

Paul Wenzel Geissler, Richard Rottenburg, Julia Zenker (eds.)
Rethinking Biomedicine and Governance in Africa

Editorial

Since the late 1970s, *empirical science studies* have developed into a key field of research at the intersection of science, technology and society. This field merges a repertoire of theories and methods stemming primarily from cultural anthropology, sociology, linguistics and history. Its main characteristic is the detailed analysis of scientific practices and epistemic cultures and how these become entangled with public discourses and everyday life. This focus tries to reveal specific, local configurations and their epistemological as well as social consequences. Beyond a mere deconstruction, science studies are constantly looking to engage with the fields in which they do their work. The goal of this book series is to offer to scholars a German and English speaking Forum that

- develops inter- and trans-disciplinary bodies of knowledge in the areas of medicine and the life sciences and makes these nationally and internationally available;
- supports young scientists through opening up a new field of work which runs across existing disciplinary structures;
- encourages the formation of *tandems* through co-authorship. In particular, it supports, evaluates and comments on collaborative projects with colleagues from the natural and engineering sciences.

The series is directed towards scholars and students from both the empirical science/social studies and the natural sciences and medicine.

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Rethinking Biomedicine and Governance in Africa

Contributions from Anthropology

[transcript]

This volume emerged from the work of the research group »Law, Organization, Science and Technology« directed by Richard Rottenburg, financed by the Max Planck Society and located at the Max Planck Institute for Social Anthropology, Halle, Germany.

Bibliographic information published by the Deutsche Nationalbibliothek

The Deutsche Nationalbibliothek lists this publication in the Deutsche Nationalbibliografie; detailed bibliographic data are available in the Internet at <http://dnb.d-nb.de>

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Cover layout: Kordula Röckenhaus, Bielefeld

Cover illustration: Collaborative medical research fieldwork in the city.

2009. Drawing from a series of illustrations of scientific research work by Johnson A. Ondiek, staff member of KEMRI, Kenya.

Typeset by Michael Rauscher, Bielefeld

Printed by Majuskel Medienproduktion GmbH, Wetzlar

ISBN 978-3-8376-2028-3

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The Politics and Anti-politics of HIV interventions in Kenya

RUTH J. PRINCE

INTRODUCTION

Following the disputed elections of December 2007, the price of food in Kenya rose steeply, as the ensuing political violence disrupted food production and distribution networks. During 2008, the price of a kilogram of maize flour doubled.¹ At the same time, the Kenyan media reported on several large-scale corruption scandals, involving government officials and politicians with financial links to maize brokers. It was alleged that maize had been sold at discounted prices to brokers, who hoarded it until prices rose. These practices continued in spite of a growing food emergency in the arid north and east of the country.² By the beginning of 2009, famine was gripping these regions, with reports of people being forced to eat the roots of plants.

Allegations of government corruption in the face of huge price hikes in the cost of basic foodstuffs produced a lot of anger in a country already battered and disappointed by the post-election violence. Editorials in Kenya's mainstream newspapers as well as the letters and comments sent in by citizens heavily criticized the coalition government, pointed out the gross disjuncture between

1 | This price rise was the subject of numerous newspaper articles. See for example, "Children with AIDS helpless victims of Food Crisis", by Professor Wilfred Mlay, *Daily Nation*, 29 November 2008.

2 | See, for example, articles in the *Daily Nation*: "Maize Scandal: Briefcase Agents Profit" by Bernard Namunane, June 27th 2008, <http://www.nation.co.ke/News/-/1056/525430/-/u1vwhs/-/index.html>; "MPs Face Arrest Over Maize Scandal", by Fred Mukinda and Bernard Namunane, January 1st 2009, <http://www.nation.co.ke/News/-/1056/517864/-/u1bugf/-/index.html>; "Government Dissolves Cereals Board" by Oliver Mathenge, 26th January 2009, <http://www.nation.co.ke/News/-/1056/519988/-/u1d9x4/-/index.html>; and in *Afro News*: "First Lady Implicated in Maize Scandal", by staff writer February 5th 2009, <http://www.afrol.com/articles/32359>.

the lives of politicians and those of Kenya's citizens, many of them unemployed, struggling to survive from day to day. In the streets of Kisumu, Kenya's third largest city³, in local government and NGO offices, among shop-assistants, street sellers, market women, men providing bodaboda (bicycle taxi) services and mothers taking their children to the clinic, the price of food and the maize scandals were constant topics of conversation. Food was a political issue.

During this time, I was conducting ethnographic research on the expansion of large-scale HIV treatment and care programmes in Kisumu.⁴ Since 2004, with vast amounts of money provided by PEPFAR and the Global fund, these programmes have offered free antiretroviral treatment (ART) and other medicines to HIV positive people, organized through complex 'partnerships' between the Ministry of Health and various NGOs and international organizations.⁵ The aim

3 | Kisumu's population is estimated to be half a million; it is the capital of Nyanza Province. (<http://www.unhabitat.org/content.asp?cid=2275&catid=206&typeid=6&subMenuId=0>).

4 | Research was conducted between October 2008 and May 2009 with additional visits in April 2008, December 2009 and September 2010. Research focused on the interface between HIV/AIDS interventions and people's lives, relations and identities, and with local economies. In a city with over 24 clinics providing HIV tests and antiretrovirals, I focused on two NGO-run and two government PSCs. I conducted over sixty open-ended interviews and numerous conversations with staff members and volunteers associated with the HIV clinics; observed clinic practice; regularly accompanied one of the staff in his 'follow-up' work with patients, and occasionally followed other community health workers and volunteers. I visited eight patient support groups in the city (there were many more), and regularly attended the meetings of two of these groups. I also built up a network of twenty families with HIV-positive members whom I (and later mostly a research assistant, Biddy Odindo) visited at home, and followed in and out of clinics and hospitals. No members of this latter group had formal employment. My competence in Dholuo aided work with these families; I mostly conducted conversations and interviews with more middle-class patients and staff members in English. I am grateful to Dr Eric Nyambetha and the Department of Sociology and Anthropology, University of Maseno for hosting me as a visiting researcher, and to the Provincial and District Medical Officers, the District Commissioner, the staff of the NGOs and government clinics in Kisumu, and the group members, families and individuals who supported my research. Special thanks to Biddy Odindo for her follow-up work with the families.

5 | In 2009, HIV prevalence in Nyanza Province was 13.9 of the population aged 15-45 years (the national average was 6.3%), according to the 2008-9 Kenyan Demographic and Health Survey (UNICEF: http://www.unicef.org/infobycountry/kenya_statistics.html). Since early 2005, the free delivery of ART has been expanded, first in the city and later into rural areas, through government health facilities, private and mission hospitals, NGOs and selected faith-based groups. See <http://www.unaids.org/en/CountryResponses/Countries/kenya.asp>. By September 2009, almost 300,000 people

of such programmes is to enable positive people to live a 'normal' life through suppressing virus levels and promoting immune defences with daily doses of antiretrovirals, multivitamins and antibiotics.

According to the message of the clinic, surviving HIV requires strict 'adherence' to the medication, orienting one's life around the requirements of the pharmaceutical regime and taking on the messages of 'positive living': responsibility for one's health, awareness of risk, and self-care. Antiretroviral treatment is indeed often experienced as a miracle, enabling and extending life for those who were facing severe illness and death. Yet, as I followed people into the clinics and into their homes, and attended the meetings of the various groups to which they belonged, it became obvious that matters of survival involve much more than sticking to medical regimens, attending one's clinic dates and thinking of one's body as carrying the HIV virus. I found that for many positive people in Kisumu, ART programmes may extend life but they do not necessarily support living. Doing well on antiretrovirals depended as much on finding an income, feeding a family, and paying school fees as on the treatment itself (see Morris 2008; Meinert/Mogensen/Twebaze 2009; Meinert *forthcoming*).

This paper considers the consequences of the increasingly medicalized economy of health care and welfare in Kisumu, where access to medical treatment and to material benefits and means of making a living are organized to a large extent around HIV. It examines the intersections between humanitarian interventions, organized by non-governmental groups and directed at poverty alleviation for those "affected and infected by HIV", with medicalized regimes of care offered by ART programmes, and with the moral economies of family life and urban survival. HIV-positive people and their families are the target of not only medical treatment but also of funding flows and projects offering various forms of material and 'livelihood' support.⁶ For many families and individuals struggling to make a living in the city, being HIV positive has, ironically, opened up pathways to scarce material resources. However, accessing such resources is often dependent upon one's visibility and legibility to the official world of NGOs and government programmes.

This situation raises questions about the economic as well as moral *value* of being HIV-positive and about the *worth* of HIV positive and negative lives. It also raises questions about the 'politics of life' (Fassin 2009) in contemporary Kenya. The politically tense issue of food prices was played out daily in concerns about

in Kenya were receiving ART (up from 10,000 in 2003); about a third of them lived in Nyanza Province. See <http://www.aidskenya.org/Programmes/Treatment--Care-&-Support/ART>, and the PEPFAR website <http://www.pepfar.gov/countries/kenya/index.htm>.

6 | These include training programmes run by NGOs that give people skills in HIV-related knowledge and thus possibilities of finding 'grassroots' work in HIV-interventions.

hunger, expressed by many of the patients I met in the HIV clinics and followed in their homes. They pointed out that their ability to survive was as much about food and income as about medicine. Yet the politics that reared above the anger at food prices and maize scandals, deeply felt and hotly discussed on the streets, in people's homes and in offices, reached neither into the clinic nor into the NGO world. In the latter spaces, hunger was constructed as a problem of poverty, to be addressed through specific projects targeting poor people. It was not considered as an outcome of the wider structures of inequality in Kenyan society, whether those highlighted by the corruption scandals or the huge gaps in income between NGO staff (especially expatriates) and the people targeted by their projects. The struggle for survival was thus not so much ignored in the massive drive to extend ART in western Kenya as deflected into humanitarian interventions organized by a plethora of different non-governmental organizations and directed at those 'affected and infected by HIV'.

Antiretroviral therapy programmes and HIV/AIDS interventions are examples of what Li describes as "vast schemes to improve the human condition", which seek their goals through working on the practices and desires of their target populations (2005: 383). Through ART programmes, individuals in Kenya are being encouraged to think of themselves in terms of the virus they carry, and HIV positive populations are being managed through bureaucratic and scientific procedures. As such, they can be described in terms of Foucault's ideas about 'governmentality' and 'biopower' (Foucault 2004 [1976]), and as an example of our modern 'politics of life' (see Rose 2007). Here, a biological definition of life is becoming central to our notions of self and to politics as the site of governing bodies and groups, but also—as biology becomes a means of assessing and claiming rights to healthcare or welfare benefits—of negotiation and debate (Rabinow/Rose 2006; Biehl 2007; Fassin 2009). The scale of ART programmes, together with the fact that funding medical care for HIV positive people in Kenya now far exceeds that provided for the health needs of the rest of the population, gives credence to the argument that citizenship—in the sense of rights and responsibilities characterising membership of a sovereign, political entity—is being reduced and circumscribed by biological conditions that open up claims to specific medical therapies (e.g. Petryna 2002; Arendt 1958). Such trends, described in terms of 'therapeutic citizenship' (Nguyen 2010) or the 'pharmaceuticalization of public health' (Biehl 2007), are defining a new era of global health and development interventions, especially in Africa. Here, project-specific 'archipelagos' of humanitarian interventions, organized by non-state and non-national groups, have become the order of the day (Hearn 1998; Redfield 2005; Rottenburg 2009; see also Mkandawire 2001).

The framework of Foucauldian biopolitics as developed by scholars such as Nikolas Rose provides a productive framework through which to understand the relations between health, biomedicine and governmentality in Africa today. Yet,

recent characterisations of the response to HIV-AIDS in terms of ‘experimental politics’ (Rottenburg 2009) or ‘government-by-exception’ (Nguyen 2009) tend to situate their analyses within these frames, rather than explore their edges.⁷ This paper addresses the question of how such a ‘politics of life’ unfolds under specific social, economic and political conditions. Drawing upon ethnographic research in clinics, community based groups and patient’s lives it offers insights into emerging practices of ‘biosociality’ (Rabinow 2005[1996]) in Kisumu, and their intersections with moral economies of NGO interventions as well as with pharmaceutical regimes of care.

‘LETS PULL TOGETHER’

On a hot Saturday afternoon, in a community hall on the outskirts of one of Kisumu’s informal settlements, members of the ‘Lets Pull Together’, an HIV-positive ‘patient support group’, arrive for their fortnightly meeting. The hall belongs to a Catholic organization, which has been active in the city for the past thirty years. During the week it functions as an HIV clinic and is packed with patients, but on the weekends it is used for meetings of various groups attached to the Catholic centre: church groups, youth and women’s groups as well as two patient support groups. The members of ‘Lets Pull Together’, many of them women, greet each other and settle into the chairs arranged in a circle near the open door. I recognize MinAchieng’, MinAnna and MinJacinta—they are members of another patient support group I had myself attended the previous day, on the other side of this provincial city. Their long skirts and blouses are newly pressed, but their feet are dusty—they have walked a long way to attend this meeting. Some of them are ‘clients’ of this Catholic-run clinic, but many get their HIV treatment and checkups from other HIV clinics.⁸

7 | As Li reminds us “(g)rand schemes [...] are contingent on a tangled set of practices, processes and relations” (2005: 383), not the outcome of a single vision, but of a complex assemblage of ideas, institutions, knowledge, science, technology, practices. Analyses of global health interventions echo earlier critiques of development as a tool of western domination (Escobar 1995), which frames problems in terms of technical expertise rather than political-economic relations (Ferguson 1994). Such critiques uncover a truth, yet leave the interesting area between policy and practice (see Mosse 2005) unexamined.

8 | During the past 30 years, this Catholic organization has provided health and other services to the low-income population surrounding the centre. In 2006, with funds from PEPFAR, the US Presidential Emergency Fund for AIDS Relief, it began to offer HIV testing and counseling, and in 2008, it entered a partnership with the American NGO

Ochieng', the chairman of 'Lets Pull Together', is a father of four, whose wife and youngest child are also HIV positive.⁹ He is one of the founders of the group, having discovered his own HIV status in 2006. He begins the meeting by asking MinJacinta to pray. He then suggests that members introduce themselves and give a short history of their HIV status and ARV medication. This procedure is part of the routine of support group meetings, but its elaboration on this day seems to be more for my benefit (it is my first visit to this group, although I've attended the meetings of other support groups attached to this clinic); most of the members already know each other and each others' situations well. Talking mostly in Kiswahili, Ochieng' then announces the agenda: the secretary—a large middle aged woman who used to be a teacher—will read the minutes of the previous meeting; Ochieng' will then introduce the visiting anthropologist to the group and afterwards give a short talk about how to "live with HIV". Finally John, the treasurer (a tall man, who, like Ochieng' and the secretary, speaks both Kiswahili and English with ease) will announce some news. It is this last piece on the agenda that many of the members are eagerly anticipating. The treasurer has attended a meeting organized by the government's National AIDS Control Council, in which 'community-based' and 'self-help' groups were invited to submit written proposals to a donor for what has become known as 'income generating activities' (IGAs) targeting those 'infected or affected by HIV'. If the application is successful, the group will receive some money to start small businesses (such as selling vegetables or trading fish). In his recounting of this meeting, the treasurer stresses that the group has to show it is serious and "accountable", well organized and committed. The group is already registered with the government's social services department; it has a bank account and a bureaucratic structure. "We can show our accounts, and we have minutes and lists of our members", he said, and suggested these bureaucratic details should be included in the proposal, as should the (un)employment and family situations of members. The group had discussed their needs for "IGAs" (everyone uses the acronym) in previous meetings: today, members talk about their lack of income, their material needs, and the challenges of feeding a family and sending children to school. Some members direct this talk directly

that receives PEPFAR funds to organize and support HIV treatment centers in Nyanza Province.

9 | Pseudonyms are used for names of people and groups. The names chosen by patient support groups—in English, Kiswahili or Dholuo—often emphasize virtues of working together for one goal, mutual support, and combating stigma. Western Kenya has a long history of what is today termed 'community-based' groups, which in colonial and postcolonial times acted as mediators between state or church authority and 'community' (see Haugerud 1993; Lewis 2000; Shipton 2007). People today often speak of how working in a group produces better results than "standing alone".

to me, assuming I am associated with an NGO, but Ochieng' skilfully turns the direction of the meeting back to proposal-writing. He talks about the many "OVCs" (Orphans and Vulnerable Children—another widely used acronym) in the community, and suggests that the group could also apply for funds to help these children's caregivers with school fees, uniforms and even food. As someone who has worked in HIV clinics, both as a volunteer and lately as a 'community health worker', and as a family father whose neighbours include many families looking after orphans, Ochieng' knows what he is talking about. He points out that many of the members are themselves already taking care of orphaned nephews, nieces and grandchildren. The treasurer suggests that the group use some of the money it has saved up to hire a proposal writer (someone who knows how to use official language, who can couch the group's intentions in a way that funders can recognize). He already has a particular person in mind who can do the job for 3,000 shillings, and he suggests that the group uses its collective funds for this purpose.¹⁰

THE NGO CITY AND THE HIV ECONOMY

Residents of Kisumu jokingly refer to their city as a "NGO city". "This city survives on NGOs", Alan, an unemployed teacher told me. This is of course an exaggeration. Most of the city's residents survive in the 'informal' economy of market stalls, vegetable selling, domestic work, tailoring, fish-smoking and charcoal-making, water-selling, bar work and transportation—and informal market stalls line the streets outside the city's central business district. The city also has some small industrial manufacturing and many small businesses, and, as Kenya's third largest town, it is an important administrative centre, housing many government bureaucrats, as well as teachers, nurses and medical staff, clerks and cleaners. Yet the number of NGOs has risen exponentially since the mid 1990s and particularly over the past decade. The last survey by the 'NGO coordination board', in 2008, lists 907 NGOs with operations in Kisumu; these range from global organizations such as World Vision to nationally-established

10 | 3,000 Ksh was about £30 at the time. Like many of the support groups I visited in Kisumu, 'Lets Pull Together' also functioned as a rotating credit group. Members contributed a small amount of money at each meeting (usually 20 shillings or 20p), which was put into a collective kitty, and either kept for collective activities or drawn upon by each member in turn or in times of special need. Rotating credit is a long-established practice of groups in western Kenya (and has been widely documented in both colonial and postcolonial Africa). Women in particular are avid members of groups, which are usually formed among people of similar income. The practice of rotating credit underlines the multiple activities and functions of groups.

NGOs to local ‘self-help’ or ‘community-based’ groups, which register themselves as NGOs with the government and hope to receive funding from the bigger NGOs.¹¹ Many of the international and national NGOs are involved in HIV-related interventions such as the introduction and expansion of anti-retroviral treatment to HIV-positive people; projects providing school fees, food and care to orphans; income-generating activities and micro-finance projects; hospice care; youth interventions, and ‘HIV prevention’.¹²

The funds that NGOs receive mostly come from outside Kenya; and these funds flow into the buildings and vehicles, salaries, and workshops associated with international and national NGOs. In Kisumu they produce signs of wealth that are strikingly absent from other spaces in the city, and they circulate resources, albeit in circumscribed ways. Thus, most of the larger four-wheel drive cars one sees on the city streets display logos of non-governmental organizations or external aid agencies. Many of the well-heeled middle class of Kisumu, those who draw a salary at the end of the month and who enjoy lunches of chicken and fish in the cafes that have sprung up in the centre of town, are employed by NGOs. Accessing this NGO world through formal employment is difficult (if not impossible) for most of Kisumu’s residents. However, as part of current donor interest in ‘community-based development’, NGOs channel a portion of their funds to ‘community-based groups’ and they target those with specific needs, if they can present themselves as organized and accountable. This has resulted in an explosion of community-based groups of all kinds—youth groups, women’s groups, widow’s groups, even men’s groups—all jostling to gain visibility and thus access funds.

In this city of groups, HIV positive Patient Support Groups are particularly prominent. These groups are attached to ‘patient support centers’ (henceforth PSCs), clinics providing free HIV tests and counselling, where HIV positive people receive free antiretroviral medicines, multivitamins and antibiotics as well as regular, if basic, medical check-ups. Since PEPFAR and the Global Fund made commitments to funding ART, the number and reach of PSCs has expanded in Kisumu.¹³

11 | See the 2007-8 report by the NGOs Coordination Board (set up by the government in 1990): <http://www.ngobureau.or.ke/Publications/National%20Survey%20of%20NGOs%20Report.pdf>. It shows that there are 117 NGOs with their headquarters in Kisumu, and 790 operating in Kisumu but with their headquarters elsewhere. The survey staff could not physically locate or interview many of the smaller NGOs, raising questions about how they operate and indeed whether they still exist.

12 | See also <http://www.kanco.org/KANCOMembers.php>, which lists NGOs working in western Kenya.

13 | By 2010, there were 25 PSCs within the city (64 in Kisumu district), ranging from the large PSC attached to the provincial hospital, to small clinics run by local

By 2008, every PSC in Kisumu had at least one 'Patient Support Group' attached to it. These groups varied in size and membership, as people joined and left, but usually contained a core group of committed HIV-positive members. Most patient support groups have a similar bureaucratic structure and similar procedures as the one described above: chairperson, secretary, treasurer; minute-taking, membership lists and registration cards. This bureaucracy is important: it lends the group status, gives it weight, and demonstrates its accountability. It reproduces known forms, making the group legible to others organizations—governmental and non-governmental—that control funds or access to them. Most groups try to register with the government as a 'community-based organization' or a 'self-help group', which makes them visible (group members may be invited to official meetings as representatives of 'the community') and gives them access to funding opportunities. To do this, they should have a bank account and a written constitution, and they have to pay a sum of money.¹⁴

Thus, while support groups like 'Lets Pull Together' provide a social location for the encouragement and management of 'positive living', where people can 'share' their experiences and challenges, they also have to a large extent become locations where people can access funding, material goods, as well as training and even employment opportunities. Through joining a support group, people learn that articulating their positive identity can open up economic opportunities.

How has this situation developed? Starting in 2000, positive lifestyles were actively cultivated in HIV positive people by NGOs and donors, backed up by the government, as part of a strategy to address discrimination and encourage people to go for HIV tests.¹⁵ HIV positive people were given something people refer to as "appreciation" money to stand up and 'witness' about their HIV positive status. They were also encouraged to start up patient support groups. Living and spreading the "HIV gospel", as Ochieng' described it to me, became a career path for the early members of support groups in Kisumu, many of

NGOs. PEPFAR provides funds to a host of 'prime partners' (<http://www.pepfar.gov/partners/103021.htm>), which organize and monitor PSCs (e.g. Global AIDS Programme (GAP): <http://www.cdc.gov/globalaids/Global-HIV-AIDS-at-CDC/countries/Kenya/>; Family Aids Care and Education Service (FACES): www.faces-kenya.org); the Catholic Relief Services (CRS): <http://crs.org/hiv-aids>); Academic Model for the Prevention and Treatment of HIV/AIDS (AMPATH): <http://www.iukenya.org/pdfs/ampath.pdf>); and Liverpool VCT (LVCT): www.liverpoolvct.org). See also Madiaga 2011.

14 | National NGOs have to pay the Board 11,000Ksh; International NGOs pay 22,000. They are issued with a certificate, but have to pay extra for it; they also have to pay 500 shillings for the approval of their name. see <http://www.ngobureau.or.ke/servicefees.aspx>.

15 | See "Reversing the Trends: the Second National Health Sector Strategic Plan of Kenya". Ministry of Health, June 2006.

whom went on to receive ‘training’ in HIV counselling or community work, and even employment in HIV-related work. During the same period, there was a proliferation of NGOs providing funds for those ‘infected or affected by HIV’.¹⁶ Support groups became the natural target for NGOs searching for HIV positive people in need of material support. Sacks of food and loans of money encouraged more people to join support groups and their membership numbers increased substantially. As HIV gained economic value, at least for the unemployed, there were even reports of people claiming to be HIV positive in order to join a support group. One group I knew began demanding that members bring their PSC cards with them in order to ensure there were no fake identities.¹⁷

When I first attended support group meetings, the leader or ‘chairperson’ would usually set off a round of introductions with each person giving a short history of their encounter with HIV and ARVS (for example: “I learned my status in 2006. I have been on ARVS since 2007.”). Often the chairperson of the group would ask one or two members, usually women, to tell their stories. Often involving sickness, the death of husbands and rejection by agnatic family, these stories were very emotional, with the teller sometimes breaking down in tears.¹⁸ After attending several meetings and several support groups, however, I realized that these narratives, while genuinely felt and articulated, were called up more for my benefit as a visitor. They could be called upon—members had learned how to tell the story of life before they came to ‘know’ HIV—but they were not part of the routine of group meetings. Instead the meeting would be devoted to more urgent matters—to discussing worries about school fees or ill family members, conflicts with in-laws, and lack of food. Other matters

16 | For example, ‘Orphans and Vulnerable Children’ (OVCs) and ‘Widows’, as well as HIV positive people, emerge in this global AIDS discourse as categories of persons in particular need of, for example, food, school fees, income generating activities, or ‘home-based care’ (see Epstein 2007).

17 | Support group membership was clearly class- (or income-) based. Those who enjoyed salaried employment did not need the material benefits associated with group membership. At the same time, due to perceived discrimination of HIV people in many workplaces, they had more reason to hide their HIV status. I met some HIV positive people who were teachers, nurses or civil servants at the PSCs, but none were members of a support group.

18 | Many of these women discovered they were HIV positive during a period of sickness, or after the death of a spouse and subsequent conflict with in-laws (Prince 2011). In these narratives it was through being tested, accepting their status, becoming clients of a PSC and members of a support group that these women managed to gain a sense of worth and rebuild their lives. In this patrilineal society, married women belong to their husband’s land and family. A rejection by the husband’s family thus amounts to a refusal of a woman’s social identity and her future (Geissler/Prince 2010b).

included information about members who were too ill to attend or who were caring for sick family members; requests for contributions to the funeral expenses of a former member of the group; discussions about whether group members should form a credit-rotation group or “merry-go-round”; exchange of information about microcredit organizations operating in Kisumu; and the exchange of news about which NGO or church group was this week or month supplying bags of flour, mobile phone credit or start-up cash for IGAs.

Not all groups are successful. ‘Let’s Pull Together’ is a particularly well-organized group, whose leaders are educated and articulate and passionate about “helping our community” and “fighting HIV/AIDS in our country”, as Ochieng’ put it. They also have good connections with both the Catholic NGO, and with other NGOs in Kisumu. For example, Ochieng’ had worked for several years as a ‘volunteer’ HIV counsellor in both the provincial hospital and the Catholic clinic, and in 2008, he had managed to get formally employed by the clinic on a one-year contract when it expanded its HIV treatment activities using PEPFAR money. Other groups lacked such well-connected leaders, although many had leaders and members who were enthusiastic practitioners of what they referred to as the “HIV gospel”.

Several months after the meeting described above, Ochieng’ wrote an email telling me that the group had been successful in its bid for funding from PEPFAR, and that it had received some money¹⁹, some of which was earmarked for IGAs for each member, and some of which was to support orphans and vulnerable families identified by the group. He was brimming with enthusiasm and elation at their success. When I returned to Kisumu for a visit in 2010, I found that several other patient support groups had become attached to the Catholic NGO, hoping, I suspect, to emulate the success of ‘Let’s Pull Together’. These groups had not been successful in applying for PEPFAR funds. But they had received a one-off gift of a few thousand shillings for IGAs from an NGO supporting people living with HIV.

Thus, the better-organized group—with well-connected leaders who knew how to write or solicit proposals—received funding, while those who lacked such skills did not. Like the village groups in the World Bank scheme described by Li, what was being offered was “equality of opportunity to compete for funds, not equality of outcome” (Li 2007: 248). In a situation in which every group is able to demonstrate a need, accessing funds depends, crucially, on a particular expertise: the ability to write a proposal or to keep records, to demonstrate accountability and efficiency. This expertise is both generated and sought

19 | Some 50,000 Ksh or £500.

after by NGOs²⁰, and pursued by individuals who need to learn the particular language and material culture of development.

Some of the NGO projects focusing on HIV affected people in Kisumu have enjoyed a degree of success. For example, some of the early members of 'Patient Support Groups', those who agreed to stand up to 'witness' about their status, invested the money they received into 'training' or small businesses.²¹ Like Ochieng' and his wife, some of them found work, first as volunteers for NGOs and later as employed 'counsellors' or 'community health workers'. However, many of these NGO-led interventions are rather transient and short-term, as they are subject to the changing concerns of donors. NGOs must continually make funding applications, and their operations are limited to circumscribed spaces. Recipients of such interventions thus experience them as extremely patchy and unstable. For example, the self-help group that MinAchieng', MinAnna and MinJacinta were members of, located on the other side of town, had for a time received funds from a UK-based charity for a project supplying food and school fees to widows and orphans. After two years the charity had suddenly withdrew its support, leaving the children they were supporting half way through secondary school with no means to pay the fees. According to leaders of the group, this abrupt change was due to the shifting priorities of the charity's donors, and thus it was not even within the control of the charity itself.

Such stories underline the fact that while NGOs may provide some basic services, these are oriented more to the requirement of donors and their funds than to the people they target. Like the healthcare interventions I will turn to below, such welfare interventions are organized through an archipelago of short-term projects and interventions, producing a patchwork of services that are limited both temporarily and spatially (see Hearn 1998). Moreover, success itself is often ephemeral. The funding of groups like 'Lets Pull Together' is supposed to make them into 'income generating' and 'self-help' groups, which can then stand on their own (see Boesten 2011). However, this rarely happens, as their 'income-generating' activities are economically insecure. And while groups like 'Lets Pull Together' may get funding for one year, they may fail to get further funding (and consequently often lose members, as people migrate to more successful groups).

20 | People learn such skills through training workshops and seminars, organized mostly by NGOs.

21 | Sometimes undergoing a training programme was a condition of the exchange they entered into.

HEALTHCARE AND ‘WELFARE’

Support groups are places where the pharmaceutical regime of the clinic meets the humanitarian economy of welfare organized through NGOs and directed towards those living with or affected by HIV. They are imagined as places where people learn to live positively with HIV and to organize their bodies and lives in terms of the requirements of antiretroviral therapy. Support Groups indeed encourage a solidification of identity around being HIV positive. People learn to tell the story of their lives within a certain genre—that of HIV—and to articulate their needs in terms of being HIV positive. Through joining a support group, people living with HIV also become visible to others. Encouraging this visibility as a way of combating stigmas and ‘normalizing’ HIV has been important to HIV positive people, and to those working to improve their lives (Ogot 2004). Yet visibility has another, economic, value for those surviving in this NGO city. It makes you visible to organizations that control the flow of funds and the projects. As the leader of another support group in Kisumu joked, “We hope that scientists do not find a vaccine for AIDS. We need HIV!”

This material suggests that the ‘new’ subjectivities inscribed by ‘positive living’ and new technologies of care, often remarked upon in the literature as life-transforming (e.g. Robins 2004; Comaroff 2007; see also Whyte 2009), are grounded in an economy in which being positive has a material value. As AIDS projects and NGOs converge on the city, having HIV is proving to be a resource. While the conditions of life in the city that I described above face all those who lack a regular income, being ‘infected or affected by HIV’ is a recognised form of suffering that NGOs respond to. Projects supporting income generating activities, micro-credit, orphans and vulnerable children, and the distribution of food all respond to the recognition that the poverty experienced by many families has been exacerbated and to some extent created by HIV/AIDS. HIV makes one eligible for interventions. Just being poor does not.²²

Joining a group and making oneself visible as a HIV positive person with certain ‘needs’ requires a certain ability to recognise opportunities. However this does not mean that group members are simply opportunistic. Life in the city is tough if you have no formal employment. There is no public housing scheme for people outside government employment; landlords erect barely finished rooms with mud walls and leaking roofs, and charge high rents for them; schooling is expensive, and many families take care of orphaned grandchildren, nephews and nieces (Nyambedha/Wandibba/Aagaard 2003; Nyambedha 2008). For many, giving the family a solid meal is a daily struggle. Many of the women who come to the ‘Lets Pull Together’ group are members of other support groups

22 | Although a pilot study by UNICEF in Kisumu introducing cash transfers to ‘vulnerable families’ has recently been introduced.

because these provide some of their few opportunities to access food or money. Many of them live alone, are widowed or separated from their husbands. They cultivate their membership alongside other ‘income-generating’ activities, such as selling vegetables, doing laundry for wealthier patrons, or making and selling chapatti; while the male members provide *bodaboda* (bicycle taxi), cart water for sale, sell sodas or tailor. All these ways of earning a living are unstable and transient—vulnerable to price changes, weather conditions, the ability to buy on credit, and the uncertainties of donor funds—and one has to be constantly alert to changes and new opportunities and able to switch between different activities.²³

In the next section I explore how the ability to survive with HIV is imagined by the clinic with its focus on pharmaceutical regimes of self-care, and juxtapose this with the realities of daily life in the city, where many people struggle to find enough food to feed their families.

REGIMES OF SELF-CARE

As a ‘community health worker’ (CHW), Ochieng’ spends his weekday mornings in the community hall, which acts as the PSC of the Catholic NGO. Together with three other CHWs, he registers new ‘clients’, updates their medical forms and takes their vitals—weight, height (for children), and pulse rate—before sending them past the curtained-off partition to see the nurse and clinical officer who ask about the patient’s health, prescribe drugs and sometimes send the patient on to the laboratory for further tests. On Wednesday mornings Ochieng’ also conducts ‘adherence classes’. According to Ministry of Health guidelines, before people can be initiated on antiretroviral therapy, they must attend three adherence classes, where counsellors teach them about HIV and ‘positive living’, the importance of taking care of your health and living ‘responsibly’ (through eating a ‘balanced diet’, not passing on the virus nor exposing oneself to re-infection), as well as how to consume the daily doses of multivitamins and antibiotics, and the various combinations of antiretroviral drugs.

Ensuring the success of the ART programmes—initiating and keeping large numbers of people on antiretroviral medication—relies to a large extent on instilling particular habits and attitudes towards medicine, one’s body, and ideas of risk. Antiretroviral medication must be taken twice a day at exactly 12-hour intervals. The strict adherence to the medication suppresses the replication of the virus and its mutations that can become resistant to the drugs (WHO 2003, 2009; Castleman/Seumo-Fossil/Cogill 2004; Laing/Hodgkin

23 | See Guyer 2004 for an ethnographic analysis of trading and other economic activities in the informal economy.

2006). Hence there is much focus on giving the patient what is referred to in the clinic as ‘correct information’. Health should be achieved through the patient knowing about the virus; such knowledge allows her to ‘take control’ of her viral condition, through close monitoring of her own health and care of herself. The use of the term ‘client’ underlines the attempt to move HIV from its associations with illness and patienthood, towards ‘autonomy’ and ‘choice’: you are not a patient, passively accepting your condition, but a person who can act upon it. Counselling and education about HIV and ARVs, about diet, medication, sexuality, the importance of keeping time, and keeping one’s clinic dates—reiterated in counselling sessions such as those led by Ochieng’—aim to produce this ideal client, at once obedient (to medical and clinic regimens) and ‘empowered’ (able to take responsibility for her own health). That this stance or orientation is normative, entwined with moral judgments, is underlined by the term used by the clinic to describe a client who does not conform to these medical regimens: ‘defaulter’.²⁴

EMPOWERMENT AND DISEMPOWERMENT

Ochieng’ is an example of how successful a decision to embrace ‘positive living’ and the regimes of the clinic can be. Both he and his wife quickly embraced their positive status, joined support groups, and through being ‘active’ members, gained access to the training in HIV counselling and community health work that was being offered by various NGOs in Kisumu. After several years of precarious survival, during which they worked as ‘volunteers’ for the clinics, they both managed to gain paid employment as ‘community health workers’, albeit on one-year contracts. On their combined monthly salaries, they are able to rent a solid three-roomed house and to put their oldest child as well as Ochieng’s younger brother through secondary school.²⁵

24 | This (English) term is used for those who do not turn up to appointments, who do not take their medicines, or do not take them properly. The etymology of ‘defaulter’—‘nonpayer’, ‘debtor’ ‘cheat’, ‘absentee from court’—illustrates the connection made in these new medical regimes between health, economy and legal regimes. While the PSC often make quite an effort to follow them up and staff is often sympathetic, there are clear guidelines concerning their inclusion. As one of the Ochieng’s co-workers explained to me: “The defaulters are given another chance. They have to enrol again in the Adherence classes and attend all three of them again. If they don’t come, and if they drop out again, they are out.”

25 | However, they are also vulnerable to increased demands from extended families members, for help with school fees, medical expenses, and looking after children.

However, when I accompanied Ochieng' on some of his 'home' visits, I was stuck by the contrast between his experiences of 'empowerment' and those of many of the people he visited. For example, Rose, a young mother of two, was struggling with her HIV status and with her treatment regimen. Her husband, a fisherman, had left her after she had disclosed her status. Having no place to go to, she had stayed on in their rented room on the lakeside of town, earning some little income by buying fish at the lakeshore and selling it in town—but she was continually on the verge of being thrown out by her landlord. According to Ochieng', Rose's health deteriorated after her husband's departure. When she missed several clinic appointments in a row, Ochieng' went to visit her and found her in a weak state. She admitted to him that she had not been taking her medicines because there was little food in the house, and taking them on an empty stomach made her feel sick. Ochieng' encouraged her to come to the clinic and continue with the medicines, but he later admitted that he felt uncomfortable offering only advice "when the problem is food". Knowing her HIV status and being initiated on ARVs had not 'empowered' Rose in the way it had Ochieng'. Moreover, the strength and life promised by ART had, in the absence of an adequate diet, failed to materialise.

TALKING ABOUT HUNGER

Food is a constant worry for many Kisumu residents. In our ongoing study of 20 families with members on ART, most of them living in Kisumu's 'informal settlements', people reported that they were often hungry and ate only one meal a day. Sometimes there would be porridge in the morning (made with flour and water, and rarely milk); sometimes only black tea with sugar. Living conditions were precarious as many had no steady income to rely on.²⁶

Many of the HIV positive people we followed reported an initial weight gain and rise in energy during the first weeks of taking ART. During this period of ART initiation, the PSC usually gives underweight 'clients' a flour supplement, particularly if they had suffered from tuberculosis or other opportunistic infections. The flour and the medicine gives them an initial weight boost, which they experience as a shift from being ill and weak to a feeling of increased strength and the ability to be mobile, work and function normally. However, the flour supplement is usually discontinued once the person reaches a 'viable' weight²⁷, and many experience a sharp rise in hunger and an intolerance of

26 | For example, selling vegetables may give one an income of 100 shillings on some days, and twenty shillings on others. Compare this to the cost of a basic family meal: 10-20 shillings for vegetables and 50-100 shillings for maize flour.

27 | For women, the cut-off point is fifty kilogrammes.

certain kinds of food. “Since I started taking these medicines I just want to eat a lot. But the challenge that faces me is, how do I get food? The ARV medicines need a lot of food”, Elizabeth told us. She was the mother of two girls, the youngest of whom she had just discovered was also HIV positive.²⁸ Irene, whose husband and child were also positive, told us: “Food is not easy to get. At times my husband goes to the market (to trade) and comes with nothing, and this makes us sleep hungry.”²⁹ We often heard people commenting: “Taking ARVs without proper food is like committing suicide”³⁰

Eating a good meal each day is a challenge facing many families, HIV positive or not. However HIV positive people reported that ARVs introduced an intolerance of hunger and a dependence on their body’s need for food to a degree they had not experienced before. At the same time, they found it difficult to ask for special treatment from family and neighbours: “People will say, ‘Why you? We are also hungry!’”, as Elizabeth once explained. In western Kenya, bodily needs should not be expressed—children are taught not to complain about hunger even if they spend a day without food—and in a situation where everyone gets one meal a day, it is hard to claim that having HIV gives you the right to more or better food. Self-care is here not a virtue but a form of selfishness.³¹

28 | (E. Atieno, Sat 12th December 2009). Elizabeth told Bidy that her husband had refused to take an HIV test, and that she had taken her daughter to get tested without his knowledge.

29 | (Irene Akinyi 14th December 2009). I am grateful to Bidy Odindo for recording these conversations.

30 | This expression seems exaggerated yet it was commonly used. To some degree people’s talk of hunger was oriented to us, as outsiders, particularly as we were initially associated with the world of NGOs and groups. However, this does not make it less real. Tragically, Elizabeth died in June 2010, and although her husband then got an HIV test and took great care of his positive daughter, at the time of writing, I have just heard from Bidy that the little girl has died. This underlines the continued problem of medication in a situation of economic precariousness. It also underlines that in the context of limited government welfare, NGO projects provide inadequate protection to such vulnerable families.

31 | Hunger is not a novel experience in rural Nyanza. During the 20th century, labour migration combined with the introduction of maize as the staple crop, led to this area experiencing a huge decline in food production (Hay 1976; Cohen/Odhiambo 1989). During the 1980s and 90s, infant malnutrition was a prominent concern of donor agencies and medical research. From the 1990s, rural hunger has been exacerbated by the deaths of economically productive household members due to AIDS, and the decline of labour migrants’ cash remittances (Francis 1995; Nyambetha/Wandibba/Aagaard-Hansen 2003; Geissler/Prince 2010a).

Paradoxically, it is in this situation that the clinic becomes a space where people can talk about food and thus about hunger and material needs. This is because here it was recognized that HIV positive people needed to eat well in order to do well on the medicine. Ochieng' spends one morning a week counselling people who are about to start on ARVs. He shows them the medicines and their strengths, but also mentions side-effects. "You have to eat well if you want to do well on these medicines", he says, "they are very strong". He points to the poster on the wall which displays the ingredients of a "balanced diet": proteins, carbohydrates and vitamins. The interaction between food and diet is also underlined in the provision of fortified flour to HIV-positive children and to severely underweight adults. This flour is given for a limited period (usually three months), often when the person is initiated on ARVs.

Flour supplements are not a response to hunger, but a medical intervention to prevent unacceptable weight loss and deterioration. However they make a huge difference to many families, who fiercely cling on to them. A nutritionist employed at a PSC told me about arguments he had had with grandmothers and mothers who refused to give up their flour supplement. One HIV-positive child in his care had been (against regulations) receiving the flour for over a year:

"This child has been receiving supplements for too long—the limit is three months. So this came to the attention of our funders and they insisted that the supplement should be stopped. I had the grandmother here, she could not understand. 'How am I to feed my grandchild?', she asked me. I told her, 'Would you die if the funders left? What were you eating before? You cannot rely on this. It is not food aid. Donors come and go.' It is difficult..."³²

There is a large gap between the forms of self-care expected by the clinic and people's everyday struggles to get enough food. Flour supplements are no solution to the problem of making an income. And like other HIV counsellors, Ochieng' is well aware that few of those attending his ART adherence classes have the means to eat 'balanced' diets. Yet, the focus in the clinic on the relations between ARVs, diet and nutrition opens up a space for talking about hunger and thus about living conditions. While this talk does not enter official space—questions concerning daily diet are not included on patient's medical forms—patients do tell the clinic staff "I cannot take this medicine when I have not eaten!" This is often done in a humorous rather than a confrontational way, but the message is clear: "We cannot survive on medicine alone."

In voicing their hunger, people pull the conditions of their survival into the clinic. However, the political challenge that lack of food and income poses seems to stop short there. During interviews with staff at patient support centres

32 | Interview with R.O., 27th September 2010.

in Kisumu, I asked what solution there could be to the problem of food faced by people on ARVs. In most cases, I was referred back to NGOs and proposal writing. “Patient support groups could write a proposal to ask for funds from a donor or well-wisher for Income Generating Activities”, staff suggested. The inequalities that the geography of hunger makes visible are channelled into requests for aid from foreign funders and NGOs. And, as the example of ‘Lets Pull Together’ demonstrates, this aid is directed to groups and individuals who can demonstrate a particular expertise.

THE POLITICS AND ANTI-POLITICS OF HIV INTERVENTIONS

ART programmes tend to construct survival as a matter of adherence to medicalized regimes of care, thus overlooking conditions of life in the city that may be more important to whether medication is successful or not. By framing matters of adherence as matters of knowledge and access to information, they exclude political questions about why some people can’t do well on medicines, not because of knowledge but because of poverty and inequality. As James Ferguson observed of development projects in Lesotho, ART programmes may “effectively quash political challenges to the system [...] by insistently reposing political questions of land, resources, jobs, or wages as ‘technical’ problems responsive to the technical ‘development’ intervention” (1990: 270). Issues of hunger and access to food are not within the province of treatment programmes: “This is not food aid.”³³ Yet to stop here would be to present too simple an analysis of what is going so. For at the same time, ART programmes bring matters of hunger and access to food into view, into the space of the clinic, where they can be articulated, albeit obliquely.

There is potential, then, for programmes that provide treatment to HIV positive people to point to the inequalities in survival chances that exist despite access to medication. When patients link their survival to food and hunger as well as to medicines, there is an “opening”, for the ignition of political practice, as “expert discourse is punctured by a challenge it cannot contain, moments when the targets of programmes reveal, in word or deed, their own critical analysis of the problems that confront them” (Li 2007: 11).

However, in Kisumu, the recognition of hunger and inequalities did not translate into a political issue in a public arena, beyond private observations and complaints. This is despite the tense political atmosphere in which food prices and economic inequality were debated in Kenya during 2008 and 2009.

33 | As I was recently told by Kenyan and American doctors and directors of the Global AIDS Programme in Kisumu during a presentation of a version of this paper to KEMRI-CDC seminar, October 1st 2010, Kisumu.

Why not? Asked what could be done about hunger and lack of food, staff at the patient support centres suggested that patients should join a group and make proposals to ‘well-wishers’ and ‘donors’. The problem of hunger is channelled into the humanitarian economy of NGO interventions, which encourage HIV positive people to form groups and write funding proposals. As for the groups themselves, any independent thinking and grassroots activism is quickly submerged by the need to account upwards. Despite the ‘grassroots’ rhetoric of interventions, groups such as ‘Lets Pull Together’ do not decide which projects and activities should be funded and where welfare should be directed. Instead they have to orient their activities to the requirements of the donors. This humanitarian economy of short term, project-specific and patchy welfare interventions thus does not encourage people to think of their health care and welfare in terms of their rights as citizens and the responsibilities of the state, but rather to think of themselves as recipients of charitable donations from ‘well-wishers’ and as sufferers having ‘needs’.³⁴

34 | The tension between responding to immediate suffering and pushing for social transformations that would target the source of suffering is much discussed in relation to humanitarianism (Calhoun 2009).