youth and the State in South Africa

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ABSTRACT

In response to its constitutional commitments and social welfare provisions in the era of democracy, the post-apartheid South African state is increasingly called upon to provide for the lives and livelihoods of its citizens. These demands have intensified amid escalating joblessness and the highest numbers of people living with HIV worldwide. Over the past decade, antiretroviral treatment (ART) has been incorporated into an ever-expanding welfare bureaucracy, in which access to state assistance is mediated by the collection and monitoring of biometric, bureaucratic data. Drawing on 18 months of ethnographic research in the Eastern Cape, this article explores how state documents bring young people on ART into an ambiguous relationship with the state — one that is at once subordinating and enabling. While social research on ART addresses both the empowering and coercive aspects of treatment taking, less attention has been given to how these modes of participation might be mutually constitutive. In this article, the authors examine how the same technologies that discipline youth on ART might also support and protect them; how welfare dependencies entail paradoxical forms of agency; and how the state's ability to control and to 'care for' citizens might be reciprocally dependent.

INTRODUCTION

South Africa's democratic agenda, in the third decade after apartheid, compels the state to provide basic services for its citizens. Worsening unemployment and an HIV/AIDS epidemic have deepened demands for

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healthcare and social support. Over the past decade, the country's HIV treatment programme has accelerated dramatically and is now the largest of its kind globally (UNAIDS, 2014: 17). The public provision of antiretroviral therapy (ART) has formed part of an expansive welfare bureaucracy, in which registration, biometrics and medical records mediate access to state assistance while also surveying beneficiaries.

This article draws on ethnographic research conducted during a large, multidisciplinary study on the medicine-taking practices of youth in South Africa's Eastern Cape. Based on 18 months of research, including over 1,000 hours of direct observation with teenagers, caregivers, health and social support providers, it explores how bureaucratic documents work through the lives of adolescents on ART, bringing them into an ambivalent relationship with the state — one that both subjugates and supports them. Through the quotidian bureaucracies of the clinic, and the circulation of official records, young ART users become legible for public service provision. It is also through these everyday encounters that such youth 'see the state' (Corbridge, 2005) and imagine their moral and material relationships towards it.

For many adolescents in this study, negotiating care, recognition and agency within state institutions is intertwined with their positions as disciplined dependants. An established literature on health citizenship, together with much development discourse, shows how patients have reconfigured state authority through adapting public healthcare. This article focuses instead on how forms of inclusion, sociality and identification are bound up in hierarchical relationships with the state, through the public provision of ART. Part of the work of this article, then, is to elucidate the nuances and ambivalences of ART 'discipline'. We use 'discipline' in the Foucauldian sense: devolved mechanisms of power through which people are regulated, often through techniques that prompt self-control. By using schools and hospitals as examples of 'disciplinary societies', Foucault (1979) illustrates an inherent dialectic between care and coercion within systems of discipline. Here, care often provides opportunity for control, just as the receipt of care might entail submission.

We mean to explore the social stakes involved in young people's compliance with the rules, practices and procedures of ART programmes. Young ART users in this study were not only subjects of public health control; they also remade, reproduced and acquiesced to disciplinary modalities, appropriating them for their own ends (De Certeau, 1984). Indeed, those caught up in webs of discipline are also involved in appropriating, re-inventing and resisting techniques of power. Consequently, as this article hopes to show, processes of receiving and administering care are often heterogeneous, uneven and ambiguous, with implications for how we understand power and agency in health settings.

We begin this article by offering a brief account of the literature on ART and citizenship, as well as a short history of welfare documentation in South

Africa. This is followed by a description of our study methodology. Our analysis explores the ambivalence of blood test results as significant mediators to service access, but also mechanisms of coercive control. We discuss the forms of tactical agency implicit in ART users' submission to bureaucratic monitoring, as well as the close connections between surveillance and care.

BACKGROUND

ART and Citizenship

As an example of post-apartheid state–citizen relations, ART participation has been interpreted both as an empowered claim to democratic entitlements and as a form of coercive discipline. Treatment programmes place increasingly strong emphasis on fostering 'therapeutic citizens' (Nguyen, 2005), who can profess the revelations of HIV treatment, and espouse empowered positive identities (Hodes, 2014: 64–9, 116–19; Nguyen, 2005; Robins, 2006; Robins and Von Lieres, 2004). Often communicated in the language of self-reliance, ART users are called upon to participate in health delivery as 'responsible' and 'empowered' citizens. This valorization of citizens' autonomy and self-sufficiency, along with the disavowal of dependency, are common features of development discourse (Scherz, 2014).

While ART has been described as a project of empowered self-care, an emerging critical literature also recognizes ART as a fundamentally disciplining project. This research argues that the production of adherent patients, now central to HIV care, rarely resembles the claimed empowerment (Cassidy and 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: 158). Critics discern an oppressive element to 'self-responsibility', in which access to life-saving medication is mediated primarily by subjugation, as opposed to empowered decision making. 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' (Hodes, 2014: 100–6; see also Gagnon et al., 2013; Mattes, 2011: 160). Inclusion and connection to the state therefore rest on a particular performance of the deserving citizen-consumer.

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. This article examines how the same technologies that discipline youth on ART might also support and protect them; how welfare dependencies entail paradoxical forms of agency; and how the state's ability to control and to care for citizens might be reciprocally dependent.

Welfare and Documentation in South Africa

Biological markers, including as forms of demographic measurement, have been collected in South Africa for more than a century (Breckenridge, 2005, 2015). Biometric registration served as the foundation of colonial and later apartheid administration. Under the colonial 'Native Affairs Department', black labourers to the sugar plantations, and later the diamond and gold mines, were the primary targets of a meticulous system of registration. These registers grew into a matrix of national record sets, which would culminate in the 1950s in the Population Register — the core of apartheid racial classification (Posel, 1971: 78–9; 2000: 128; Szreter and Breckenridge, 2012: 15).

While the apartheid government aspired to a thoroughly engineered society, premised on techno-scientific expertise and elaborate statistical data (von Schnitzler, 2015: 8), the state's imagined omniscience was belied by its administrative failures of biometric identification (Edwards and Hecht, 2010: 626). Many black South Africans deliberately eluded state authorities, exhibiting a 'reluctance to be counted' (Posel, 2000: 137). Black South Africans forged documents and evaded state enumeration to avoid forced removal from 'white cities'. Sustained resistances to registration meant that black South Africans often confounded state surveillance, manoeuvring outside the margins of legality.

The reach of the state's bureaucratic vision was also limited by practices of selective ignorance, particularly regarding welfare. From as early as the mid-19th century, colonial health interventions were targeted towards the maintenance of the black labour force, particularly miners. High rates of black infant mortality, as well as diseases affecting black residents on the 'reserves',¹ were largely ignored. This was attributable, in part, to the fact that 'African' deaths remained unrecorded (Reynolds, 2014: 140). By choosing not to collect certain data, the apartheid governments also systematically excluded some lives from view.

From 1948 onwards, the apartheid welfare system, which had served for whites only, was increasingly deracialized as 'non-white' South Africans gained incrementally greater access to welfare benefits, particularly pensions (Bundy, 2015). Nevertheless, the coming of democracy marked a dramatic shift in welfare provision. The post-apartheid government now delivers public welfare on an unprecedented scale. Most cited are the 16 million citizens who benefit from social grants (SSA, 2014b: 20), the 3.1 million homes built since 1994 (ANC, 2015) and, more recently, the estimated 3 million people receiving state-provided antiretroviral treatment (Ramaphosa, 2015).

As the ANC-led government seeks to secure its electoral dominance by 'claiming to provide for the wellbeing of the population', so too does 'good

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

governance' come to rest on the 'efficient management of men [people] and things' (Marinetto, 2003: 109). Recording, measuring and tracing the biological data of welfare recipients — from biometrics, to civil registration documents, to blood counts — is now integral to the functioning of the post-apartheid state. Meanwhile, it has become increasingly valuable for people to make themselves legible to government, claiming eligibility for housing, social grants and a host of other state resources and services. Despite South Africa's long history of measurement, it is in fact 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 and Breckenridge, 2012: 19) — that is, people *consensually* giving over their information — and relatedly, the benefits of this bureaucratically signified membership.

In this article, we explore how some HIV-positive adolescents and their families have used, and been organized by, bureaucratic technologies as they negotiate life with ART. In doing this, we seek to expound the nature and reach of 'discipline' among adolescent ART users. We argue that participating in bureaucratic discipline in the form of public HIV treatment programmes is bound up in ambiguous processes of clinical consent and democratic inclusion.

The Study

The analysis presented here draws on 18 months of ethnographic fieldwork with 30 HIV-positive youth (aged 10–19) in the Eastern Cape. The Eastern Cape is among South Africa's poorest provinces. Close to 13 per cent of inhabitants are believed to live below the poverty line (SSA, 2016) 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 (SSA, 2014a). Every household in our study benefited from government social assistance.

In addition to childcare assistance, several youth in our study received care dependency or disability grants on the basis of their HIV status, with many more hoping to apply. As primary caregivers, female family members were principal grant recipients, receiving either foster child or child support grants. Most of the households in our study were headed by grandmothers or elderly aunts who received state pensions. Most participants had lost one or more parents to AIDS; numerous others had lost parents to violent crime. Most teenage participants with living parents were either estranged or separated from their parents, and saw them fewer than twice per year.

This article draws on research from three Eastern Cape sites: one rural, one peri-urban and one urban. Between August 2013 and April 2014, we conducted fieldwork in villages, small towns and informal settlements in the south-east of the province. Among the rural families with whom we

worked, only one household had a permanently employed member: she was a domestic worker in her village, but had lost her job before fieldwork ended. Most of these rural homes survived from a combination of social grants, subsistence farming and irregular remittances from relatives working in nearby towns or farms. Among the urban and peri-urban families with whom we worked, 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.

Of the 30 adolescent participants for this study, 14 were recruited primarily through ART support groups run by non-governmental organizations (NGOs), while 16 participants were identified through public health clinics because of their initiation in ART programmes. The length of time on ART varied within the cohort (anywhere from one to 11 years), depending on treatment access and eligibility. There was an almost equal distribution of male and female, as well as older (above 15 years) and younger (below 15 years) adolescents in the cohort, although the sample is slightly skewed towards older and female participants.

Since all the adolescents in this study were enrolled in HIV treatment services, and in most cases received additional NGO support, this sample is likely to represent an especially compliant group of young ART users. Those who were less adherent to clinical care would already have fallen out of the public healthcare system. This signals the particularity of our research sample. There was a world, outside the reaches of discipline and largely beyond the temporal bounds of the research reported here, in which adolescents were unable or unwilling to initiate treatment, staying away from clinics, dying or already dead. In the initial phase of this research, it seemed that ART was only for certain people — those willing to participate in, and be encompassed by, a programme that ordered and subordinated, but also protected and validated them.

Five adolescents among our research cohort had been categorized as treatment ‘defaulters’. They were all older adolescents, who were less subject to the authority of adult guardians than their younger counterparts. Indeed, within this sample of youth, the everyday challenges of ART compliance were less gendered than they were age-based: among younger adolescents, deference towards adult caregivers included obeying healthcare workers, thereby bolstering their compliance. While participants across age groups could experience ART discipline as simultaneously protective and caring, older adolescents were more likely to articulate their participation in ART bureaucracies as a form of tactical submission.

Throughout fieldwork, researchers visited the young participants and their families regularly, immersing themselves as far as possible in their everyday lives. This was complemented by more structured research methods, including semi-structured interviews with both youth and caregivers. 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 observed their clinical engagements. Over the course of their fieldwork, researchers visited 13 community clinics and five hospitals, accompanying young people and their families on regular appointments. We observed participants' consultations, engaged in informal discussions with healthcare workers and, in some cases, conducted formal interviews. Fieldwork was carried out using a combination of Afrikaans, English and isiXhosa. Translation occurred in real time to allow for immediate, follow-up probing. These in-situ translations may have subjectively coloured the data. Formal interviews were audio-recorded, while informal interviews, observations and ethnographic interactions were documented in field notes.

Researchers engaged in regular concurrent analysis throughout fieldwork, adapting data collection in reflection of emerging themes. Data were then thematically coded, comparing findings regarding young people's experiences of ART. State documents emerged as important mediators in participants' experiences and interpretations of ART, illuminating how young people saw their relationship with state care institutions. Ethical approval for this study was granted by the Universities of Oxford and Cape Town, and the Eastern Cape Department of Health.

DISCUSSION

The Case of Thembakazi

We begin our discussion by relating the encounter of Thembakazi (age 18) with a group of hospital nurses. In her attempts to foster productive relationships with these state providers, Thembakazi found herself tactically negotiating the volatile intersections between submission and care. Thembakazi had been living with HIV since birth, and had started ART nine years previously. On the day in question, 16 November 2013, she hoped the doctor would refer her for a disability grant. Having recently turned 18, Thembakazi was newly eligible for this form of state welfare, an economic lifeline for poor, unemployed, working-class and rural South Africans. Unlike child support/care dependency grants, which would have been administered by her grandmother, this would give Thembakazi direct access to her welfare monies.

After completing her school day, Thembakazi stopped first at the village clinic to collect her medical records, and then at the social services office for the grant application forms. Before 3 p.m., she was seated in the waiting area of the hospital foyer, holding the documents she had collected during the afternoon. When Thembakazi was finally called to the nurses' desk, she was told that the doctor had already left the clinic, and then reprimanded for having come to the hospital 'so late'. One of our researchers asked what time they should return to secure a doctor's appointment. 'It depends', one

nurse replied, not looking up from her paperwork. The researcher persisted: ‘we don’t want to come here again, using time and petrol money, if we aren’t going to see a doctor’. Many participants in this study spent significant portions of their household incomes travelling to health facilities — a drain on a meagre pool of household resources. The only way that the journeys could be afforded was through the re-apportioning of resources from other essential items, principally food. ‘Come by 11 or 12 [o’clock] at least’, the nurses replied. This prompted the researcher 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 she was quickly silenced by Thembakazi, who insisted that they stop pressing the nurses and that they leave the hospital.

Outside the hospital, Thembakazi explained that by ‘causing trouble’, she risked being punished or refused treatment at her next visit. She described how rights were privileges reserved for those with ‘money and power’, and how, by confronting state patrons with rights-based claims, she jeopardized her access to these services. Thembakazi is among an estimated one fifth of South African women who are living with HIV in their ‘reproductive ages’ (SSA, 2015).

This kind of strategic submission to the hospital nurses, which Thembakazi believed secured her access to essential services, occurred on numerous clinic visits with other research participants. A few weeks before, a rural family in the study had explained: ‘when nurses shout at us, we just keep quiet, otherwise we won’t get what we need’ (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 a course through a paternalistic, disciplining relationship with state welfare institutions.

In the lives of young ART users in this study, compliance and care were often interrelated. In Thembakazi’s case, this may initially appear as a straightforward transaction: compliance 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. Benevolence and coercion could be two sides of the same coin with variable consequences for young people’s experiences of ART programmes.

This care–control nexus is explored here through the everyday employment, and deployment, of state documents. As a technology of governance, 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 within its protectorate. The workings of state welfare documents evince a tension in state governance and the self-making of citizens: bureaucratic power is premised on subjects’ wilful participation, but citizens must subject themselves to state power in order to access benefits.

Thembakazi's trip to the hospital was illuminating in this respect: our team accompanied her 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, 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 functioning of her immune system, and creating barriers to service access, declared her membership in a welfare system that enabled her survival. In addition to receiving state-provided HIV treatment, Thembakazi also benefited from a care dependency grant, and her grandmother from a state pension. These were her household's sole sources of income. While her participation in a public ART programme ensured her clinical well-being, the social significance of Thembakazi's participation deserves greater scrutiny. ART provided for her physical survival and located her as a deserving state recipient. At the same time, her enrolment in the programme rendered her an object of official surveillance.

This article asks how young ART takers like Thembakazi use state documents, and how these documents, in turn, regulate and govern their relationships with the state. It explores how, and why, these adolescents are brought into a bureaucratically mediated, dependent relationship with the state. The analysis explores an intractable dialectic between coercion and care, thereby illustrating the ambivalence of adolescents' ART discipline. We argue that young people enact complex forms of agency within public health programmes. Rather than being automatons in an all-powerful, top-down system of coercion, there is, as Thembakazi shows us, subtle agency implicit in acts of submission and moments of rebellion within a system of onerous discipline.

For many young people in this study, participation in ART programmes is often as tenuous and fragile as it is imperative, as demanding as it may be exasperating. Yet in the moments when discipline succeeds in ordering the lives and behaviours of teenagers, it is because adolescents and their families opt into it, tactically deploying technologies of control, subjugation and surveillance. They do so not simply as expressions of self-sufficient responsibility, but more prominently as a means of forging rewarding connections with state patrons. These are attachments that, however subordinating, hold moral, medical and material appeal.

The Blood Panopticon

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.

To achieve viral suppression and remain healthy, ART patients must be monitored and supported. Clinical oversight of ART users may take many forms, from periodic consultations with healthcare workers, to ART support groups and treatment literacy programmes (Hodes and Naimak, 2011: 418–23). Technological advances, developed partly in response to activists' growing demands for better public care, have revolutionized the diagnostic and monitoring procedures for HIV patients in hyper-endemic settings (MSF, 2012; WHO, 2013). Consequently, HIV care now entails extensive bureaucratic and bodily surveillance: first, for the mass monitoring and support of patients' immunological and treatment adherence; and second because, for those who remain asymptomatic, surveillance technologies illuminate the body's inner workings.

The three most widely used HIV diagnostics in South Africa's public health sector are the HIV rapid test, CD4 count and viral load. The rapid test, which is used to determine HIV status, detects whether those antibodies that respond to HIV infection are present in the body. Thereafter, the most widely used measures of the advancement of a patient's HIV disease are the CD4 count and the viral load, two laboratory tests. While the CD4 count tracks immune cells, viral load measures how active HIV is in the body. All three tests — HIV status, CD4 count and viral load — use blood drawn from the patient.

ART care is therefore mediated through blood surveillance technologies. It is blood tests that qualify patients for ART initiation and codify their progress on treatment. In addition to granting access to ART programmes, blood indices also serve as a basis for incorporation in the broader welfare project, determining eligibility for HIV support programmes and illness grants. Hence, the operationalization of blood tests by patients and care providers illuminates intersections between surveillance and care.

While a rising CD4 count and decreasing viral load are crucial markers for immune recovery in HIV-positive patients (Philips et al., 2010), these trends may not characterize the trajectory of every ART initiate. Fluctuations in these blood indices can be attributable to numerous factors outside of deteriorating immunological health.² Nevertheless, popular accounts of HIV treatment — disseminated among healthcare workers and patients — often exclude these qualifications. Healthcare workers, patient advocates and adolescents in this study associated a declining CD4 count and an increasing viral load with a patient's failure to adhere to medicines and to take care of her health, while an escalating CD4 count and decreasing viral load were indications of patient success and compliance.

2. See: www.healthline.com/health/hiv-aids/cd4-viral-count#TherapyTypes5 (accessed 10 May 2016).

Every year, and sometimes biannually, ART users in our study should have attended the clinic to have their blood checked. 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 to risk discovery and reprehension. 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 research sites, was referred to as a ‘passport’. Highlighting the ambivalences of bureaucratic governance, the terminology signalled the document as an instrument of surveillance and discipline, but also a token of entry and protection. These books contained the handwritten medical records of each patient, and had to be prefaced by patients’ national identity numbers (a practice enforced by nurses). Instead of being kept at the clinic, these records were brought to and from medical appointments. Written prescriptions and appointment dates were carried home in ‘passports’ and repeatedly checked, 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 potential indiscretions might soon be unmasked.

While blood tests are a central feature of the ART surveillance apparatus, they are not consistently conducted in South African public health facilities. Only 50 per cent of those on ART receive viral load testing (Motsaedi, 2014). In our research areas, blood tests were more accessible, and more regularly conducted, in peri-urban Ridgetown than in rural areas. As a result, they played a greater role in how these 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 errant 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 clinical authorities.

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 youths lived long distances from the nearest health facility. Given this, it is even more remarkable that the state could 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 periodic, retrospective) scrutiny. Those retained in ART care consent to this watching and willingly participate in it. This 'agency' is of course attenuated, since the cost of rebelling is to fall ill or die. Nevertheless, the efficacy of blood tests worked best when patients imagined their disease in these terms — monitoring their bodies to align with desirable blood results. For patients who felt well, blood counts revealed 'how the disease was doing' and 'how they were doing' in managing it (Meinart et al., 2009).

Thembakazi (age 18) — introduced earlier — reflected on a 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 keeping her healthy. The CD4 count gave Thembakazi a way of visualizing 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 visualizing 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.

Thembakazi monitored her health partly through blood test results. This self-management was not exclusively motivated by a will for empowered self-sufficiency. Nor did this mode of discipline situate her — or other adolescents in this study — as passive or subordinate. Rather, participating in self-surveillance often served as a tactical move which, rather than assertions of adolescents' independence, sought to bring them closer to the representatives and resources of the state. It was often only as documented, disciplined

patients that adolescents and their families could petition for care and make claims on resources.

After telling us that she was trying to improve her CD4 count, Lulama explained that she had not been able to access the fixed-dose combination (FDC) — that is one pill per day — because her viral load was too high. The guidelines for rolling out FDC in South Africa prioritize pregnant women, patients with excessive pill burden, and those initiating ART for the first time. Ridgetown nurses explained to us that those who did not fall into these categories were required to have an undetectable viral load to make the switch to FDC. Lulama said she was ‘working towards that’ (4 April 2014), hoping her next blood result would support her claim.

Ridgetown nurses reported that many long-term ART patients were now ‘chasing’ an undetectable viral load. Despite not being due for ‘bloods’, these patients would request an early test in the hopes that they would read ‘undetectable’ and qualify for FDC (18 March 2014). By exerting pressure on health staff to conduct ever-more frequent blood tests, patients used surveillance technologies to their advantage. In these instances, blood results not only set the standard for good adherence but also served as the currency to access bio-technological rewards. By taking treatment properly, and successfully suppressing their viral load, ART users demonstrated that they were rightful recipients of generously provided treatment. Their success was presented to the clinic in the form of numerical blood counts and this in turn entitled them to further rewards.

This is a pertinent example of how systems of documentation might work *for* people. By leveraging the bureaucracy itself, patients solicited recognition and entitlements from state bureaucrats. The blood panopticon therefore also entailed a productive power. This is what Alice Street (2012) describes as the ‘underside of disciplinary power’: its ability to empower the subjects it produces while at the same time constraining their agency.

By requesting more frequent blood tests from their health staff, patients expressed a will to be documented and to make themselves legible. Similarly, in his examination of squatter populations in Mumbai, Arjun Appadurai (2001) has illustrated how such tactics of visibility mediate access to state resources and services. Rather than prompting state representatives to document them, Mumbai squatters used self-conscious strategies of self-surveying and self-enumeration. Many lived in residences that would otherwise have fallen outside of documentation. Through their own data gathering, they provided a social infrastructure for the transfer of claims, entitlements, goods and services. Similarly, Steven Robins (2014) has described how civil society organizers at the Social Justice Coalition conducted their own social audit of toilets in Cape Town. Through data-driven activism, they sought to make chronic poverty legible to city government. Here, the positive content of ‘citizenship’ rests on positioning oneself as a rightful and deserving state dependant (Chatterjee, 2004; Ferguson, 2013: 237).

Tactical Agency, Qualified Submission

Implicit in the relationship between state benefactors and their beneficiaries are reciprocal (if lop-sided) obligations. Dominik Mattes (2011: 164) describes ART as a 'lifelong contract': the patient complies with a treatment regime and collaborates with health professionals, in exchange for freely provided biomedical technology. 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).

For these nurses, connection to the ART programme and its medical resources demanded that a patient demonstrate commitment to a particular ethic of disciplined pill taking, which is also essential for the prevention of viral resistance. While state providers might have expectations of their beneficiaries, this relationship of unequal reciprocity also entails obligations for government institutions, whose legitimacy increasingly rests on their ability to provide for the well-being of their 'dependants'.

Nurse Hlope used an illustrative strategy for retaining HIV-positive patients who were not yet eligible for ART in clinical care. 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.

Zethu, a rural health monitor, 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). She used her bureaucratically signified membership — that is the fact that she was under surveillance — to hold state emissaries to account.

So, for adolescent ART users in this study, an attitude of subordinate compliance could also entail tangible rewards and subtle power. Take for example the act of queuing. 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 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 5 a.m., 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 complaint, 'Why do you come to the clinic so late?' might thus be interpreted as a way for nurses to indicate offence: 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 emphasize their subordinate position and thereby bolster their ability to make claims on healthcare workers.

Similarly, in Scott's *Weapons of the Weak* (1985/2008), peasants and serfs were shown to appropriate rituals of submission for their own ends. Beneath public shows of deference were everyday 'hidden transcripts' through which subordinate classes exercised attenuated power and agency. While Scott was concerned with feigned compliance as a mode of non-cooperation and resistance, we are interested in how HIV-positive youth and their families have opted into systems of discipline and deference, not to unsettle them, but precisely because conforming has had social, material and moral valence. Rather than seeking the empowered self-sufficiency so often celebrated in the health citizenship literature, many adolescents and families in this study seemed to be pulling closer to clinic representatives, occasionally asserting personal connections.

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 (aged 13) shared the nurse's surname. In doing so, she attempted to call upon a family-type obligation, which would require that she and her son be privileged. Saki's mother was therefore seeking a less mediated, more personalized relationship with state patrons. In the process, she imagined state documents as a source of recognition and belonging, in a context in which they might also propel cruel, bureaucratic indifference.

Surveillance as Care

Our research indicates that adolescents' compliance with ART was not guaranteed. There were instances in which young participants missed scheduled clinic appointments or defaulted from their treatment-taking routine. Sub-Saharan Africa is home to 1.4 million HIV-infected adolescents (UNICEF, 2016), whose long-term survival and health depend on strict adherence to ART. The limited research conducted with adolescent ART users in Africa shows that many miss doses of their medicines every week (Cluver et al., forthcoming; Nacheqa et al., 2009).

Five of the young people in this study were consistently not adhering to ART and one had stopped attending medical appointments altogether. Why might some young ART users consent to, and actively participate in, this system of demanding discipline, while others do not? One answer might be that their survival depends on it. But given the high numbers that don't comply with the prescribed clinical care, despite these risks, the imperative of survival was understood and enacted differently by various adolescents in this study.

We found that young people's adherence to medicine taking and their retention in clinical care was associated with how they, and their families, understood the relationship between discipline and care, or more specifically, whether they experienced forms of discipline *as* care. The focus on blood tests, as means of both patient monitoring and support, reveals the ambivalent interconnections between discipline and care, which are at the centre of this study. Nurse Thulani's explanation given to patients initiating ART is illuminating here:

[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 prevent 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.

According to Nurse Thulani, blood tests make visible the inner workings of the body. They 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 dose (10 March 2014). Bongani recalled affectionately how he and his aunt did weekly pill counts to check that he was taking his medicines properly (field notes, 3 April 2014). Reminiscing 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’ transcended the home and the clinic space, aligning ART surveillance with familial inclusion. To become visible to state ART programmes is to step into an ambiguous spotlight — one that simultaneously recognizes and regulates. Paying attention to these protective, intimate aspects of surveillance might further our understanding of the ‘discipline’ entailed in ART.

Documents as Recognition

In this study, folders and ‘passports’ signified adolescents’ membership of their ART clinics and illustrated their entitlement to its services. In one Ridgetown clinic we visited, access to a doctor’s appointment was further dependent on getting one’s name onto a waiting list, marshalled by two female healthcare workers. We 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 healthcare workers, 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. Not being on the list was not only a barrier to their service access. Rather, it made them invisible to these state providers. This suggests a more profound lack of recognition, akin to dismissal and marginalization.

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. Documents were imagined as a way to make oneself visible to state institutions as deserving of care, respect and inclusion. Scribbled with nurses' shorthand, these documents remained largely indecipherable to patients, who nevertheless protected them until they were worn and flimsy.

The 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, 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 dependants. 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. In households that often lacked the resources for other forms of material memorialization — framed photographs, family albums — the box provided succour for 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 whatnots . . . Your birth certificate, your mother's death . . . certificate' (4 September 2013). Here documents offer a form of recognition and dignity — a testament to the life, and death, of a person (Thomas, 2013: 24).

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 itself offered a powerful form of recognition.

Similar forms of social recognition are manifest in the use of bureaucratic markers 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).

While documents could serve as testimonies of membership, through which people compelled the state to see them, they could also swallow people up by reducing them to standardized categories. Siya, for example, was occasionally resentful of how documents amalgamated his identity with a population of patients. During one visit to the hospital, when healthcare workers 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’ (fieldnotes, 22 October 2013). Although his material needs and treatment access had been swiftly addressed in the clinic, his moral and social needs remained unmet.

Like others in this study, Siya found himself striving for more personalized relationships with providers. Recall how Siya had celebrated that the receipt of his new clinic folder coincided with his status as a ‘new man’, signalling something personal about him. Siya was also known to disregard hospital rules by carrying his medical folder to and from appointments (these were normally kept at the clinic; see below). He explained that this 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. Ironically, this rebellion worked not to disrupt the system, but to enhance its efficacy for Siya.

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. As with a spotlight, to be seen is also to be exposed. The bureaucracy of ART could 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 — required a particular form of organization at 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.

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. When young people felt recognized by the state, both the state–citizen relationship

and disciplinary mechanisms were bolstered. The operations of bureaucracy in the lives of HIV-positive adolescents reveal state treatment as an ambivalent process of social incorporation, marked by rich and dangerous potential.

CONCLUSION

By exploring how medical technologies and bureaucratic documents operate, and are operationalized, in the lives of youth on ART, this article has elucidated inherent and ambivalent interconnections between care and coercion within treatment programmes. Many adolescents entered their relationship with the state in a position of disciplined submission, experienced through the bureaucratic technologies that monitor and regulate ART. The question that came to the fore in this study was not whether dependent relationships with the state were good or bad. Rather, it was what these relationships might reveal about the material and moral needs of HIV-positive adolescents.

In accounts of the subordinating effects of state discipline in ART and other large-scale health initiatives, something important is lost: the recognition that people consent to, and wilfully participate in, these programmes. This presents a conceptual bind: how to reconcile consent, participation and voluntarism with the scientific realities of a disease that may only be treated, and survived, through practices of patient discipline. This study reveals how autonomy and agency are imbricated with regulation and submission in South Africa's ever-expanding bureaucracy of HIV care. 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. Among those adolescents in this study that were compelled to self-govern, it seemed that the primary motivation for ART compliance was not to achieve autonomous self-sufficiency, but rather to locate themselves within a structure of vertical dependencies — relationships that had both material and moral appeal.

We 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 involved tactical forms of agency, in which young ART users and their families compelled the state to recognize them as loyal, deserving subjects. 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. To take up ART was to initiate a process of precarious and ambivalent social incorporation, in which agency, recognition and care entailed submission to censure and control, at the same time that it provided for the health and survival of the teenagers in this study.

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