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*Mobilising AID(S)? Contesting HIV as a Social and Economic Resource among Youth in South Africa's Eastern Cape**

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

Drawing on eight months of qualitative fieldwork, we examine the ambiguous position of young ART users. While many perinatally infected youth endure compounding burdens of chronic morbidity, daily medication-taking and parental loss, they also capitalise on the particular weight ascribed to these burdens within South Africa's care economy. The additional assistance they receive can produce community and family resentments, born out of the scandalous confluence of access to resources with a stigmatised and incurable illness. Thus, in addition to its scientific properties, HIV treatment also has symbolic and social roles for youth. The ways in which young people use ART should be interpreted amid a preceding social order, in which post-apartheid communities partake in contentious struggles for survival and upward mobility. Future policy and programming can benefit from a deeper understanding of the social stakes involved in young people's engagement with ART support services.

Young ART Users in a Young Democracy

This article explores how some perinatally infected youth in the Eastern Cape province of South Africa mobilise their position as ART users for survival and social mobility. These young people are among the first generation of HIV-positive babies to benefit from the national roll-out of ART and reach adolescence alive. Today, they form part of the estimated 300,000 adolescents (aged 10–19) living with HIV in South Africa.¹ Their health, longevity,

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1 UNICEF, 'Scaling Up National Responses for Adolescents Living with HIV – An Overview of UNICEF, WHO and UNFPA Support', in S. Kassede and R. Olesen (eds), *AIDStar-One Regional Consultation* (Gaborone, USAID/PEPFAR, 2012).

and reduced infectiousness will depend on strict adherence to medical treatment. In addition to being among the first generation of ART recipients in South Africa, these young people are also members of the 'born free' generation and are coming of age alongside the country's new democracy.

Over the course of their lives, therefore, young people in this study have seen a radical expansion not only of HIV treatment, but also of social welfare, driven by democratic aspirations of social justice and redistribution. While inclusion in the social grant system has defined liberation for many South Africans, producing new forms of citizenship and patronage,² it has also been concomitant with widespread unemployment and deepening inequality. As a result, the apportioning of social assistance, and indeed broader questions of resource access, produce new cleavages and contestations. It is in this context that young people's positioning within a proliferating national and global AIDS economy becomes scandalous, over and above the traditional stigmas of HIV.

The advent of AIDS has seen a dramatic increase in disability, care dependency and foster-child coverage in South Africa.³ Today, these join the retirement pension as the most generous social grants in the country. In comparison to the conventional childcare grant (R280), the foster-child (R840), care-dependency (R1,350) and disability (R1,350) grants offer significantly higher monthly rates. This creates a household economy in which death and illness sit uncomfortably as both material linchpins and heavy burdens, attributing paradoxical value to AIDS orphans, and, thereby, new social meaning to their position in many homes.

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

As a contribution to this part-special issue on *Science and Scandal*, this article explores how youth membership to the scientific category of 'HIV-positive ART user' can become a source of gossip and resentment. Here, scandal stems not only from the traditional sex- or death-related stigmas of HIV; it also relates to the assistance that HIV-positive status attracts when coupled with youth and orphanhood and brought under the aegis of state and donor care programmes.

(ART)ful Tactics: Contributing to Existing Literature

The mobilisation of health or biological status to claim material benefits has been a topic of growing import in the medical humanities. Adriana Petryna⁴ first introduced the concept of 'biological citizenship' to explore how victims of the 1986 Chernobyl nuclear disaster

2 E. Bähre, 'Liberation and Redistribution: Social Grants, Commercial Insurance, and Religious Riches in South Africa', *Comparative Studies in Society and History*, 53, 2 (2011), p. 3.

3 F. Booyesen, 'Social Grants as Safety Nets for HIV/AIDS-Affected Households in South Africa', *Sahara J: Journal of Social Aspects of HIV/AIDS*, 1, 1 (2004), p. 46.

4 A. Petryna, 'Biological Citizenship: The Science and Politics of Chernobyl-Exposed Populations', *Osiris*, 2, 9 (2004), pp. 250–65.

mobilised evidence of their damaged biology to claim compensation. Nikolas Rose and Carlos Novas⁵ reconceptualised the term to refer to biological identities, positing that contemporary identity might be increasingly linked to biological consumption, whether in the form of pharmaceuticals or enhancement technologies.

Vin-Kim Nguyen's seminal research introduced the related concept of 'therapeutic citizenship', to describe how ART users articulate the rights and responsibilities of medical treatment, and thereby garner material and social benefits.⁶ Nguyen's work has explored the formation of therapeutic communities in which ART patients employ solidarity and 'self-help' techniques to garner food, medicine and social ties. These patient groups enact performances of 'empowerment' that give testimony to the struggles of HIV and profess the revelations of biomedicine.⁷

Similarly, we explore how ART users mobilise health categories to make resource claims. Like Nguyen, we also give import to the ways that HIV is performed and narrated in this claims-making process. But the forms of therapeutic citizenship under discussion here privilege instrumental involvement over the pursuit of empowered identities. These frequently contingent forms of ART participation are gaining growing attention from anthropologists in contexts of severe economic constraint.⁸ In Tanzania, Dominik Mattes⁹ explores how poverty and the deterioration of kinship-based support networks determines people's engagement with ART support groups, over and above claims to the rights and responsibilities of treatment. These groups offer an additional social support network, which members can rely on should they fall ill or need someone to watch their children. Similarly, Rebecca Cassidy and Melissa Leach¹⁰ show how Gambian ART users masterfully appropriate funder and non-governmental organisation (NGO) discourse to access lunches and *per diems*. They describe the utilisation of HIV identities as conditional and fragile, reflecting a less empowered form of 'getting by'.

What sets these accounts apart from Nguyen's original explication of 'therapeutic citizenship' is their attention to the social stakes involved in operationalising ART identities. To this end, Emily Frank and Alexander Rödlach¹¹ explore both the new opportunities and new stigmas generated by ART enrolment in southern African contexts: while ART support programmes enable access to privileged resources, the attainment of these advantages, in a context of generalised poverty, also attracts resentment from neighbours, thereby threatening informal support networks. Here, ART users receive resources on the basis of their biomedical categorisation, which undermines historically entrenched practices of soliciting neighbourly assistance in times of hardship. Central to ART usership, then, is the ongoing mediation of cross-cutting imperatives, born out of social tensions unique to the ART era.

5 N. Rose and C. Novas, 'Biological Citizenship', in A. Ong and S. Collier (eds), *Global Assemblages* (London, Blackwell, 2005), pp. 439–63.

6 V.K. Nguyen, 'Antiretrovirals, Globalism, Biopolitics and Therapeutic Citizenship', in Ong and Collier (eds), *Global Assemblages*, pp. 124–44.

7 V.K. Nguyen, 'Trial Communities: HIV and Therapeutic Citizenship in West Africa', in P. Geissler and C. Molyneux (eds), *Evidence, Ethos and Experiment: The Anthropology and History of Medical Research in Africa* (New York, Berghahn Books, 2011), p. 429.

8 M. Colvin, J. Leavens and S. Robins, 'Seeing Like a PWA: A Study of Therapeutic Citizens and Welfare Subjects in Cape Town, South Africa', *Chronic Poverty Series Working Paper*, 144 (June, 2009); E. Frank and A. Rödlach, 'To Disclose or Not to Disclose, That is the Question! Antiretroviral Therapy, Access to Resources and Stigma in Southern Africa', *Journal of Southern African Studies*, 39, 1 (2013), pp. 119–33; D. Mattes, '"We Are Just Supposed to Be Quiet": The Production of Adherence to Antiretroviral Treatment in Urban Tanzania', *Medical Anthropology*, 30, 2 (March 2011), pp. 158–82; R. Cassidy and M. Leach, 'AIDS, Citizenship and Global Funding: A Gambian Case Study', *Institute for Development Studies Working Paper*, 325 (June 2009), pp. 1–31.

9 Mattes, '"We Are Just Supposed to Be Quiet"'.

10 Cassidy and Leach, 'AIDS, Citizenship and Global Funding'.

11 Frank and Rödlach, 'To Disclose or Not to Disclose'.

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

Literature on AIDS-affected youth has revolved around the ‘tragic’ image of the AIDS orphan: first reflecting moral panic about the impending social breakdown that would result from rising numbers of parentless children,¹² and later concerning itself with psycho-social distress among orphans.¹³ Much less attention has been paid to the tactical, even ambiguous, agency deployed by young people in conditions of heightened vulnerability.

In an effort to address this oversight, Helen Meintjies and Sonja Giese¹⁴ offer a provocative account of the tactical agency exercised by South African children and their families, who use categories of ‘AIDS orphanhood’ in order to win gains from NGOs and international donors. While these ‘orphans’ are not dislocated from adult care, as dominant policy and donor discourses presume, using AIDS-orphan rhetoric allows access to a range of material benefits and social interventions. Importantly, this tactic is employed in spite of local stigmas surrounding orphanhood: the term ‘orphan’ is used pejoratively in many local languages to describe children who are ‘destitute’, ‘unloved’ and deserving of pity.¹⁵ In this context, AIDS-affected families must precariously straddle two socio-cultural institutions: while the former attributes orphanhood unique clout, the latter positions it as a source of shame. Consequently, the meaning of ‘AIDS orphan’ is rendered ambiguous, demanding careful, frequently perilous, negotiation.

Young people’s attempts to mobilise ART usership for survival and social mobility can be similarly precarious. In deploying categories of ‘HIV’ and ‘orphan’ as potential resources, adolescents not only take on the derisive connotations of the categories themselves – as Meintjies and Giese aptly point out.¹⁶ But more so, the *activation* of these traditionally stigmatised categories for special assistance also becomes contentious, giving rise to new dilemmas and vulnerabilities.

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

Inequality and Suspicion in the Eastern Cape

Democracy has had profound implications for the social imaginaries of black South Africans. Legal and political rights have been accompanied by new material aspirations, in response to

12 R. Bray, ‘Predicting the Social Consequences of Orphanhood in South Africa’, *African Journal of AIDS Research*, 2, 1 (June 2003), pp. 39–55.

13 B. Atwine, E. Cantor-Graae and F. Bajunirwe, ‘Psychological Distress Among AIDS Orphans In Rural Uganda’, *Social Science & Medicine*, 61, 3 (2005), pp. 555–64; L. Cluver and F. Gardener, ‘The Mental Health of Children Orphaned by AIDS: A Review of International and Southern African Research’, *Journal of Child and Adolescent Mental Health*, 19, 1 (2007), pp. 1–17; D. Makame, ‘Psychological Well-Being of Orphans in Dar Es Salaam, Tanzania’, *Acta Paediatrica*, 91, 4 (2002), pp. 459–65.

14 H. Meintjies and S. Giese, ‘Spinning the Epidemic: The Making of Mythologies of Orphanhood in the Context of AIDS’, *Childhood*, 13, 3 (2006), pp. 407–30.

15 *Ibid.*, p. 422.

16 *Ibid.*

the visibility of a growing black middle class and the African National Congress mantra of ‘a better life for all’. Yet ‘glimpses of vast wealth’, which are seen passing into the hands of a few South Africans, are accompanied by a wider sense of desperation at being excluded from the promise of prosperity – ‘the *telos* of liberation’.¹⁷ Indeed, enduring structural legacies of apartheid, together with deepening poverty and unemployment, undermine the possibilities of the ‘new’ South Africa. Thus enfranchisement, a rising black middle class, and the ‘freedom’ to accumulate have also been attended by extreme poverty and exclusion. These contradictory trends have amounted to a dramatic rise in inequality among the black populace.¹⁸

The Eastern Cape remains the poorest province in South Africa, and poverty continues to deepen along with income inequality.¹⁹ Fieldwork for this study was conducted over eight months in two Eastern Cape sites. We worked for the first four months in rural villages of a municipality that we call Mtembu,²⁰ while for the second four months we worked in peri-urban informal settlements on the outskirts of a small town in the adjacent municipality. We refer to this town as Ridgetown and its municipality as Masola.²¹

In Masola, 15.3 per cent of households live below the multi-dimensional poverty line, which is based on health, living standards, education and unemployment.²² This is also true of 30.4 per cent of Mtembu households.²³ Only 34 per cent of Masola residents, between the ages of 15 and 64, are employed. In Mtembu, this figure is less than 10 per cent.²⁴ In both Mtembu and Masola, participants’ families struggle to find stable employment, with some reporting that they occasionally go without food. In rural villages, these families live off a combination of subsistence farming and social grants. Only one household had a permanently employed resident. In Ridgetown, those able to find jobs had posts as domestic workers or security guards, while others served short-term positions on municipal projects and nearby farms. Young people in our study worry about basic needs, but many are also excited about consumer goods, including brand-name clothing and cell phones. Access to the latter remains limited in both research sites, particularly since many teenagers are interested in only the latest smart phones. Acquisition of consumer items not only facilitates young people’s imagined transition into adulthood, but also their perceived linkages to global modernity.

Both the urban and rural communities in which we worked are visibly unequal, with middle-class and poor residents sometimes living in close proximity. In two Mtembu villages, these inequalities and their accompanying patronage networks are partially attributable to AIDS interventions. Middle-class NGO workers form a new social class, linking local spaces to global development circles and altering village power relations as residents attain more or less access to the networks and resources of intervention programmes.

17 J. Comaroff and J. Comaroff, ‘Occult Economies and the Violence of Abstraction: Notes from the South African Postcolony’, *American Ethnologist*, 26, 2 (1999), p. 284.

18 J. Steinberg, ‘Aids and Aids Treatment in a Rural South African Setting’, *Institute for Security Studies Monograph*, 149 (August 2008), p. 45.

19 For deepening poverty, see Eastern Cape Government, *Socio-Economic Review and Outlook* (2013), available at <http://www.dedea.gov.za/research/Research/Eastern%20Cape%20Socio-Economic%20Review%20and%20Outlook%202013.pdf>, retrieved 4 November 2014; for income inequality, see Eastern Cape Social and Economic Consultative Council, *Eastern Cape Development Indicators 2012* (June 2012), p. 17, available at http://www.ecsecc.org/files/library/documents/EasternCape_withDMs.pdf, retrieved 4 November 2014.

20 Xhosa surname.

21 *Ibid.*

22 Statistics South Africa, *The South African MPI: Creating a Multi-Dimensional Poverty Index Using Census Data* (Pretoria, Statistics South Africa, 2014).

23 *Ibid.*

24 For unemployment figures, see Statistics South Africa, *Local Municipalities* (Census, 2011), available at <http://beta2.statssa.gov.za>, retrieved 9 June 2014. In reference to this particular age bracket denoting ‘youth’, globally, youth unemployment is measured from the age of 15, to denote when mandatory schooling ends and to recognise young school-goers who are also actively seeking full-time work.

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

The social stigmas attached to young people's mobilisation of HIV-related resources emerge amid this pre-existing politics of resentment. In many South African communities, these politics play out in suspicions and accusations of witchcraft.²⁶ The better off fear bewitchment by jealous and less fortunate neighbours, while the latter accuse the former of prospering through illicit, magical means. These discourses signal moral struggles over the distribution of scarce resources, and contestations over the way in which flows of power operate within intimate communities.

In our study, anxieties about palpable and proximate inequality could certainly be read in local discourses of witchcraft. These were voiced in both research sites, but were more prevalent in rural areas. Some adolescents described witches and their animal familiars roaming the villages after dark,²⁷ while others professed to have been targeted by jealous witches because their family was building a new house.²⁸ In Ridgetown, an NGO worker told an elaborate story of youth spirit possession: for a R100 bottle of alcoholic drink to a local traditional leader, young people could ask to be overtaken by ancestral spirits, who would help them to 'do well in school, at sports, and everything'.²⁹ The accusation of spirit possession designates young people's success as suspicious in a context in which youth aspirations are all too often unrealised.

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

The tensions associated with adolescents' mobilisation of HIV-related resources are not isolated. The fragile and varied means by which people gain access to resources in post-1994 South Africa have at times produced fraught cleavages, often along gender and generational lines.³⁰ The broader politics of need, acquisition and resentment play out in the lives of youth on ART as they manoeuvre to gain from a range of social care institutions – both state and non-state. In this article we are concerned with the new signification that this attaches to HIV, its treatment and the place of youth within the epidemic.

Growing Up with HIV

We draw on eight months of qualitative research with 23 Xhosa-speaking teenagers (aged 10–19) on anti-retroviral treatment. We focus on 19 of these, who are perinatally infected.

25 Steinberg, 'Aids and Aids Treatment', p. 45.

26 A. Ashforth, 'An Epidemic of Witchcraft: The Implications of Witchcraft for the Post-Apartheid State', *African Studies*, 61, 1 (2002), pp. 121–43.

27 Field notes, Mtembu, 31 January 2014.

28 Field notes, Ridgetown, 20 October 2013.

29 Field notes, Ridgetown, 8 February 2014.

30 S. Mosoetsa, *Eating from One Pot: The Dynamics of Survival in Poor South African Households* (Johannesburg, Witwatersrand University Press, 2011).

Adolescent participants were recruited through non-governmental ART support groups and public health clinics. For the purposes of this article, we give particular, though not exclusive, attention to youth enrolled in two such groups – one rural and one urban. We refer to these as Kholo (Faith) and CareProject.

The proportion of young participants enrolled in support groups biases the sample, since many HIV-positive youth remain undiagnosed and untreated, and very few have access to additional ART support. In sub-Saharan Africa, children and adolescents who are eligible for ART are half as likely to access it as their adult counterparts.³¹ Participation in these therapeutic communities may have cultivated a particular aptitude in this group of young people, who have learnt to ‘work’ systems of care and have mastered the discourses and currencies that carry import in these institutions.

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

Indeed, elderly pension recipients are frequently at the centre of household economy in the ‘new’ South Africa, given the extent of joblessness and the absence of social assistance for able-bodied, working-age adults. More specifically, women and children have been brought under state protection through old-age and child-support grants that privilege matri-focal – ‘even granny-focal’ – domestic arrangements.³² Meanwhile, men have been increasingly delinked from wage labour, leading to a drastic decline in marriage.³³ Here, the state can be imagined as taking on the symbolic role of husband or father.³⁴ There are only two perinatally infected youth in our study who are living with their fathers, and in only one of these cases is the father involved in deliberations about household spending.

In addition to many of their parents dying as a consequence of delayed ART roll-out, our perinatally infected participants have suffered in other ways owing to late treatment: being small for their age, experiencing severe learning difficulties and afflicted by a range of chronic conditions.³⁵ Rural respondents travel long distances to health facilities and carry heavy financial costs. Peri-urban teens are closer to services, but spend long hours in clinics as a consequence of overcrowding and understaffing.

Adolescents in our study lament being dependent on long-term daily medication, even when they take it diligently. ART-related support has by no means transformed a positive HIV status into a privileged position. HIV continues to compound social and economic pressures on some of the country’s most marginal families. It also remains a source of perceived, internalised and enacted stigma. We argue that, in a context of generalised vulnerability and severe socio-economic inequality, ART might be attributed ambiguous meaning because of the resources associated with it. Being able to navigate this contradictory

31 UNAIDS, *Access to Antiretroviral Therapy in Africa: Status Report on Progress Towards the 2015 Targets* (Geneva, UNAIDS, 2013), available at http://www.unaids.org/sites/default/files/media_asset/20131219_AccessARTAfricaStatusReportProgressTowards2015Targets_en_0.pdf, retrieved 7 October 2013.

32 J. Ferguson, ‘Declarations of Dependence: Labour, Personhood, and Welfare in Southern Africa’, *Journal of the Royal Anthropological Institute*, 19, 2 (2013), p. 231.

33 *Ibid.*, p. 230.

34 *Ibid.*, p. 235.

35 K. Buchacz, A. Rogol, J. Lindsey, C. Wilson, M. Hughes and G. Seage, ‘Delayed Onset of Pubertal Development in Children and Adolescents with Perinatally-Acquired HIV Infection’, *Journal of Acquired Immune Deficiency Syndrome*, 33, 1 (2003), pp. 56–65; S. Wood, S. Shah, A. Steenhoff and R. Rutstein, ‘The Impact of AIDS Diagnosis on Long-Term Neurocognitive and Psychiatric Outcomes of Surviving Adolescents with Perinatally Acquired HIV’, *AIDS*, 23, 14 (2009), pp. 1859–65.

terrain is central to young people's taking of ART. Further, the delineation of 'HIV'- and 'orphan'-related needs, as distinct from those of the broader community, whose lives have also been deeply affected by HIV/AIDS, may produce new stigmas.

Looking and Listening at the Intersections between State, Clinic and Home

Throughout the fieldwork, the authors visited young people regularly, immersing themselves as far as possible in their everyday lives. They spent time cooking, washing clothes and walking through neighbourhoods. More structured activities were also incorporated into these visits, including semi-structured interviews with young people and their families. Despite this, the research only touches the surface of day-to-day life in young people's homes, a greater exploration of which might have further uncovered the relationships and contexts that shape the experiences of youth on ART.

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

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

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

Analysis methods were based loosely on Grounded Theory.³⁶ Given what is now a vast, varied and contested literature³⁷ on the applications of Grounded Theory, we identified three associated procedures, which were appropriated for this study: Participants were sampled not for representativeness, but for theory construction. Data collection and analysis began concurrently, as emerging findings were discussed and infused into ongoing fieldwork. The analysis emerged not from preconceived hypotheses, but instead from an iterative process of 'building up' from the data. Following Miles and Huberman,³⁸ the first author identified and refined emerging themes, comparing and contrasting across the data, and finally writing up the analysis.

Participants and research sites are referred to by pseudonyms. Locations and identifiers are kept deliberately vague in order to protect anonymity. This study forms part of a collaborative, mixed-methods research project on adolescent health in the Eastern Cape – titled *Mzantsi Wakho*. *Mzantsi Wakho*'s extensive ethics protocol was approved by the

36 B. Glaser and A. Strauss, *The Discovery of Grounded Theory* (Chicago, Aldine, 1967); K. Charmaz, 'Grounded Theory', in J. Smith, R. Harre and L. Langenhove (eds), *Rethinking Methods in Psychology* (London, Sage, 1995), pp. 27–50.

37 J. Corbin and A. Strauss, *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* (Thousand Oaks, Calif., Sage, 1990); N. Glaser, *Theoretical Sensitivity* (San Francisco, Sociology Press, 1978); K. Charmaz, *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*, (London, Sage, 2000); G. Thomas and D. James, 'Reinventing Grounded Theory: Some Questions About Theory, Ground and Discovery', *British Educational Research Journal*, 32, 6 (2006), pp. 797–5.

38 M. Miles and A. Huberman, *Qualitative Data Analysis: An Expanded Sourcebook* (Thousand Oaks, Calif., Sage, 1994).

Universities of Oxford and Cape Town, and by the Eastern Cape Departments of Health, Education and Social Development.

The Resources and Networks of AIDS Interventions

'I'm going to get a bicycle', Anele (aged 11) bragged. The group of teenagers, still dressed in their school uniforms, were sprawled on the concrete outside the small meeting room where they congregate every week for a support group. They were eagerly anticipating their *indodla* (social grant), which is deposited around the first of every month. It was five days before grant day – when the clinics are emptied as families spill into town and join the long queues for the cash machine. 'People don't get sick on payday', the local nurses jested.³⁹ At this support group meeting, a lively discussion had ensued among the teenagers about what they hoped to buy with their grant money. Sitting on the chair in the centre of the courtyard, Mpho (aged 12) announced with a wide grin on her face that her fridge is always full because there are so many grant recipients in her home. Mpho lives with an aunt, who receives, in addition to Mpho's grant, a child support grant to help fund the upbringing of her younger cousin, and Mpho's grandmother receives a pension. 'We also have dish [satellite TV]', she added cheekily. Mpho said she would make sure her grant went towards maintaining this household standard and then she would use the excess to buy a cell phone. 'Me too, I also want a phone', exclaimed Thandi (aged 10). Throughout the conversation, the group made reference to *indodla uyagula* or disability grants, despite the fact that most were benefiting from foster-child grants. The tone was playful, but also brazen, as the group laughed, gossiped and teased.⁴⁰

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

This unique access to some of the highest-paying social grants in South Africa has situated sick and orphaned children as primary 'breadwinners' in many households – paradoxically rooting their power and their subjection in the self-same place. Indeed, over tea with a grandmother in Mtembu, we witnessed her celebrating the fact that her grandson's illness, and the 'disability grant' he would access, would help alleviate poverty in her home.⁴¹ Their position as household providers endows the adolescents who receive these grants with a perceived, perhaps subversive, authority. Indeed, their discussion at the support group unsettles conventions about the nature and content of 'youth talk', as adolescents stake their claim in conversations about household resources and spending, which are usually reserved for adults.

While grandmothers most often manage adolescents' social grants, young ART users – some of whom describe illness or child grants as 'my money' – also influence spending decisions on grant day. Anele's grandmother, for example, complained that Anele could always persuade her to buy more than she intended, and made sure that they went to Kentucky Fried Chicken before visiting the grocery store.⁴²

39 Field notes, Ridgetown, 2 April 2013.

40 Field notes, Ridgetown, 26 March 2014.

41 Field notes, Mtembu, 8 November 2013.

42 Field notes, Ridgetown, 2 April 2014.

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

This has required that youth utilise their HIV illness, often using scientific markers as reference. Thami, the support-group facilitator, explained that *CareProject* used CD4 counts, which measure the number of T-helper cells in the body, to prove eligibility for both disability and care dependency grants, sometimes instructing social grant officials to 'go and visit this patient and see how sick they are'.⁴³ CD4 counts serve as a marker of immunological health in HIV-positive patients and often determine social and clinical responses to them. CD4 counts, among other things, are used to determine the following: if a patient can initiate ART, if they are succeeding on their current treatment regimen, if they have clinical AIDS, and if they are eligible for a disability grant.

In addition to blood tests, medical records and doctors' assessments, eligibility criteria for illness grants also demands the meticulous compilation of a plethora of legal and registration documents. Scientific and identity documents are brokered within the social security system, giving rise to new forms of 'biological citizenship'.⁴⁴ Here, documents themselves are embedded with distinct power in a system of bureaucratic governance. Youth on ART, despite being ineligible to vote, claim these forms of citizenship by mastering bureaucracies of state welfare.⁴⁵

Access to foster-child grants is similarly mediated through a range of official documents. These include birth certificates, biometrics, identity documents, child medical records, school enrolment certificates and affidavits. Claimants also require a statement of support from a reputable social service provider or community leader and, where relevant, parental death certificates. The application is further subject to a social worker investigation and a ruling from the court, both of which entail subjective interpretations of whether the child has any 'visible means of support'.⁴⁶ This list of bureaucratic and legal requirements produces significant delays in access. Applicants for foster-child grants must decode these complex requirements and compile a mass of documents, despite many being illiterate grandmothers. Linkages to non-governmental ART programmes, which facilitate strong relationships with providers and assist with grant applications, are particularly advantageous, given these bureaucratic and procedural hurdles.

As an indication of how the category of 'foster parent' has gathered rhetorical power and prevalence within state and NGO care programmes, an adolescent guardian in Ridgetown once announced to us that she was not the biological parent of her child, but the 'foster parent'.⁴⁷ Importantly, the whole statement was made in isiXhosa, except 'foster parent', which was said in English. This is significant not only because we had never heard this respondent speak English before, but also because the very concept of 'foster parent' has been manufactured by an external frame of reference. Like many others in South Africa, she is

43 Field notes, Ridgetown, 2 May 2014.

44 Rose and Novas, 'Biological Citizenship'.

45 P. Henderson, 'South African AIDS Orphans: Examining Assumptions Around Vulnerability From the Perspective of Rural Children and Youth', *Childhood*, 12, 303 (2006), pp. 303–27.

46 K. Hall and P. Proudlock, 'Orphaning and the Foster Child Grant: A Return to Care or Cash Debate', *Children Count Brief* (Cape Town, Children's Institute, July 2011), pp. 1–6.

47 Field notes, Ridgetown, 8 March 2014.

caring for the child of a close relative. Using the term ‘foster parent’ to describe this arrangement arises from its circulation and valence within health and social welfare programmes.

Let us reflect further on the paradoxical resources associated with parental death: *CareProject* has often been intimately involved in caring for dying parents. Indeed, it is through death that many orphaned youth are first enrolled in the support group. Immersing itself in the deeply private and guarded spaces of AIDS deaths within families, the organisation negotiates with relatives about who will take in orphaned children, and also assists dying parents in accessing life coverage (sometimes by setting aside portions of their disability grant). Through foster-child grants, life coverage and links to future NGO support, dead parents may be said to continue to provide for their children from beyond the grave. Indeed, in some homes, the dead are primary contributors to household income.

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

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

There are benefits. You can get transport to the hospital, and when you get discharged, they can pick you up. Because sometimes you don’t have money to go to the hospital, or if you get discharged [and] you don’t have money to get back home, or if it’s late and you need to go to the hospital. If there’s something wrong with Mpho, I will be able to take her to the doctor because of *CareProject*.⁴⁸

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

Like *CareProject*, *Kholo*’s adolescent support programme also enables privileged access to doctors, provides transport to clinics and hospitals, and distributes intermittent food parcels and clothing. Further, both *Kholo* and *CareProject* have established ways of manoeuvring within the health system to their own, and their patients’, advantage. This is often through personal connections to health personnel and astute knowledge of the system. For example, some lay care-givers have learnt to dress like ambulance drivers as a tactic for skipping hospital queues.⁴⁹

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

The following is an illustration of the role of AIDS interventions in young people’s social imaginations: youth at the support group made reference not only to their unique position as household providers (who help to keep the ‘fridge full’), but also to their material aspirations. Adolescents celebrated the satellite TV, new cell phones, and bicycles they hoped to purchase

⁴⁸ Interview with Mpho’s grandmother, conducted by the authors, Ridgetown, 5 March 2014.

⁴⁹ Field notes, 23 September 2013.

with their special grants. By offering (limited) linkages to middle-class spaces, networks and modes of consumption, AIDS interventions (and, paradoxically, illness itself) entail a re-imagining of young people's relationship to centres of power.

Mobilising AIDS Interventions

While enrolment in ART support programmes enables immediate access to their associated resources, youth also mobilise these linkages in artful ways. Thembakazi (aged 18) has travelled to major cities to share her experiences of living with HIV, and has educated children at the local clinic about ART. She cites these occasions as the times in her life when she felt 'most powerful'.⁵⁰ By giving 'testimony' to life with HIV and the revelations of AIDS science, Thembakazi selectively deploys performances of 'therapeutic citizenship'.⁵¹ Indeed, Thembakazi is celebrated as a model of 'positive living' by local NGO staff, who advocate for HIV disclosure, treatment literacy and adherence.

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

But despite outward appearances, Thembakazi does not exemplify the typical health citizen. She is not especially treatment-literate and sometimes struggles to interpret blood-test results.⁵² She also carries HIV-related body shame, and is particularly self-conscious about what she believes is uneven weight distribution.⁵³ Yet Thembakazi has capitalised on her position within ART-support programmes and learnt how to tap into selected discourses and practices in order gain privileged support. Similarly, it became increasingly evident that none of the adolescents who attend *Kholo's* support-group retreats do so in response to an empowered HIV identity. Rather, they see it as an opportunity to escape their homes, see friends and eat good food.

Illustrating this, but referring this time to a weekend away organised by our research team, Andisiwe (aged 11) said she had been spoilt by her grandmother and excused chores after returning with a hamper of leftover food.⁵⁴ When we asked how other children in her house had felt about her privileged treatment, she said that they too believed she should be rewarded. Here, Andisiwe is recognised for her contribution to the household economy – for her ability to bring in food by virtue of her relationship with us as researchers, which was itself dependent on her HIV status.

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

Zandile said that she had wanted to do something that was fun with the kids – to ensure that they would look forward to camps and would always come back. She vividly described

50 Interview with Thembakazi, conducted by Beth Vale, Ridgetown, 27 October 2013.

51 S. Robins, "'Rights" to "Ritual": AIDS Activism in South Africa', *American Anthropologist*, 108, 2 (January 2008), pp. 312–23.

52 Interview with Thembakazi, Ridgetown, 27 October 2013.

53 Field notes, Ridgetown, 9 September 2014.

54 Field notes, Mtembu, 24 October 2014.

how she had dressed up like a *makhulu* (grandmother) with a *doek* (cloth) wrapped around her head and ‘Ponds’ (face cream) slapped over her face. Imitating an old woman, Zandile’s body and voice slowed and trembled as she moved through the corridors of the *Kholo* building. She visited the offices of each of the *Kholo* staff asking for money. The kids followed her, highly amused. At each office, she pleaded with *Kholo* staff, saying that she was old, with many grandchildren to look after. The staff did not recognise her. Eventually, she arrived at Cally’s office. Sympathising with her plight, Cally started writing the *makhulu* a cheque. To Cally’s embarrassment, Zandile then revealed herself! She laughed out loud as she relayed to us her stellar performance.⁵⁵

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

Zandile’s story recalled another occasion, in which a family in our study was recounting to us their daily struggle to put food on the table, while one of the women shoved a bag of meat out of view.⁵⁶ Undoubtedly this family did struggle with food security, but in order for their audience to buy the story, the performance demanded that the meat was out of sight. Similarly, part of the entertainment in Zandile’s role-play is the success of the ruse. Food insecurity is a particularly potent subject for AIDS interventionists, given the prevalent prescription to eat before taking HIV medicines.

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

Care Contestations

We have discussed how some adolescents on ART mobilise their illness, orphan status and youth as currencies within state and non-state institutions of care. This endows them with particular forms of power. But this power is inherently unstable, and regularly contested. In the discussions that follow, we describe the conflicts and tensions that arise as a result of

⁵⁵ Field notes, Mtembu, 5 November 2013.

⁵⁶ Field notes, Mtembu, 11 September 2013.

the particular recognition and assistance granted to these youth on ART. These contestations are evident within homes, between families and in the community-ascribed meanings attached to HIV-positive youth.

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

The child, we were told, was very poor and did not look like other adolescents in the group. Zandile used her own money to buy her toiletries, gave her clothes from the *Kholo* garage, and fixed her hair to look 'as nice as the other kids'. But at the next retreat, she returned in her old clothes and without her hair done. A while later, Zandile visited the child's family, concerned that she kept returning to the retreat without the toiletries or clothes that had been given to her. The family said that whenever the child returned from retreat, she was always nicely dressed. This made her older siblings jealous. Believing that they deserved first access to nice things, the siblings had taken the clothes and toiletries for themselves. To which Zandile replied: 'This is my child and I bought her these things'.⁵⁷

This story points to struggles over resource allocation within homes, which unsettle, and give rise to, internal hierarchies of power. The child in the story is awarded disproportionate assistance as a result of her enrolment in an HIV support programme. This privileged access unsettles pre-existing systems of resource allocation within her home, which appear to function according to an age-based hierarchy. Conventionally, older siblings would have had first access to external resources by virtue of being first to enter the job market. But diminishing job prospects, along with the special resources awarded to their younger, HIV-positive sibling, have called this assumption into question. We observed that tensions over household resources were often sharpened when the HIV-positive sibling was a foster child and a latecomer to the family. Here, both biological and foster-siblings purported to be unequally treated.

Some HIV-positive adolescents also came into conflict with their guardians over household resource allocation – particularly grant money. Thembakazi, who was born with the name 'Lulama', has quite literally had her identity shaped by conflicts surrounding her grant.⁵⁸ While it remains unclear whether Thembakazi's family were receiving a disability, care dependency, foster- or child-support grant for her care, both Thembakazi and her aunt attach the money to her HIV status. Indeed, Thembakazi says that conflict in her home arose after her diagnosis.

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

Thembakazi says that she never benefited from her grant while growing up and believes she should have controlled how it was spent. Having turned 18, she now intends to make an independent application, so that the funds are directly deposited into her account. Thembakazi believes that her aunt keeps her apart from her estranged mother for fear that she might relocate to her mother's home and 'take her money with her'.⁵⁹

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

⁵⁷ Field notes, Mtembu, 5 November 2013.

⁵⁸ Field notes, Ridgetown, 12 November 2013.

⁵⁹ Interview with Thembakazi, Ridgetown, 27 October 2013.

These cases speak to struggles over resources, but also over parenting. Contestations over child care arose between family members, as well as between families and social service providers. Zandile's story about the newly clothed child reveals a tension about who the rightful care giver is: as Zandile asserts, 'this is my child'. Indeed, AIDS has not only invited health and social-care programmes into intimate spaces of birth, death and sex, it has also co-opted their care workers into the parenting of AIDS-affected children. NGO workers from both *Kholo* and *CareProject* take on a variety of parental roles: feeding and clothing adolescents, following their schooling, supporting them through criminal cases, advocating for them in disputes over grant money, and mediating inter-familial conflict. While the support offered by these pseudo-parents has been a great asset to young people and their families, it has also given rise to deep tensions. The aunt of Naledi (aged 16), for example, had a fraught relationship with NGO staff, whom she resented for having become Naledi's first port of call, over and above her own family.⁶⁰

Scandals of Survival and Success

Cognisant of perceptions that she was using Thembakazi as a source of income, Thembakazi's aunt was adamant about insisting that she 'loved Thembakazi deeply', and not because 'she's sick and getting a grant'.⁶¹ Similarly, when the grandmother of Siya (aged 18) returned home with a sick baby after the death of her daughter, neighbours accused her of 'liking money'.⁶² Young people are equally sensitive to resentments over disparate resource access. Amanda (aged 13) reports that since becoming part of *Kholo*, she is accused of acting 'too big for her shoes'. As a consequence, she was nervous to be seen with us in public, given our position as well-resourced outsiders.⁶³ In order to grapple with how such resentment operates, we turn our attention to two youths in our study who believed they had been bewitched.

Khaya (aged 18) is considered a model patient by nurses at his clinic and has been tasked with educating others in his neighbourhood about HIV. He is also a youth leader in a number of community and religious organisations. Khaya has travelled to Johannesburg with the local HIV organisation and is in regular contact with their staff, often making requests for material support. In October 2013, he told us he was having nightmares about an old woman in his community killing black cats, which he took as a sign that he had been bewitched. 'People are jealous of my success', he said.⁶⁴ But while Khaya believes that he is envied, he also feels judged because of his HIV status.⁶⁵ Initially, it seems paradoxical that these two sentiments of repudiation and jealousy could co-exist. But the scandal arises from the fact that Khaya is successful *with* HIV – from the pairing of these seemingly opposing positions.

Similarly, Thembakazi has been able to capitalise on ART support programmes in order to access travel, clothing, praise and grant money. Yet both she and her priest had dreams suggesting that she was bewitched. When we asked why people were bewitching her, she responded, 'they are jealous. When I got diagnosed with HIV people thought I wouldn't cope, but I did'.⁶⁶ Thembakazi locates others' resentment in her ability to do well *in spite of*, and

60 Field notes, August–October 2013.

61 Interview with Thembakazi's aunt, conducted by the authors, Ridgetown, 10 September 2013.

62 Field notes, Mtembu, 7 October 2013.

63 Field notes, Mtembu, 24 September 2013.

64 Field notes, Ridgetown, 19 October 2013.

65 Field notes, Mtembu, 8 November 2013.

66 Interview with Thembakazi, Ridgetown, 27 October 2013.

perhaps *because of* HIV.⁶⁷ Here, it is not only disproportionate resource access that attracts resentment, but also the *conditions* and *means* by which access is attained.

Thembakazi's community might ask how someone like her survives, and (in relative terms) prospers, despite her circumstances. Her mother left her with a lifelong, stigmatised illness; she has never known her father; she is one of four children being cared for by her elderly aunt; and none of her family members is employed. Given her parentlessness, impoverishment and stigmatised condition, Thembakazi's survival, and relative success, are rendered mysterious – even scandalous. Although witchcraft discourses in South Africa have generally been characterised as malicious jealousy levelled at those who are conspicuously better-off, suspicion and resentment can just as easily revolve around impoverished people who have managed to survive despite being noticeably 'people poor' – that is, without able-bodied or working household members to support them.

In KwaZulu-Natal, Isak Niehaus⁶⁸ observes that such people, rather than feeling vulnerable *to* witchcraft (as was the case in this study), might be accused *of* witchcraft – namely zombie-keeping. Zombie-keepers employ the labour of the dead as an illicit means of survival. Here, the inexplicable survival of impoverished families is explained through public revelations and accounts (including in the media) of this scandalous trade. The resentment that circulates around the mysterious survival, and even relative success, of AIDS-affected households might be similarly associated with perceptions that they are brokering the dead. Even where adolescents' parents are not deceased, families' attempts to win gains from AIDS interventions could be read as a trade in bodies – of blood results and scientific categorisations.

Navigating a Pluralistic Social World

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

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

To access these myriad resources and networks, Thembakazi must perform versions of therapeutic citizenship to AIDS interventionist audiences. These audiences hold different cultural and moral views, compared with the audience that might view Thembakazi's resource access with resentment. Yet both operate within the same physical and temporal

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

68 I. Niehaus, 'Witches and Zombies of the South African Lowveld: Discourses, Accusations and Subjective Reality', *Journal of The Royal Anthropological Institute*, 11, 2 (2005), pp. 191–210.

spaces in Thembakazi's life. 'What doctors say' has no relevance for Thembakazi's attempts to understand the moral economy of her local community, nor does it contribute to her efforts to negotiate community belonging amid her perceived difference. For her, the 'black spots' in her brain are not about stress, but a sign of her tenuous, fragile relationship with family and neighbours.

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

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

Conclusion: The Social Stakes for Youth in Using ART

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

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

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