

# Seeking Recognition, Care and Connection : Critical Perspectives from Kenya on Living with HIV

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## Seeking Recognition, Care and Connection: Critical Perspectives from Kenya on Living with HIV

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Recent anthropological scholarship on the globalization of HIV/AIDS treatment and activism has given paid much attention to new HIV-based subjectivities and the possibilities and politics opened up by globally circulating languages of rights to treatment. While global discourses of rights and entitlements surrounding HIV do circulate in Kenya, my ethnographic work on HIV clinics in Kisumu suggests that people are more concerned with creating and acting upon claims and obligations in their immediate social fields than with using a language of rights. Based on research in western Kenya on the roll-out of US-funded free antiretroviral treatment programmes for HIV-positive people, and associated poverty-alleviation projects set up by NGOs and community-based groups, I examine this field of claim making; the ways in which it is shaped by the humanitarian AIDS economy as well as the perspectives it gives into personhood, community and moral economy.

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### 1. Introduction

My arguments in this paper are based on ethnographic research conducted in the city of Kisumu in western Kenya, from 2008-10, on the moral economies that are

negotiated around health interventions and poverty alleviation programmes largely focused on HIV/AIDS issues. These range from large-scale antiretroviral programmes ‘rolled-out’ with PEPFAR funds (the US Presidential Emergency Fund for AIDS Relief), to numerous projects, run by various NGOs and directed at those “infected or affected by HIV”.<sup>1)</sup>

The starting point of the research was to question accounts of new HIV-based subjectivities and the possibilities and politics that these opened up. Rights-based politics focused on HIV, such as those that have emerged in South Africa around the Treatment Action Campaign, have been largely absent in Kenya or confined to a small sector of the Nairobi-based middle class. Most people in western Kenya, with or without HIV, did not take up these globally circulating languages of rights and entitlements. This does not mean that HIV was not being converted into opportunities to make claims, however. This field of claim making – and the ways it relates to the moral economy of HIV/AIDS interventions – is the focus of this paper.

Another line of argument that has been pursued in the literature on HIV and ART has taken the opposite tone. Rather than celebrating the new politics of rights and activism, it points to a) the attenuation of the public’s claim to health-care to biological life and bare survival organized by shifting and transient configurations of non-governmental organizations; and b) the narrowing down of well-being to the individual’s capacity to take up messages of self-care, thus to the responsibility of the individual. The now well-documented literature on this issue posits or describes a process of shifting politics away from political being to biological being (the Greek *Zoë*) such that “bare life” or “survival” becomes the ground of political claim-making (Petryna 2002; Ticktin 2006; Nguyen 2011).

These arguments about humanitarian concerns and interventions creating a political space around forms of “suffering” and “survival” based on biological life apply to the moral economies emerging in Kenya around the funds and resources available to those with HIV. Antiretroviral therapy programmes and HIV/AIDS interventions are examples of what Tania Murray Li (2005: 383) 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).

The recipients of free ART programmes in Africa, however, appear less concerned about the disciplining aspect of these new biomedical regimes and more appreciative of the forms of biopolitical inclusion they offer. The new HIV clinics

provide care, testing and treatment, a recognition of the burden of HIV, and hope for the future. Recipients of this care may experience frustration at the limitations of these programmes, but they still appreciate the recognition and concern that they represent. Moving closer in, this paper attends to the negotiations emerging on these grounds and in these spaces, following both practices of care and what emerges from thickly layered “matters of concern” (Latour 2004). I begin from the observation that, while global discourses of rights and entitlements surrounding HIV do circulate in Kisumu, people seem more concerned with creating and acting upon claims and obligations in their immediate social fields.<sup>2)</sup> I thus direct my attention to the actually existing relations and claims people make upon each other, and seek to act upon. At the same time, the new discourses that have been promoted around HIV – about “positive living”, health, and gender relations and so on – are not simply impositions of globally-circulating discourses that are either irrelevant or, worse, oppressive. They may also open up new possibilities, as by acting up on them, people open up new pathways and trajectories.

The introduction of free ART programmes in Kenya, and in the city of Kisumu, has produced an economy of health care and welfare in Kisumu in which access to free medical treatment and to material benefits and means of making a living are organized to a large extent around HIV. 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.<sup>3)</sup> For many families and individuals struggling to make a living in the city, being HIV positive has opened up pathways to scarce material resources. However, accessing such resources is often dependent upon making one’s needs visible and legible to global health, humanitarian and development project and programmes.

Below I examine, first, the work of ‘groups’ – and their leaders – in making these needs visible, and second, the role of community health workers and volunteers, as ‘brokers’ or ‘street level bureaucrats’ in mediating and extending modalities of care and recognition connected to particular ART programmes, which are embedded in HIV clinics known locally as Patient Support Centers. It has been argued that the model of ‘demonstrating needs’ in the competition for donor funds undermines solidarity (Boesten 2011), creating a ‘politics of the queue’ and a jostling for favours (Beckmann and Bujra 2010). However, competition and opportunism are not the only qualities fostered in this landscape. Staff and volunteers working in the ART programmes and clinics also strive to make multifaceted ‘needs’ visible in order to foster and forge forms of solidarity and care that extend beyond the biopolitical focus on HIV. Elsewhere I’ve written about how the clinic’s focus on adherence to medication and care-for-the-self was often at odds with the lives of people struggling to make a living, as the ability to flourish on the new medicines was compromised by poor nutrition and poverty and

the multitude of other responsibilities and concerns people were embedded in (Prince 2012a; 2012b). I described how HIV identities accrued value in the AIDS economy, as with them one could become visible to NGOs providing material support or income-generating projects for those living with HIV. I discussed the injunction to demonstrate and perform knowledge of HIV within a language of empowerment in order to gain recognition, and further opportunities for material support from NGOs. I observed that in this NGO economy, in a city of over 800 NGOs and CBOs that are competing for funding, people articulated and made claims in terms of their needs, rather than in a language of rights and entitlements. This language of needs appears to contradict the rhetorics of self-reliance and sustainable development promoted by NGOs – promoted in workshops and trainings – and articulated in terms of empowerment. I also discussed the work of volunteers attached to clinics, and the temporalities of their labour in the broader NGO economy of projects that ‘come and go’ (Prince 2013; 2014).

In this paper, I return to this language of ‘needs’ in the light of recent anthropological research on living with ART in Africa and of recent debates in anthropology about dependence, autonomy, and personhood. What is expressed in this language of needs? To whom, and in which ways? Why, despite global emphasis on rights to health and globalization of access to treatment, do people in Kisumu prefer a language of needs than a language of rights? The language of needs, I argue here, is not only a set of externally imposed, donor-induced practices, induced by competition for donor funds. From another angle the language of ‘needs’ can be understood as a language of obligation, and responsibility and as a means of “declaring dependence” (see Ferguson 2013). The question we should be asking, then, is what are people aiming for when they talk of their needs? Rather than striving to be self-reliant, empowered, biological or therapeutic citizens, my informants struggle to gain recognition as people to whom larger institutions – NGOs, state, donors- should have particular responsibilities, which, moreover, should extend beyond the remit of particular programmes and projects. In a landscape of inequality, where entitlements must be negotiated, claim-making underlines interdependence in an ongoing relationship. I address the work of patient support and community based groups in articulating these claims and the struggles of community health workers and volunteers to act as brokers between ‘community’ and clinic.

## **2. The “NGO City”**

During the past 15 years the western city of Kisumu (population ca. 500,000 in 2010) emerged as an epicentre of the regional AIDS epidemic. This attracted international attention and resources, drawing in external funds and institutions. A

plethora of organizations conducting research on HIV and other diseases began to operate in the city and its hinterlands alongside government and non-governmental groups running projects directed at “those infected or affected by HIV”.<sup>4)</sup> Since 2004, with large amounts of money provided by PEPFAR and the Global fund, programmes offering free antiretroviral treatment (ART) and other medicines to HIV positive people have been introduced, organized through complex partnerships between the Ministry of Health, NGOs and international organizations.<sup>5)</sup> PEPFAR has continued the tradition of USAID and the World Bank of promoting “community-based development” and has encouraged “community-based organizations” (CBOs) to apply for funding for projects targeting AIDS-related issues. This lent support to an already thriving NGO and CBO industry in Kisumu (and in Kenya more broadly). By 2008, in Kisumu alone, an official total of 907 NGOs and “community-based” groups had registered with the government’s NGO coordination board to run projects ranging from anti-retroviral treatment to orphan care, micro-credit and income-generation, health education and “the environment” (see Prince 2013; 2014).<sup>6)</sup>

Since 2005, the city and its hinterlands had seen the establishment of a growing number of HIV clinics supported by PEPFAR, within government hospitals, clinics and district health centers, and within NGOs operating various projects concerning poverty alleviation and health care in the area. During 2008-2009 I spent a total of 10 months following this roll-out, focusing on two clinics in particular, the Catholic NGO and a government health centre also located in the city. I shadowed, and interviewed staff and volunteers working in the clinics, visited patient support groups attached to them, and accompanied community health workers as they traversed the city, following up patients. I, and later my research assistant, regularly visited 20 families with HIV-positive members, for a period over 24 months, from January 2009 to March 2011, during which we discussed their lives on ART.

### **3. The Politics of “Civil Society”: “Lets Pull Together” and “NETS”<sup>7)</sup>**

The changing fortunes of two “community-based” groups provide us with insights into the AIDS economy. NETS group (a pseudonym) is a youth group formed in 1985 by two Catholic missionary fathers, as a Catholic youth group where Catholic youth can meet for religious activities and community service. It has its own website and meeting house, which is attached to a Catholic centre in one of Kisumu’s informal settlements, where members have access to an office with electricity and a computer (although electricity supplies are unstable). When I was introduced to the centre in 2008, many of the youth attached to it were not

Catholic, although they were, like many Kenyans, active Christians, and felt a strong attachment to the group itself. Most of these young people had secondary school education, spoke English and Kiswahili well, and were hoping to gain experience and access, through volunteering, to further training opportunities and even, they hoped, to employment with an NGO. During this time, NETS housed several projects and activities, including a “patient support group” which was set up in 2006 as a meeting forum for people living with HIV/AIDS at a time when the Catholic NGO as well as the Ministry of Health and NGOs receiving funds for HIV treatment activities were encouraging such support groups. In 2006 NETS received funds from Action Aid, a UK-based charity, for the support of “widows and orphans”, and began to channel these resources to the members of the group, providing them with a weekly lunch as well as occasional food baskets. Action Aid also provided funds to support children in secondary school and the youth group members worked as volunteers in connecting these funds with vulnerable families, particularly the families of the mainly women who attended the support group. Group membership flourished, as news spread that NGOs were providing “people living with HIV/AIDS” with material support, and some individuals who had discovered their HIV status and were struggling to survive economically became members. NETS’s patient support group became very popular until, according to its leader, she had to insist that members brought their clinic cards with them to weekly meetings to give evidence of their HIV status. NETS itself was thriving in the midst of this activity as Action Aid also began to provide financial support for some of the youth volunteers as well as some of the patient support group members to attend training workshops run by other NGOs in the city on issues such as HIV counselling and prevention work.

However, in 2008 this funding came to an abrupt stop, for reasons that remain obscure to the NETS members I talked to. NETS members found they could no longer channel support for school uniforms and fees to support group members, and the cooked lunches and food parcels dried up. As resources to support NETS volunteers also dried up, they also drifted to other organizations and activities, and the meeting house went from being full of enthusiastic youth, to being a place where people just hung out without having much to do. For some months, some members were recruited as volunteers for a World Vision project that sent them to conduct questionnaires on “psychological stress” in the surrounding mostly poor neighbourhoods – but they received little remuneration for this and became quite disillusioned. As for the patient support group for the HIV-positive, membership gradually declined, as members pursued their connections to other, more successful patient support groups in the city. Most of the members were single HIV-positive women who had already given birth and were either widows or separated from their husbands. They lived in single rooms without water or electricity hastily

erected by landlords and rented for around 500 shillings per month, and they survived by selling vegetables or making and selling fried foods in the neighbourhood. While the patient support group had been imagined as a “speaking therapy” (see Nguyen 2011), once members found that simply talking about their problems did not bring them an income, there was little enthusiasm for continuing. Meetings did continue – members “shared” their worries about feeding families, teenage children, school fees and income and medical expenses, as well as side-effects of anti-retroviral therapy, but I noticed that these “sharing” sessions seemed to have been stimulated by my own interest in the group (and to expectations that I had access to NGOs).

The decline in the fortunes of NETS’s support group reflected a trend in access to resources for “PLWHA” (Persons Living with HIV and AIDS) in Kisumu. In the first half of the 2000s NGOs working with the government tried to encourage people living with the virus to “speak out” and “witness”, often through providing material support to such groups – sacks of flour, mobile phones, and credit – taking members for “training” seminars in HIV-related skills, and giving them loans for “income-generating activities”. However, as “speaking out” became more widespread, and support group membership rose, resources dwindled and competition for those resources available increased. Funds were no longer given to patient support groups; instead these groups, like other “community-based” groups in the city, were encouraged to submit proposals to the NACC (National AIDS Control Council) funding rounds for “Community-based” response to HIV/AIDS (through which NACC distributed funds received from PEPFAR for such purposes). NETS’s patient support group had already, by 2008, gone through a serious crisis, as the first members who benefited from the resources and opportunities available were accused by others of “eating” funds. Membership broke up, as the pioneers landed work as HIV counsellors for NGOs or invested their windfalls into small businesses such as vegetable stalls or even a small shop. Thus by 2008, those left were people, mostly women, who were relatively new to the group and who had few other options. Their leader herself was struggling to make an income and spent much of her time developing relationships with other NGOs through “volunteering”. Although she tried to interest micro-credit organizations in the fortunes of the group – meeting the director of one of these micro-credit banks, these initiatives never took off because the group members could not raise adequate funds as a down-payment for opening a bank account, and thus were not judged to be reliable enough.

As the fortunes of NETS’s support group declined in 2008-9, those of other groups in the city rose. “Lets Pull Together” was one of several patient support groups attached to a thriving HIV clinic that was run by the Catholic NGO but financed by PEPFAR funds channelled through an NGO set up by a US University.



The rising fortunes of “Lets Pull Together” give us insight into the qualities and capacities that determined success in an increasingly competitive funding environment. This group, which was also founded in 2006, had received a few thousand shillings from the Catholic NGO to register itself as a community-based group and thus had a bank account. Like most other groups in the city, it had a tight bureaucratic structure: a chairman (who led the meetings), a secretary (who took minutes) and a treasurer (who kept account of its finances). They were well-educated – all had secondary education and one was a teacher. It was quite unusual for patient support members to come from the “working classes” (those with salaries), as such people often tried to hide their HIV status, nor did they need the material support that poorer members hoped for. However, in this case, all three leaders were very keen to do something about the problems they could see all around them and through the course of several group meetings they decided that their efforts should focus on providing support to families with orphans. Providing support to “orphans” was what group members were doing anyway, as aunts and uncles or grandmothers. Many of the group’s members were supporting the children of deceased relatives, and quite a few of these children were, it was surmised, HIV positive. After attending a meeting coordinated by the National AIDS Control Council, in which CBOs were invited to submit proposals for what are known as “income generating activities” and for activities targeting those “affected and infected by HIV”, the treasurer suggested that the group use some of its funds to hire a proposal-writer for 3,000 shillings, to write the proposal for them.

“Lets Pull Together” was successful in its funding application, and received, I was told, about 50,000 shillings (ca. US\$ 800 at the time) to allow “vulnerable” families to set up income-generating activities – (mostly providing women with some capital to start up small fish or vegetable selling business) as well as to buy school uniforms and materials. Other groups whose leaders were not as articulate and computer-savvy, or who were not as well-connected with the NGOs and government officials who hold “stakeholder meetings” were not successful in their bids for funding. The case underlines how, 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. 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). This expertise is both generated and sought after by NGOs<sup>8)</sup>, and pursued by individuals who need to learn the particular language and material culture of development.

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. 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).

#### **4. Humanitarian Economies and HIV Identities**

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. Robbins 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. Meinert, Mogensen and Twebaze (2009) have argued that new medical technologies such as CD4 counts are being used by people in Uganda to connect fluctuations in their immune status with wellbeing and in doing so both comment upon and make claims on material support of husbands, brothers and other family members. The material presented here underlines that HIV-positive identities are also allowing people to make themselves visible to NGOs and to make claims on the flow of resources that target “patient support groups” and CBOs. 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.<sup>9)</sup>

The picture presented here is of a public sphere of group making and claim making that is heavily bureaucratised and accountable upwards, to donors, rather than downwards, to the needs of the grassroots. It is also heavily competitive: some groups and some individuals are more successful than others in securing funding or becoming leaders. This paints a rather different view of “civil society” than that imagined by donors funding NGOs. Yet it does not mean there is a lack of accountability. Group leaders are accountable to the group members, although not always in ways imagined by funders. This is because groups are not imagined as collectives of individual members in equal relationships, but as hierarchical

organizations in which leaders may benefit most, but are also under certain obligations to their followers. This hierarchy is acceptable, even sought after, because it is enacted within a framework of responsibilities and hence, of obligations and claims (see Englund 2011). Of course there is also a potential for exploitation, as leaders are in a position to make off with resources or favour their own family members and friends. Yet, if that does occur, people also vote with their feet, leave the group and join another. The constant fusion and fission of groups that I observed in Kisumu would seem to emerge out of these kind of dynamic.

## **5. Connecting-up Care: the Role of Community Health Workers**

In this section, I explore further the role of middle figures or ‘street level bureaucrats’, such as community health workers and volunteers, and their work of connecting clinics to people who belong to what is often referred to as ‘the community’. I follow, in particular, the figure of Ochieng’ and his everyday labour of traversing the city’s informal settlements, visiting HIV-positive individuals and families to check on their medical routiness, find out more about their living situations, and bring them (back) to the clinic.

In 2009, I spent some months accompanying Ochieng’, a community health worker and volunteer who was attached to one of the new clinics – known as ‘Patient Support Centers’ – that provided the free treatment alongside HIV tests, CD4 counts, and regular checkups to HIV-positive individuals. The clinic, funded by US PEPFAR through an American NGO established in Kenya to oversee the distribution of funds alongside capacity training, was located in a Catholic NGO, itself established in 1978 by a priest, and well-regarded by residents in the city for its work on health-care and poverty-alleviation. The Catholic NGO had long provided a clinic serving one of the city’s largest informal settlements and offering malaria tests and subsidized medicines. It was headed by a nurse who was paid by the government. This older clinic still operated out of a set of small rooms, some given to HIV counselors, while the much larger community hall had been given over to the ‘patient support centre’ set up in 2007.

One day in April 2010, I meet Ochieng’ at his house in one of the informal settlements and we set out on bicycles in a new direction, towards the lake and an informal settlement inhabited by men and women involved in what is left of local fishing industry by the export orientated Nile perch industry. It’s a poor area. The houses have been hastily constructed by landlords and are badly made, single-rooms rented to young men and women and their families. In one of these Ochieng’ introduces me to a young HIV positive mother, a client of the Catholic NGO’s ART programme, who has not turned up to her last two clinic

appointments. He explains her situation to me as we cycled over: her husband, the father of her last child, is a fisherman, but he has paid no bridewealth and is often away on fishing trips elsewhere on the lake. She struggles to make a living by buying omena (small protein-rich fish not used for export) in small amounts and selling them at the roadside. “Her situation is bad”, he says, “usually there is no milk for the children, usually they just drink strongi (black tea sweetened with sugar, if available) in the morning. And there is the problem of disclosure: she feels she cannot tell her husband about her status, so where, then is she to keep her medicine? I try to encourage her, but...” We knock gently at the door and are invited in. Ochieng’ talks gently about her situation and the importance of taking her medicine. She points to the children, the empty table. Our cycle ride has enabled Ochieng’ to save the transport money he is given by the clinic, and he leaves her 50 shillings to buy milk.

We move on, to a small house owned by a local businessman, solidly built, where we visit a young man, nephew of the house owner, who also began taking ART but did not appear at his last clinic appointment. He is lying on the sofa with a swollen leg. No-one else is at home. Ochieng’ asks the young man why he has not been coming to the clinic. “The medicine does not help me”, he replied, “look at my leg”. Instead he travelled back home, to get herbal medicine. “This one has defaulted”, Ochieng’ explained, “he does not accept care. But I will come back to see him”.

As a Community Health Worker, Ochieng’'s time was divided between three mornings a week, during which he conducted ‘adherence classes’, teaching people who were to be started on ART how to take the drugs, how to live positively, and eat a balanced diet, and the afternoons during which he visit people in ‘the community’ as he liked to call it, who were ‘clients’ but were facing problems with taking the medicine. During the mornings then, he tried to enroll people as new therapeutic clients, to embrace therapeutic and clinical regimes, while in the afternoons he attended to those who had difficulties conforming to or following these regimes. His manner during these visits was kind, attentive and polite.

Over time, I came to understand these visits as enacting a topography of care and connection, which extended beyond the clinic’s injunction to embrace HIV identities and positive living. The biographies and labour of community health workers and volunteers like Ochieng’ were crucial in extending these topographies of care. As a resident of one of the city’s informal settlements himself, with his own four children plus those of his relatives to take care of, Ochieng’ was attuned to the complexities of live on ART, complexities that extended far beyond medical regimes and involved relationships with intimate others, spouses, siblings, children, and other relatives. Walking through the city, connecting the clinic to these households, Ochieng’ was making these lives visible and identifying needs, thereby

enacting and asserting the clinic's responsibility for them.

Attending to this work of connection is important, because it makes visible firstly, the inter-subjectivity of care (care is relational), and secondly, the question of temporality. Alongside the 'positive living' model and rhetoric with its focus on individual empowerment through new regimes of knowledge and treatment and self-care, lies another, no less powerful injunction: care through connection and the importance of recognition. While Ochieng's adherence classes attend to the first model, but his work in the community is about the second. What people most desired in relation to the HIV clinics was a connection. To be seen and counted. One way of doing this was through the language of needs.

The question of temporality is more complex. Scholars, including myself, have observed how global health initiatives, including ART programmes, create islands of intervention, resource and care in sea of neglected public-health care. These islands are appreciated – as here, the HIV-positive at least, are offered treatment, and care. Not only are these programmes spatially fragmented. Their futures are also deeply uncertain, linked as they are to cycles of donor funding and concerns about sustainability, while being rolled out in a landscape of uncertain relations between donors, NGOs and government.

In their work on ART programmes and their roll out during the first decade of the 21<sup>st</sup> century, Susan Whyte and her colleagues show that, while ART is accessed in a landscape that is described as deeply 'projectified', at the same time, staff and patients work to anchor the provision of ART in social relationships that can reflect and extent institutional presence. Whyte and colleagues's notion of 'therapeutic clientship' powerfully draws attention to relationships of exchange, transaction, obligation and responsibility that characterize care, from the point of view of the patient (Whyte 2014). Here, connections and care are made more robust through specific personal relationships between providers (staff members or volunteers) and clients, and through institutional forms of patronage and clientage, in which the relationship between provider and user is articulated as a transaction involving mutual obligation and responsibility. Challenging accounts that focus on disciplining aspects of new clinical regime, their account underlines that people appreciate the forms of care offered by HIV clinics/ART programmes, as they offer a form of recognition and ongoing connection, of being cared for and counted in a health-care landscape characterized by neglect, poor access to health-care, low quality, and often costly forms of public-health care provision.

My material suggests that clinic staff, including community health workers and other volunteers, strive for these social continuities of care. Volunteers like Ochieng' strive for continuity of care, the extension and endurance, or durability of care, across space but also through time. This point becomes clearer if we turn to Ochieng's biography, and the way in which he connects the space of the clinic to

that of the community through his social networks and personal biography. Before he began working as a CHW with the Catholic NGO, Ochieng' had spent over 5 years as a volunteer HIV counselor attached to the hospital's maternal health programme. Through these activities he became known as a person with connections, who can connect others to forms of care. It is notable that in his account of this time, he was hoping not only to gain a livelihood and provide for his family, by combining volunteer work with petty trade, but also to gain a connection to a more stable institution, to something larger, and not only to be part of what we could call 'development' or 'progress', but to also make a contribution to it. His current position enables him to solidify and extend this position, and, as I came to appreciate during our walks through the city, his social networks were extensive. While specific intervention and projects may "come and go", then, volunteers and community health workers like Ochieng' struggle to make connections between them, to maintain and extend practices of care and recognition. The irony of course, is that such attempts to connect-up fragmented nodes of care and support comes up against the limitations of this model of health-care and welfare provision. Ochieng's struggles to extend care meet the limitations of a model of care that distributes scarce resources through a form of triage that relies on demonstration of need.

## 6. Discussion

Much of the work on ART programmes – clients, expert clients – explores the new forms of identity and sociality that accompany extension of the 'confessional technologies' of positive living and free antiretroviral treatment around the globe, as individuals sought to orientate their selves around new biomedical technologies and rationalities (e.g. Nguyen 2011; Mattes 2011). While observing the clinic's injunction to 'live positively and the transformations of subjectivity associated with being HIV positive, recent anthropological work cautions that these identities must be constantly strived for and that their performance may be situated and specific (which does not make them any less real or authentic) (Marsland 2012; Qureshi 2014). In this paper I have explored the various registers through which people relate to the HIV clinics and ART regimes of care – showing that registers of therapeutic empowerment were often subsumed to registers of dependence, transaction and obligation within specific relationships of care and connection.

It has also been observed that ART – alongside global health and development projects – produces collectivities. Vinh-Kim Nguyen (2011), describes the struggles of west African HIV-positive people for access to therapy in the years before free ART programmes in terms of therapeutic citizenship – claims made according to biological (HIV) status concerning access to and rights to medicine, and the forms

of triage resulting in the selection of worthy recipients, at a time when ART was difficult to access in west Africa. While his work emphasized triage and inequality surrounding access to ART, Susan Whyte and colleagues (2014) describe a different kind of vernacularization of ART programmes in Uganda. In the years after ART prices fell and free ART programmes were rolled-out, Ugandans pursued a model of ‘therapeutic clientship’. By following lives of people on ART from different walks of life in Uganda, this work is closely attuned to ways in which Ugandans mediated and negotiated ongoing access to ART.

The pursuit of clientship suggests that being a dependent is socially valued as it positions one within forms of hierarchical obligation and responsibility. Demonstrating one’s needs opens up a path through which to pursue opportunities. These are enacted through relationships cultivated with (more powerful) others. Community health workers and volunteers, like Ochieng’, do not only enroll the HIV positive in regimes of the clinic. By extending networks of those in ‘need’, they also struggle to mobilize organizations and their projects to recognize obligation, and thus to extend forms of recognition and connection.

Still, these struggles over extending recognition and care exist in ambiguous relations with other models – dominant in global health and HIV/AIDS projects – of sustainability, self-reliance, autonomy and entrepreneurship (see Scherz 2014). Rather than ignoring them people like Ochieng’ must position themselves in relation to them. This material suggests that individuals may occupy several identities and subject positions simultaneously, and that they seek to implicate themselves in others’ projects, to better make claims and enact obligations (see Shipton 2007). By following the articulation of needs, we begin to appreciate the multiple, coexisting, contradictory values surrounding personhood, morality, exchange that people living in Kisumu had to contend with, and navigate, and the multiple ethico-moral imperatives, frameworks and schemes that people must orientate themselves towards, both within the biomedical clinic, and beyond it.

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## Notes

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- 2) This resonates with Harri Englund's recent work (2011) on radio programmes and human rights in Malawi, in which he argues that Malawians are more concerned with making claims and acting upon obligations in the sphere of already existing webs of relationships – often personal ones – than with the more abstract discourses of human rights.
- 3) 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.
- 4) US funding has dominated these projects; Since 2004, USAID, which already had a large presence in Kenya (see Hearn 1998), has worked closely with the US PEPFAR fund on HIV-interventions, while the Global Fund and the Gates fund, as well as the Clinton Foundation and well-known international NGOs such as Care and Action Aid, are present.
- 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 (Internet, 25th July 2017, UNICEF: [http://www.unicef.org/infobycountry/kenya\\_statistics.html](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 Internet, 25th July 2017, <http://www.unaids.org/en/CountryResponses/Countries/kenya.asp>. By September 2009, almost 300,000 people 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> (Internet, 25th July 2017), and the PEPFAR website <http://www.pepfar.gov/countries/kenya/index.htm> (Internet, 25th July 2017)
- 6) See the 2007-8 report by the NGOs Coordination Board (set up by the government in 1990): Internet, 25th July 2017, <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. See also Internet, 25th July 2017, <http://www.kanco.org/KANCOMembers.php> which lists NGOs working in western Kenya.
- 7) Pseudonyms are used.
- 8) People learn such skills through training workshops and seminars, organized mostly by NGOs.
- 9) Although a pilot study by UNICEF in Kiusmu introducing cash transfers to 'vulnerable families' has recently been introduced.



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