SEVEN

Care, Context, and Chronic Illness
Lessons from HIV-positive Adolescents
and their Families in South Africa’s
Eastern Cape

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INTRODUCTION

HIV/AIDS has been the most devastating epidemic in recent history. Since the early 1980s, over 78 million people worldwide have been infected with HIV (UNAIDS, 2014). The worst of the epidemic is in Eastern and Southern Africa, where 19.6 million people were living with HIV in 2018. Since the early 2000s, we have seen a dramatic scale-up of biomedical HIV treatment in Eastern and Southern Africa. The roll-out of antiretroviral therapy (ART) has made it possible for people living with HIV to suppress the virus and live long lives on medication. As the epidemic of HIV/AIDS is increasingly classed as a chronic condition the diagnosis of other, non-infectious chronic conditions has been on the rise. Africa is experiencing the highest
increase in premature deaths from non-communicable diseases (NCDs) worldwide. Consequently, there is an urgent need to explore practices and prospects for NCD care in African contexts, where health systems are under-resourced and heavily burdened by infectious diseases. How has care been constituted in these contexts and how might this inform our response to long-term illness?

In South Africa, this growing concern with NCDs emerges amidst the world's largest HIV epidemic and its largest ART programme. Drawing on the care experiences of 23 HIV-positive adolescents and their families living in the Eastern Cape, this chapter considers broader implications for chronic patients in under-resourced settings. It makes three interrelated claims about care in these contexts: first, where health facilities are overburdened, the quest for care entails a quest to ‘be seen’ by health providers, both literally and metaphorically. Second, care for chronic patients spans clinic and home, involves both family and health workers, and is often enacted within pre-existing structures of authority. These caring relationships are regularly expressed through generational hierarchy and mutual obligation. Third, where livelihoods are precarious, securing medical care forms part of a wider, and often hostile, pursuit of survival and support. NGOs, government departments, homes, and communities all constitute a complex economy of care in which power and resources are unevenly distributed and social stakes are high. The ways in which homes, communities, and health facilities have enacted care in response to long-term HIV can inform responses to other chronic illnesses.

While the concept of care is now widely and varyingly used, it retains important analytic utility. By being precise about how care articulates in different contexts, we might also trace geographic and temporal change in how it is understood and practised. Part of what this chapter aims to do is situate care in – and as a response to – context. How care is enacted is informed by flows of power and resources in clinics, homes, and communities. Claiming, providing, and sustaining care is about navigating these flows: working within constraints, making oneself visible in the right ways and to the right audiences, and strengthening social ties.
METHODS

The empirical components of this chapter are situated in the context of a broader consideration of the outbreak and relative containment of HIV as epidemic, and the coexistence of HIV care with the management of multiple NCDs. The empirical components draw from an eight-month ethnographic study, exploring the practice of antiretroviral therapy among a cohort of 23 HIV-positive adolescents (age 10–19 years) in South Africa’s Eastern Cape. By ‘practice’ I mean the precarious, situated, and relational ‘work’ that goes into young people’s everyday achievement of ART, including taking daily medication, regularly attending health appointments, and participating in HIV treatment support groups. Data for this study was gathered through multi-method ethnographic fieldwork with HIV-positive youth, their families, and local health workers. Fieldwork was conducted alongside a research assistant, Mildred Thabeng, who played an invaluable role in data collection and concurrent analysis.

Research was conducted in two Eastern Cape sites: one rural and one peri-urban. By making this selection we hoped to cover the contexts in which most South Africans experience care, while also comparing rural and urban experiences. 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. Among the 13 Mtembu families with whom we worked, only one household had a permanently employed member. She was employed as a domestic worker in her village but lost her job towards the end of the research period. Most of the households 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 informal settlements of a small town I call Ridgetown. Including its informal settlements, Ridgetown has an estimated population of 125,000 people. At the time of the research, 66 per cent of working-age (15–64) residents in the municipal area were thought to be jobless (Stats SA, 2014). Among the nine Ridgetown families in our study, many adult members struggled to access stable jobs. Those fortunate enough to find contract work were employed 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 adolescents had spent on ART varied (from 1–11 years). Since all adolescent participants were enrolled in ART programmes, and most were receiving additional NGO support, this sample is likely to represent an especially compliant group of young treatment-takers. Recruitment did not reach those who had long fallen out of ART care, and those receiving inadequate treatment support are under-represented in this sample.

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 ongoing struggles with treatment adherence were often older adolescents, who were less subject to the authority of adult caregivers. One of these older adolescents, for example, had stopped taking treatment altogether, another only took treatment when food was available, and a third found he forgot his pills when he was out with his friends.

Fourteen of the adolescents in this study had lost at least one parent to AIDS illness; three had parents killed in violent crime; and eight had a parent who was either absent or estranged. As a result, most young participants were not living with biological parents, but instead with relatives. In addition to child support grants, a few adolescents in our study benefitted from care dependency or disability grants on the basis of their HIV-positive status. Grandmothers on state pensions were most frequently household heads. Eleven of our adolescent participants lived with at least one other person on HIV-treatment and many elderly caregivers took diabetes or high blood pressure medication. During one of our conversations with Nurse Kani in Ridgetown, he commiserated about the number of medications that could be found in a single household: ‘Medication for high blood pressure, medication for diabetes, antiretrovirals, TB-pills …’ (interview, 3 March 2014, Ridgetown). The extent of chronic illness requires families, like those in this study, to visit public health facilities regularly and follow their prescriptions diligently. This requirement shapes when households wake in the morning, what and when they eat, and how they demonstrate and enact care for one another.

Throughout fieldwork, Ms Thabeng and I visited young people and
their families regularly, engaging as far as possible in their everyday lives. Hours of informal conversation were had while cooking, washing clothes, sharing food, walking, and playing with friends. This was complemented by more structured research methods, including semi-structured interviews with both adolescents and their caregivers. These interviews centred on adolescents’ HIV diagnosis, treatment-taking, family life, and interactions with clinics. In addition to spending time in participants’ homes and communities, we also observed their interactions with health facilities. Over the course of our fieldwork, we visited nine community clinics and four hospitals, accompanying young people and their families to appointments. While observing participants’ consultations, we also had informal discussions with health workers, and in some cases conducted formal interviews.¹

The small ethnographic study from which this chapter draws formed part of a larger, interdisciplinary research collaboration called Mzantsi Wakho (Your South Africa). Mzantsi Wakho is a research partnership between the universities of Oxford and Cape Town. 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.ii

¹ Fieldwork was carried out using a combination of both English and isiXhosa. Translation occurred in situ to allow for immediate, follow-up probing. These complex on-site translations have subjectively coloured the data and may have produced misinterpretation. Structured interviews were audio-recorded, while informal interviews, observations, and ethnographic interactions were documented in fieldnotes. Throughout fieldwork, Ms Thabeng and I were involved in ongoing, concurrent analysis, adapting the data collection to further our understanding of emerging themes. Data was then thematically coded, comparing and contrasting themes that revealed adolescents’ interpretation and practice of HIV treatment.

ii Ethical approval for this study was granted by the universities of Oxford and Cape Town, and the Eastern Cape departments of Health, Social Development, and Education. Written informed consent was given by all adolescents and their primary caregivers, and consent information was read aloud in case of low literacy. Consent materials were written and discussed in English and/or isiXhosa, depending on the preference of the participant. There were no financial incentives, but we often brought refreshments to meetings and assisted adolescents with transport, grant applications, and other referrals. Confidentiality was maintained except in cases of risk of harm: if adolescents reported abuse, suicidality, rape, or severe illness. In these cases, referrals were made to relevant social or health services and followed up to ensure that services were received.
Although South and Eastern Africa accounts for only 6.2 per cent of the global population, it is home to half of all people living with HIV (UNAIDS, 2017a). In 2016, the region suffered nearly half a million AIDS deaths (UNAIDS, 2017a). In the same year, South Africa accounted for one third of the world’s new HIV infections, with a further 50 per cent of new infections attributable to these countries: Kenya, Mozambique, Zambia, Tanzania, Uganda, Zimbabwe, Malawi, and Ethiopia (UNAIDS, 2017b).

The human impact of HIV/AIDS in Southern and Eastern Africa has been immeasurable. The virus is borne most heavily by adult women and men in the prime of their lives, stripping economies of workers and households of important caregivers. The epidemic has deepened inequality in the region, burdened public institutions, destabilised family livelihoods, and amplified tensions in our most intimate lives. Its impact has been felt across generations, affecting children, parents, and grandparents, regardless of whether the virus itself is shared by all (Scherr et al., 2014).

The extraordinary impact of HIV/AIDS has prompted an unprecedented global effort to guarantee access to ART in order to treat HIV among those living with it. This has resulted in significant declines in AIDS-related deaths worldwide, and a related rise in global HIV prevalence (Kharsany & Karim, 2016). Despite the continued severity of the HIV/AIDS epidemic in the region, immense progress has been made, particularly over the past decade. Sixty per cent of people who live with HIV in East and Southern Africa are now receiving treatment (UNAIDS, 2017c). Between 2010 and 2016, new HIV infections among adults declined by 29 per cent, while the number of children being newly diagnosed more than halved (UNAIDS, 2017c).

A key feature of Africa’s HIV/AIDS pandemic is ‘that it appears as both a crisis and a systemic condition’ (Poku & Whiteside, 2004). It is now widely acknowledged that, in order to curb the HIV/AIDS epidemic in Southern and East Africa, we need more than a crisis response: we need a systemic one. Encouraging people to practise safer sex, test for HIV, or adhere to their treatment is not sufficient on its
own. We must also address the social and environmental conditions that support or constrain their choices and abilities. This means focusing on health systems – practices and places of care, as well as the conditions that constrain them.

With access to ART having increased dramatically in this region over the past decade, the urgent, acute aspects of the disease have slowly been de-emphasised in favour of a focus on long-term survival. The certainty of death is incrementally being replaced by ‘the uncertainties of life on HIV treatment’ (Whyte et al., 2014: 69). One of the most devastating infectious diseases of the last century, HIV/AIDS is increasingly framed not as an acute, terminal condition, but as one that is made both treatable and less infectious through life-long chronic medication. As with other forms of chronic illness management, ‘good’ HIV care is now frequently defined by adherence to treatment, regular check-ups, ‘lifestyle’ changes, and self-regulation (McGrath et al., 2014).

Like much of the world, South Africa is increasingly orientating its primary health system towards long-term illness, and high rates of co-morbidity. Compounding the country’s burden of HIV and TB are the rising numbers of patients suffering from NCDs (Lawn & Kinney, 2009; Coovadia et al., 2009). Indeed, the arrival and mass distribution of HIV treatment is concomitant with the unprecedented roll-out of other long-term medication, particularly for high blood pressure and diabetes (Magadzire, 2016). While ART availability transforms HIV into a chronic (rather than a terminal) illness, it also increases overall chronicity and the risk of co-morbidity. This is not only because HIV-positive patients live longer, but also because they do so at increased risk of additional chronic conditions.

Experiences of NCDs in Africa are markedly different from the global north: health systems in Africa are under-resourced, heavily burdened by infectious diseases, and, consequently, poorly orientated towards non-communicable chronic conditions. And yet, ‘HIV programmes are, in fact, the first large-scale chronic disease programmes in many [Southern and East African] countries’ (Rabkin & El-Sadr, 2011). These programmes have had to develop effective systems of care with very few resources. The continent’s HIV/AIDS response holds many lessons about the practices and stakes of long-term care in these contexts, which
might inform our response to rising chronicity (Rabkin & El-Sadr, 2011).

This chapter draws on a small South African case study to explore what the HIV/AIDS response can teach us about health systems in Africa. The case study emerges from an ethnographic study with 23 HIV-positive adolescents, and their families, living in rural and peri-urban Eastern Cape. In South Africa, adolescents who contracted HIV in infancy are some of our longest-surviving HIV-treatment users. They have been taking medication and regularly attending clinics most of their lives. Yet they are the only population group for whom AIDS-related deaths have risen since 2001 (WHO, 2013; UNAIDS, 2013). This is attributed in part to a lack of retention in care and poor adherence to HIV treatment (Denison et al., 2015). Their experiences hold relevance for the challenges and possibilities of chronic care in African settings.

Drawing on practices and experiences of care among HIV-positive adolescents, their families and their health workers, the chapter makes three claims about what constitutes ‘care’ where illness is long-term and resources are scarce:

1. **Where health facilities are overburdened, the quest for care entails a quest to ‘be seen’ by health providers.** A rising burden of chronic, routine patients – together with high rates of acute illness – means that health facilities in under-resourced settings are frequently overcrowded and understaffed. Those who visit clinics and hospitals, particularly those who are not acutely ill, can expect to spend hours queueing. In an effort to secure a consultation (‘be seen’), adolescents and families in this study employed a variety of tactics to make themselves visible (‘be seen’) to health staff. This included building personal relationships with staff, finding means to jump the queue, demonstrating good behaviour, or acquiring supporting documents. Similarly, in her examination of hospitals in Papua New Guinea, Alice Street (2012) found that there was a power in ‘making oneself seen’ particularly where the state was deemed weak or absent.

2. **Treatment and care for chronic patients spans clinic and home, involves both family and health workers, and operates within pre-
existing structures of authority. Caring relationships are regularly expressed through hierarchy, mutual obligation, and entitlements. The work of ‘being seen’ highlights the relational nature of care in these settings. Adolescent participants and their families were interested in bolstering relationships of care, both in health facilities and their own homes. The obligations and entitlements associated with HIV treatment helped to strengthen reciprocity and caring roles. The ‘proper’ provision of care was often framed in terms of ‘disciplining’ the ART-user, thereby reinforcing the moral authority of the care provider. Conversely, the ‘proper’ reception of care frequently entailed forms of deference, respecting and thereby cementing bonds of mutual obligation across generations. As observed in other Southern African contexts, ‘the work of nourishing and extending relations, whether as patient or caregiver, professional or volunteer, becomes an important means through which caring futures are constituted’ (Mkhay, 2018).

3. Where livelihoods are precarious, securing medical care forms part of a wider, and often hostile, pursuit of survival and support. Rather than being about recovery, chronic care is about living well with illness. Adolescents and families in this study participating in HIV-treatment programmes formed part of a wider moral economy of survival, linking them to a range of NGO and state support services, which not only provided biomedical treatment but also sustenance and social support. Indeed, research with ART patients in Western Kenya has shown that although HIV-treatment programmes often medicalise survival they have also created linkages to other crucial forms of sustenance and support that become essential to how care is constituted (Prince, 2012). While adolescents and families in this study lived in neighbourhoods in which poverty was generalised, HIV (along with other chronic conditions) could make one visible to funders, government agencies, and non-governmental support in particular ways. Where resources for care are scarce and unequally distributed, the pursuit of care becomes both more urgent and more contested, since who is cared for, and who is not, can become a source of injury, resentment, and even persecution.
COMPARING HIV/AIDS AND NCDS

Before exploring what might be drawn from experiences of the HIV/AIDS response to tackle rising chronicity on the continent, it is worth signalling some of the similarities and differences between HIV and NCDs. The most immediate difference is that HIV is classed as a ‘communicable’ condition, while NCDs, by definition, are not. However, this dichotomy is murkier than it seems. While the HI virus is of course infectious, adhering to ART makes it possible to achieve viral suppression, in which a person with HIV is in fact relatively un-infectious. Second, although NCDs are technically not ‘communicable’, in some places the dramatic ‘spread’ in the number of diagnoses and rising awareness of conditions like hypertension and diabetes can feel like ‘contagion’ (Whyte, 2012). As a result of shared life conditions (poor diet, pollution, physical inactivity, alcohol — even genetics), which enhance vulnerability to NCDs, household members can also share non-communicable ailments, just as HIV/TB have often affected multiple family members.

Both HIV/AIDS and NCDs are ‘chronic’ in the sense that they can be managed through long-term treatment and monitoring. Both demand a health system in which continuity of care (between clinic and home), as well as retention in care, are paramount. In both cases, what is needed is a sustained commitment by patients, in the form of regular clinic attendance and adherence, and regular monitoring from the health system. These are lifelong commitments (Rabkin & El-Sadr, 2011). But this does not mean that HIV and NCDs are always experienced as chronic: left untested, or untreated, both HIV and NCDs can arrive in a person’s life as acute (McGrath et al., 2014). Indeed, both NCDs and HIV can remain asymptomatic for long periods.

HIV has been highly stigmatised (partly due to its infectiousness), with severe implications for people’s willingness to be tested and treated. This stigma has been significantly less prevalent for NCDs. Yet in most Southern and East African settings people are less likely to be tested and treated for NCDs than they are to be tested and treated for HIV. This is partly due to a lack of awareness about NCDs, and partly because access to screening is limited (Whyte, 2012). Finally,
while it is primarily young people, and children, who have contracted HIV, the aged are more likely to be diagnosed with, and die from, an NCD. This is notwithstanding rising NCD rates among young adults (Kaba, et al., 2017).

Drawing from the HIV/AIDS experience in order to frame and better respond to NCDs is not simply a public health recommendation (Rabkin & El-Sadr, 2011). It has also been observed in lay practice on the continent. Research from Southern Africa suggests that local understandings of NCDs are often framed in relation to HIV. In a Ugandan study, *plesa* (high blood pressure) and *swekile* (diabetes) were described as ‘new sicknesses’, while HIV was understood as ‘old’ (Whyte, 2012). Similarly, in a South African study HIV was described as ‘ordinary’, while diabetes was ‘new’ (Mendenhall & Norris, 2015). Patients across studies compared possibilities for managing and controlling these conditions long term. What this research suggests is that in many parts of Africa HIV and NCDs are not experienced in isolation but as parallel epidemiological patterns. Households and communities experience both infectious and non-infectious conditions simultaneously, and in relation to one another. The experience is one of lifelong, compounding illness concerns with implications for how families, communities, and clinics practise care. Understanding what constitutes chronic HIV care is therefore immensely relevant for how we tackle chronicity in the region.

**ART AND SOCIALITY**

*AIDS has taught us both the power of science and its limitations. It has given us incredible technologic successes.*

*But fully implementing those successes still escapes us*  
(Dr Gerald Friedland, Yale University, in Zuger, 2003).

The HIV/AIDS epidemic has taught us that, however exceptional our medical technology may be its efficacy depends on the ways in which it is interpreted, and taken up, in local contexts. At its heart, this chapter is about the forms of sociality entailed in the ways that HIV-positive adolescents, their families, and health workers practise and claim care.
Epidemics and the Health of African Nations

It suggests that these forms of sociality, and the implications they hold for care, are born out of the experience of long-term illness in under-resourced settings and therefore have broader implications for chronic illness in Africa. Anthropology has a rich legacy of theorising health socialities, including biosociality (Rabinow, 1996), illness identities, biological disruptions, and forms of health citizenship (Nguyen, 2005; Robins et al., 2008). Much of this literature has centred on chronic and not acute conditions.

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: 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 private pharmacy might be. Nor is a client simply a patient. Instead, clients participate in institutions of care with associated expectations and entitlements.

In a context of rising chronicity, interactions with medical facilities are less ad hoc and less determined by desperately sick bodies. Instead, an estimated 70 per cent of patients in South Africa’s health facilities are regular attendees.iii Their experience of care is increasingly characterised by the ritualised collection and consumption of medicines, and lifelong participation in health surveillance. More and more, patients do not visit health facilities: they enrol in them.

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 form of 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

iii Extrapolated from District Health Barometer 2016/17, Health Systems Trust.
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 competitions for donor spoils, negotiating multiple relationships of hierarchy and dependency (Beckmann & Bujra, 2010: 1051). 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: 549).

Indeed, there is another meaning of clientship 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 recount 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: 56). In ART programmes, the personal, emotional quality of these ‘lopsided friendships’ (Pitt-Rivers in Wolf, 1963: 17–19) is often mediated through a nexus of paradoxically impersonal, bureaucratic procedures.

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 integration into society. ART prompts people’s struggle for work, partners, and a ‘normal’ life, rather than necessarily encouraging them to foreground their HIV identities as ‘therapeutic’ or ‘responsibilised’ citizens. Biehl (2007: 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.

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: 1). While the
growth of social welfare preceded 1995, the extraordinary expansion of the number of people on state benefits has been the most striking characteristic of policy and practice since democracy and has had a significant impact on alleviating poverty (Bhorat & Cassim, 2014).

A context of mass unemployment and social exclusion has arguably provoked new kinds of dispositions towards the authority of the state (White, 2012). Many people are seeking less mediated, paternalistic relationships with government patrons – a relationship that is sometimes imagined through welfare. This growing ‘politics of distribution’ (Ferguson, 2013) 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: 375).

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. Bureaucracy becomes a central feature of care. 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: 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, the 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.

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: 58). Increasingly, HIV-positive patients enrol in organisations which 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’ – communities of care, which offer resources, services, and networks, but which also have their own rules and systems of privilege. Each of these communities calls on ‘networks of obligation and reciprocity’ which become part of what it means to negotiate life on ART (Nguyen, 2005: 126).

In some situations, HIV can be an asset, opening up spaces for recognition and entitlements, and making one visible to the organisations that distribute material resources. 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: 549). Those participating in contemporary ART programmes negotiate highly ambivalent social worlds in which openness and solidarity are idealised, while secrecy, fear, and discrimination persist (Comaroff, 2010: 26).

FINDINGS

Health facilities: being seen rather than swallowed
In mid-November 2013, Ms Thabeng and I accompanied 18-year-old Thembakazi to a scheduled hospital appointment. We travelled 50km, on predominantly dirt roads, from her rural Eastern Cape village to the nearest town where the hospital was located. Like most other adolescents in our study, Thembakazi had been born with HIV. When we met her, she had been taking HIV treatment for nine years. While receiving state-sponsored HIV treatment, Thembakazi also benefited
Thembakazi’s ability to access the more lucrative care dependency grant, as opposed to a child support grant, is testament to the strong, long-term relationships she and her family had built with NGO workers throughout the course of Thembakazi’s life. Thembakazi was one of the first children in her village to be initiated onto ART, which was privately sought through the NGO in 2003. In order to qualify her for a care dependency grant, Thembakazi’s family, alongside the NGO doctor, would have needed to make a case for Thembakazi’s long-term ‘severe disability’ and navigate a host of bureaucratic procedures.

For Thembakazi, enrolling in HIV treatment served as an ambivalent form of social inclusion. It was not simply a matter of initiating biomedical treatment: rather it meant being encompassed into a number of care institutions spanning NGO and state. Thembakazi is recognised as an entitled state dependent, NGO beneficiary, and recipient of life-saving resources. But she is also an object of discipline, subject to blood tests and pill counts. Wrapped up in the care she receives, then, are deeply intertwined forms of validation and support, compliance and obligation.

On this particular day, Thembakazi hoped her doctor would be referring her for a disability grant. Having just turned 18, she now met the age requirement, although age is only one of a number of eligibility criteria. After collecting Thembakazi from school, we stopped first at the village clinic to collect her folder and then at the social services office for the grant application forms. Before three o’clock, we were seated in the hospital waiting room, holding the necessary documents.

In a context where health facilities are overcrowded, and many will not be seen by a nurse or doctor, these documents play a significant role in making oneself ‘visible’ in the correct ways. To be documented is to demonstrate one’s legitimacy and one’s compliance with the procedures for welfare access, and to call upon state obligations towards you. In one Ridgetown clinic, for example, access to a doctor’s appointment was dependent on getting one’s name onto a waiting list,

iv  Intended to provide support to caregivers of any child with severe mental and/or physical disabilities up to 18 years, requiring full-time home care.
marshalled by two female health workers. 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’ (fieldnotes, 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 health 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 and they were barred from health care access.

In his effort to skip hospital queues, another adolescent from Thembakazi’s village, named Siya (age 18), had taken possession of his hospital folder, which is supposed to be kept on site. ‘The hospital always loses it,’ he told us, and a lost folder could keep him waiting for hours. Instead, Siya sneaked his folder home with him, and then brought it along to each appointment. Already having his folder meant his visibility in the system was assured, saving him the time and the frustration of having it located and given to him.

When Thembakazi, Ms Thabeng and I were finally called to the nurses’ desk, we were told the doctor had left, and then reprimanded for having arrived at the hospital ‘so late’. I asked what time we should return to secure a doctor’s appointment. ‘It depends,’ one nurse replied, her eyes still fixed on her paperwork. I persevered: ‘We don’t want to come here again, using time and petrol money, if we aren’t going to see a doctor.’ We were well aware that many people in this area spent precious resources travelling to clinics and hospitals and could not afford to be turned away. ‘Come by 11 or 12 [o’clock] at least,’ said the nurse.

I followed with another line of questioning about whether school learners, like Thembakazi, would be expected to miss their classes in order to attend doctor’s appointments, but I was quickly silenced by Thembakazi and Ms Thabeng, who hurried me out of the hospital doors. I continued to grumble about the barriers to access, while Thembakazi and Ms Thabeng pleaded that we stop pressing the hospital staff and resign ourselves to leaving without having seen the doctor.

Back in the car, Thembakazi explained that by ‘causing trouble’, she risked being punished or denied treatment at her next visit. ‘But patients should stand up for their rights!’ I insisted. ‘You are entitled
to this health service. It’s [intended] for you!’ As we journeyed home, Thembakazi and Ms Thabeng argued that ‘rights’ and the ability to assert them were reserved for those with ‘money and power’. By challenging state patrons on the basis of rights-based claims, the less fortunate risked losing the few services available to them.

Thembakazi’s strategic submission to the hospital nurses, which she believed protected her access to care, was not uncommon. Not long before, another rural family in our study had told us that, when confronted or reprimanded by nurses, they ‘just keep quiet, otherwise they won’t get what they need’ (fieldnotes, 16 October 2013). This tactic is far from that of the imagined ‘empowered’ ART-user. While the agency exercised here is not devoid of power, it is an agency that aims to protect fragile relationships with health officials. Rather than being a once-off, rights-based claim, accessing care meant protecting long-term social ties with health staff, however hierarchical these might be. Researchers in Zimbabwe also found that ART patients perform within the confines of the ‘good patient’ in order to access ‘good care’ and ensure continued access to treatment (Campbell et al., 2015). ‘Good patients’ were characterised as obedient, polite, patient, and grateful.

The ethnographic vignette I recount here is one in which I, as the researcher, am on the scene. On this occasion, I was attempting to straddle dual roles – as an anthropologist and as an advocate for Thembakazi’s health care and rights as a citizen. While our study did not offer adolescents or families monetary compensation for research participation, we did occasionally assist with referrals or transport to health facilities. On this day, I attempted to negotiate access for one such adolescent participant, Thembakazi, but in the process, I also unintentionally provoked a significant moment of analytical development and researcher reflexivity. In our encounter at the hospital, both Thembakazi and Ms Thabeng would challenge my rights-based, individualistic assumptions about health access. In doing so, they also helped frame the nature of ‘care’ in the health facility. In our peri-urban fieldwork, too, we witnessed adolescents and their families attempting to nurture relationships with health providers.

Although Ridgetown clinics only opened at 8 am, patients could be seen queuing as early as 5 am. It was around 5.30 am on 13 February
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2014 when Ms Thabeng and I sat with Saki (aged 13) and his mother, waiting for the clinic gates to be unlocked. While we sat in the car, Saki’s mother explained the rhythms of the clinic:

Gates open at 7.30 for the cleaner. That’s when everyone goes inside, but the nurses won’t see anyone until 8 am. The clinic usually opens with a prayer. Then the nurses say who should stand in which queue. Often, they will make an announcement about staff shortages – the fact that they are supposed to have six nurses, but only have two. At 10 am the nurses usually break for tea. At 1 pm there is a full lunch break: all the nurses will stop for an hour and there is no rotation. At 2 pm, the school children arrive for the contraceptive injection as do the high blood pressure patients, and the clinic becomes full. Sometimes the nurses send you home at this point even if you have been there since the early morning.

Contained in this description are a number of assessments about the nature and constraints of care at the clinic. Saki’s mother describes the various ways in which opportunities to be ‘seen’ and cared for are delimited. She references persistent staff shortages and the volume of patients. By describing staff shortage announcements as routine, she suggests that shortages are the norm, rather than the exception. Reflecting on overcrowding, Saki’s mother makes particular reference to other routine visitors, like those coming for contraceptives or high blood pressure treatment. Like Saki, these patients will visit the clinic regularly regardless of whether they feel sick that day. Saki’s mother’s description also makes implicit judgements about ‘uncaring’ health professionals. She references nurses’ apparent refusal to rotate shifts or to begin work before 8 am. She also notes the injustice of a system in which you can be turned away despite having waited a full day.

Despite this, one can also read in this account efforts by the nurses to enact care in different forms. Starting with a prayer gives clinic operations a sense of earnestness and invokes a moral code. Nurses make an attempt to create order and fairness, and to induce acceptance, in an overcrowded system, allocating people into different queues and setting specific times for teenage or high blood pressure patients. By
announcing staff shortages, nurses are also appealing to patients for patience and understanding. In response to patients’ protests at being sent away at the clinic’s closing time, a Ridgetown pharmacist once said:

*You guys think we don’t do anything. We are so tired. It’s almost four 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* (fieldnotes, 6 March 2014).

The very description of the clinic routine suggests that caring relationships are fraught, demanding ongoing nurturing. Both patients and nurses are operating in a system that makes the provision and reception of care very difficult to achieve. Attempting to ‘be seen’ in the right ways is a central part of these operations.

Mastering the clinic queue becomes an important site in the struggle to ‘be seen’. We saw patients pay friends R15 to stand in the queue for them, others skipped the queue by taking a seat alongside someone they knew, while others used our presence as noticeable ‘visitors’ to get faster access to nurses. Similarly, in rural hospitals, we saw NGO workers lobby for their adolescent patients to skip the queue. On one occasion, this required that a community health worker disguise herself as an ambulance driver. In her bid to skip the clinic queue that day, Saki’s mother appealed to one of the nurses by pointing out that she and her son shared the nurse’s surname. By doing this, she was attempting to call upon a family-type obligation, which demanded that she and her son be privileged (fieldnotes, 6 March 2014).

Many sought to ‘work’ the queue. Some succeeded. But patients also protested about those cheating the system. On one occasion, we saw a Ridgetown patient request a clinic transfer because he was not satisfied with the long queues, or nurses’ relatives getting special assistance. In order to protect their moral authority, and avoid the collective anger of those queueing, it was important that nurses be seen as fair. For this reason, many nurses were wary of being seen to give special assistance. For this reason, Saki’s mother’s appeal to the nurse who shared her surname had no impact.

After many hours of waiting, we, along with Saki and his mother,
were finally called into Nurse Mtambo’s consultation room. A moment later, a young female patient arrived at the door begging 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?’ By responding in this way to the woman at the door, Nurse Mtambo implicitly recognises our patience and understanding, and demonstrates her own sense of fairness. Both patient and provider are deemed to have ‘done their part’ in making care possible under difficult circumstances: the patient has waited patiently and the provider has protected their entitlement to ‘be seen’. This mutual recognition, in which obligations are shared even if power is hierarchical, was fundamental to what constituted care in these settings.

On the day we travelled with Thembakazi, we (like the young woman who interrupted Saki’s consultation) had been reprimanded by nurses for arriving ‘so late’. Indeed, in clinics and hospitals throughout our study, we regularly witnessed nurses scolding patients for their ‘lateness’ and ‘impatience’. These reprimands might be read as a way for nurses to show offence: it is an offence to demand care, rather than wait for it. Rather than simply being callous, nurses are often trying to engender, protect, and even enforce a semblance of order in a context in which injustices abound.

Building connections with health workers through displays of deference was central to the practice of showing and receiving care. Adolescents took on similarly deferential roles with caregivers in their homes. Indeed, adolescents’ treatment-taking, and caregivers’ attempts to support it, were located in practices that reinforced family roles and obligations. In doing so, these care practices entailed a bolstering of social ties. Where illness is long term, and there is a scarcity of material and human resources for care, these social ties become central to how care is constituted.

**ART AS A PRACTICE OF SOCIALITY IN THE HOME**

A large majority (19) of the adolescent participants in our study had contracted HIV at birth. Many had since been orphaned by AIDS, while others were estranged from their biological parents. Eighteen adolescents in our study had mothers who were either dead or absent. Of these, all but two also lived without their fathers. As a result, 11 of
the 18 are now cared for by grandmothers, often in combination with other relatives.

HIV treatment enters these homes after the family has undergone significant trauma. Our findings suggest that it is often adolescents’ dead or absent mothers who are blamed under these circumstances. In South Africa, caregiving has for centuries been a responsibility borne disproportionately by mothers. Initially, years of migrant labour kept many men from their homes. In the post-apartheid context, escalating unemployment has limited men’s ability to afford lobola and provide for families. Female-headed homes have been further entrenched, not only by declining marriage rates, but also increased access to social grants (for which women are the primary recipients). Hence, in many households grandmothers have replaced wage-earning men as economic linchpins (Bank, 2002: 641). The immense responsibility, shouldered by women, to run households and raise future generations also exposes them to blame should they be considered to have ‘failed’ in their duties. In relaying family narratives both to us as researchers and to their HIV-positive adolescents, older female relatives were often engaged in attempts to position themselves as morally capable care providers, sometimes shifting blame onto other (younger) women (Vale & Thabeng 2016; Vale et al., 2017). Although men were rarely on the scene, and the majority of homes in the study were female headed, the context in which care was constituted was nevertheless deeply patriarchal.

Some grandparents, uncles, and aunts in our study told stories of adolescents’ dead and absent mothers having flouted tradition, behaved recklessly, or abandoned their responsibilities – with their child’s inherited illness being one of the consequences. Some mothers had been completing school during their pregnancy and were considered too young to care for their babies. Others were demonised for having had a child outside of wedlock, their purported promiscuity, or their heavy drinking (Vale & Thabeng, 2016). Absent mothers were regularly accused of neglecting their children and negating their responsibilities. Bongani’s (age 17) paternal aunt, for example, said: ‘I would never give him [Bongani] away to his mom because she never really looked after him’ (5 March, 2014).

Among those mothers who had died were those who had started
ART but were said to have failed in taking their treatment properly. Andile’s (age 13) aunt told us: ‘He [Andile] 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 instances, dead mothers were held up as a ‘warning’ and an indication of what not to do. By referring to their mothers’ mistakes, adolescents were encouraged to live responsibly with HIV. Wandi (age 19) told us this: ‘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).

Many of these guardians described adolescents’ adherence to ART as a way for them to demonstrate obedience and good discipline to their elders, and thereby avoid their mothers’ fate (Vale & Thabeng, 2016). By diligently taking their medication, adolescents were offered the chance to ‘redeem’ the memory of their mothers who, despite their failings, were ultimately ‘good’ and ‘loved them’. Thus, taking treatment would serve as a means to suture familial wounds and restore intergenerational forms of care and respect.

Like many other absent mothers in our 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 HIV treatment. During our interview with her, however, Naledi’s grandmother was eager to illustrate to us that Naledi was not like her mother. She showed us this by referencing her 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 grandmother then went on to talk about other examples of Naledi’s obedience and her contributions to the home: ‘She cleans, she cooks, she put in the tiles in the doorway.’ In this way, Naledi’s grandmother aligned ART with other practices of care, home-making, and intergenerational respect.

Indeed, taking ART diligently was often narrated as an act of care and deference towards one’s elders, rather than an act of autonomous empowerment. When Anele (age 13) was resisting taking his medication, his grandmother described him as ‘not listening to her’ (fieldnotes, 2
April 2014). Relatedly, when we asked Xolani (age 11) about why he took his pills so well, he said ‘because Makhulu (grandmother) tells me to take them’ (fieldnotes, 3 October 2014). Treatment-taking was firmly located within pre-existing structures of care, which needed to be nurtured in order to sustain care and support long term.

Adolescents in this study often expressly included discipline and protection as part of their articulation of care. Some adolescents described the act of ‘checking up’ on pill-taking as a form of positive caregiving. Nonkosi (age 17) said he appreciated that his grandmother ‘guarded’ him when he took his medication, describing how she would watch as he swallowed his daily dose (fieldnotes, 10 March 2014). Bongani (age 16) described, with affection, how his aunt did weekly pill counts to ensure that he was taking his pills properly (fieldnotes, 3 April 2014). When Lisa (age 19) told us about her deceased mother, she remembered fondly that her mother was ‘always someone who knew where I was. Even when I went to play, she looked where I was playing [...]’ (interview, 10 December 2014). As we saw in the clinic, to ‘be seen’ becomes essential to the experience of care. Not only are routine monitoring and constant oversight essential to the very nature of chronic illness management, but more so, in social contexts where the risk of feeling abandoned is great – perhaps due to overcrowded clinics, parental loss, or poverty – being ‘seen’ is a rare commodity, and an important source of dignity.

Hence, in both clinics and homes, relationships of care were often defined by consensual, hierarchical dependencies and forms of deference and discipline. The relationships were defined by mutual obligations and entitlements. Care had moral and material valence for both the caregivers and the cared for. Tied up with ‘making a life’ on ART was making a life with others — one that embedded itself in existing structures of care, respect, and authority.

COMMUNITIES: CARE AND SURVIVAL

Living with HIV, as with other long-term conditions, means locating biomedical treatment within the wider project of ‘making a life’ – sustaining health, livelihood, and sociality. Where resources are scarce, and survival precarious, building and sustaining networks of
care becomes even more critical. This chapter has already discussed the ways in which adolescent participants and their families secured and experienced care in clinics and homes. In both spaces, being ‘seen’ and protected by caregivers in ways that might nurture caring relationships was important. But ART also linked adolescents and their families to other sources of care. Not only were adolescents in this study visiting clinics on a regular basis for pill collection, monitoring, and blood tests, many had also been enrolled in NGO-run support groups. In Mtambu’s rural areas, this meant quarterly weekend-long gatherings filled with treatment literacy and psychosocial support. In Ridgetown, some of our participants attended weekly support group meetings. Both rural and peri-urban support groups dealt not only with the challenges of ART, but also assisted adolescents with schooling and family troubles. To add to this, all of the adolescent participants in our study had a community health worker or ‘treatment buddy’ occasionally visiting their home.

Beyond this system of ART support was a larger social services system. Participation in the former often helped one gain entry to the latter. Community health workers mediated access to a range of social grants on families’ behalf: foster child grants, child support grants, and care dependency grants. Some families were referred for food parcels. For adolescents in this study, to initiate HIV treatment was to slowly enter into a web of caring connections that provided for their life and their livelihoods.

South Africa’s expansive social welfare system is the largest in the region. The organisation of state assistance in South Africa aims to alleviate the plight of the country’s poorest citizens by targeting those among them who are either unfit to work or are caring for children. The result is an arbitrary divide between the poorest households that have no state support at all and the otherwise very similar households that receive comparatively generous support simply because they include grant-eligible children, elderly persons, or disabled persons (Ferguson, 2013: 78). 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: 383). Some families may rely on their youngest children for material support – those in whose
names grants are available (Henderson, 2012).

In addition to childcare assistance, a few adolescents in our study also benefited from care dependency or disability grants on the basis of their HIV status, with many more hoping to apply. Thus, in this study, it is the youth, chronic illness, and sometimes orphan status of young participants that brings them under multiple forms of state paternalism. While these categories signal marginalisation and exclusion, at the same time they also bring youth on ART under unique state protection.

HIV-positive adolescents in this study have negotiated both the burdens and potential resources of HIV, as they work to make a life on ART. Some adolescents and their families have been able to mobilise their HIV and orphan status to tap into the resources and networks of a burgeoning AIDS industry, often with significant social stakes. Their ability to do this is 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.

This is not to say that illness and orphanhood do not place immense strain on the lives of adolescents and their families, but rather that the dynamics of making a life on ART are often complex and contradictory. I have written elsewhere (Vale & Thabeng, 2015) about how 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.

In our study, the worry that accessing care might attract community resentment was a source of significant stress among caregivers and adolescents alike. Aware of the perception that she was using Thembakazi (age 18) to add to her income, Thembakazi’s grandmother made sure to tell us that she ‘loved Thembakazi deeply’, not because ‘she’s sick and getting a grant’ (interview, 10 September 2013). She feared that her care for Thembakazi would be perceived as self-interested and exploitative because of the state support she received.
Similarly, Siya’s (age 18) grandmother told us that when she returned home with a sick grandchild after her daughter’s death, neighbours accused her of ‘liking money’ (fieldnotes, 7 October 2013). Amanda (age 13) said that since joining her HIV-support group, other children in her village had bullied her, saying she thought she was ‘too big for her shoes’.

Fear of neighbours’ ‘jealousy’ made some of our participants feel vulnerable to witchcraft. Indeed, two adolescent participants were, at the time of our study, consulting healers about the threat of neighbours’ resentment. Both adolescents felt that their neighbours were jealous of their ‘success’ and survival, despite and perhaps because of HIV (Vale & Thabeng, 2015). Hence, for some adolescents and families in our study, the pursuit of care could be volatile and double edged. Accessing HIV-related care could threaten community relationships. For these adolescents and families, sustaining care meant managing a delicate balance: pursuing HIV care and wider networks of support, while also maintaining relationships with neighbours.

CONCLUSION

NCDs pose a growing threat to African health systems, which are already heavily burdened by infectious diseases, among others, and are often severely under-resourced. Rising chronicity has important implications for how we think about the provision of care on the continent: care will increasingly be long term and routine; it will necessarily span clinics, communities, and homes; it will need to encompass biomedical treatment, nutrition, and social support; and it will include both those who are acutely sick and those who are ostensibly well.

Despite growing rates of NCDs in Africa, little research has been conducted on what this might mean for the nature of care in these settings. This chapter suggests that there are lessons to be learned from experiences of HIV care, which is increasingly framed in terms of chronic illness management. It draws on ethnographic research with HIV-positive adolescents and their families, living in rural and peri-urban areas of South Africa’s Eastern Cape. These adolescents and
families have long-term experience managing HIV, and have found ways to claim and sustain care under volatile health system conditions.

Indeed, this chapter shows that where resources for care are scarce, unequal, and precarious, this has significant implications for how care itself is constituted. In overburdened health facilities, ‘being seen’ became a significant component of what it meant to access and experience care. Adolescents and families employed different tactics to gain the attention of health professionals, document their entitlements, and ultimately secure a consultation with a nurse or doctor. It was also important that one ‘be seen’ in the right ways: as patient, respectful, and compliant. Acts of deference bolstered the moral authority of health staff, boosting their sense of competence in a context where their own capacity to care was regularly called into question. In order for patients and health staff alike to ‘be seen’, we will need to increase the numbers of health workers in clinics and reduce waiting time to every extent possible. This will mean improving the efficiency and accessibility of pill collection and monitoring for chronic patients.

As in the clinic, sustaining care in the home entailed significant relational work and mutual obligation. Adolescents’ disciplined pill-taking formed part of the myriad ways to obey and respect one’s elders, contribute to the household, and strengthen familial ties. Reinforcing familial roles became particularly important in households where a generation had been lost and relations of care had been unsettled. Thus, larger contexts translated into how care was enacted. To provide a strong continuum of care for chronic conditions, we must view health systems as extending into homes, and find ways to support families in grappling with both the emotional and physical labour of chronic conditions in their homes.

The larger context also reflected in the moral economy of HIV care in adolescents’ communities. While the stigma (and indeed the deaths) associated with the HIV/AIDS epidemic have placed strain on everyday social relationships, HIV/AIDS has also been attendant with a multitude of care responses at the household, local, national, and international level. ART, like any other chronic illness treatment, forms part of this everyday politics of survival and repair. Achieving care entailed that adolescents and their families mastered the bureaucracies
of health systems and social services and built relationships with important gatekeepers, while also maintaining intergenerational and neighbourly ties. Making a life with chronic illness often required that adolescents repaired, appealed to, and guarded their attachments. This was made all the more complicated in that their ability to access HIV-specific resources, in a context of generalised poverty, could fuel resentment and threaten neighbourliness. We would do well to locate chronic care in Africa within a wider economy of material and social survival, in which there are significant stakes and inequalities.

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