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## When families fail: shifting expectations of care among people living with HIV in Nairobi, Kenya

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The availability of free antiretroviral treatment in public health facilities since 2004 has contributed to the increasing biomedicalization of AIDS care in Kenya. This has been accompanied by a reduction of funding for community-based care and support organizations since the 2008 global economic crisis and a consequent donor divestment from HIV projects in Africa. This paper explores the ways that HIV interventions, including support groups, home-based care and antiretroviral treatments have shaped expectations regarding relations of care in the low-income area of Kibera in Nairobi, Kenya, over the last decade. Findings are based on 20 months of ethnographic research conducted in Nairobi between January 2011 and August 2013. By focusing on three eras of HIV treatment – pre-treatment, treatment scale-up, and post-crisis – the authors illustrate how family and community-based care have changed with shifts in funding. Many support groups that previously provided HIV care in Kibera, where the state is largely absent and family networks are thin, have been forced to cut services. Large-scale HIV treatment programmes may allow the urban poor in Nairobi to survive, but they are unlikely to thrive. Many care needs continue to go unmet in the age of treatment, and many economically marginal people who had found work in care-oriented community-based organizations now find themselves jobless or engaged in work not related to HIV.

**Keywords:** HIV/AIDS; care; community-based organizations; social support; Kenya

### Introduction

On Wednesday, 12 May 2012, in Nairobi's notorious Kibera neighbourhood, 11 people gathered for their first support group at HAKI, a community-based organization (CBO). Closely following a programme pioneered by Médecins Sans Frontières (MSF-Belgium) in Kibera in 2002,<sup>1</sup> the treatment literacy training sponsored by HAKI is meant to educate and empower community members who have recently begun antiretroviral treatment. Having completed a training the week before, these four women and seven men – following a script that has become routine in HIV support groups worldwide – shared their experiences of HIV, including fears of death, experiences with stigma, difficulties with disclosure and with taking medication, and expectations and disappointments with social support. Twenty-seven-year-old Jacob's story was both typical and compelling:

When I came to Nairobi in 2003, I only knew my cousin who lived in Kibera. He took me in and when I got a job we decided to live together and share rent. We were casual workers in the industrial area and were paid our wages weekly. We were very close . . . we lived together,

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socialized and enjoyed life...we did almost everything together. Things dramatically changed in 2011 when I started getting ill and could not work. As a casual worker you are paid when you work. This meant I did not have money. My cousin changed. He started not coming home on Fridays when he was paid and only came home when he had no money... he would disappear, abandoning me in the house for two or even three weeks. I suffered... I had no food and no one to care for me. I thought I would die.

Fortunately a neighbour heard about me and brought me food and water. My cousin came back one day and told this neighbour to raise bus fare to send me back to my rural home. Instead, my neighbour – a married woman with children! who is not my relative! – took me in. She told me I would die if I went home, but that she would take me to MSF for treatment and that, as long as I committed to taking medicines, I would live. I lived in her house for two months. She cleaned me, washed my clothes, gave me food and ensured I took my medicines. HAKI staff heard about my case; they visited, brought food and encouraged me.

My cousin never came to visit... I never heard from him during the time I lived with my neighbour... After two months my health improved greatly. I went back to where I lived with my cousin. He was shocked to see me. Since I was not strong enough to look for work, I told him that I should not go hungry... that he should buy me food. Still, he would disappear on Fridays and only come back when he did not have money. He even stopped paying rent. When I confronted him, he responded, 'Your HIV has made you so harsh... I am not the one who gave you HIV'.

Jacob's story points to several aspects characteristic of the last decade in Kenya, a country that has witnessed a rapid turnaround with regard to HIV/AIDS. Antiretroviral treatment has become widely available and, especially for those living in cities, the possibility of living a relatively healthy life after an HIV diagnosis has become imaginable. Simultaneously, however, access to reliable and ongoing care has become more challenging in the age of treatment, as resources to fight the disease are channelled into programmes that provide medication rather than care.

This paper examines the ways HIV and the availability of HIV treatment have altered the terrain of care for people with HIV and AIDS in Kibera, one of the poorest neighbourhoods in Nairobi, Kenya. 'Care' here is defined in relation to antiretroviral treatment, the biomedical response of choice routinely provided by both donors and the Kenyan state to people with HIV in Nairobi. Unlike biomedical treatments, which target the virus, HIV care encompasses the physical, emotional, social and economic needs of people infected with HIV, which generally exceed the efficacy of biomedical treatment. Care thus defined – in Africa as elsewhere – is rarely offered by the state. Instead, care is something that is done by family, friends, occasionally the wider community and, increasingly, the self; the act of caring is often what defines people as friends and family. In the case of HIV, such care has also been done by people working or volunteering for non-governmental organizations (NGOs), including church groups, social support groups and other community-based entities. Some, like burial societies and saving associations, emerged prior to HIV, offering ways for people to unite and provide support in times of need. Others, like home-based care (HBC) programmes, HIV support groups and post-test clubs, emerged in response to the care needs of people with AIDS that were not being met by existing, often overburdened, social institutions, including the public health system and the family.

It is not unusual to hear stories such as Jacob's, in which family members disappear when they suspect or learn of a relative's HIV status to avoid offering care, economic help or emotional support. Providing care and support to someone with HIV can be challenging for family members, especially when the person is extremely sick. It requires

physically tending to individuals who may not be able to bathe or feed themselves, and reassuring them that there is no shame in not being able to control one's bowels. As De Klerk (2011) has eloquently argued, there is a physicality to care that often goes unrecognized, requiring family members who may be old, undernourished, overworked or otherwise overburdened to lift, carry and clean loved ones (Geissler and Prince 2010). The task is also often emotionally taxing, requiring caretakers to stare death in the face while providing support to a loved one who may have brought shame on the family (Dilger 2006, 2008). It can also be financially devastating, especially if more than one family member is sick or if the sick family member has dependents that require support.

Despite such challenges, many who experience HIV-related sickness or social challenges expect their families to care for them. Jacob believed it was his cousin's duty to care for him in the absence of other family members, and expressed shock that a neighbour who was not his kin would volunteer to care for him. Aside from familial duty, Jacob and his cousin had a close friendship, which Jacob expected would yield some benefit in a time of need. It was unsettling to him that the care he thought was his right should be denied.

Fortunately for Jacob, Kibera is densely populated and there is little privacy, meaning neighbours know what goes on in each other's homes. It is typical that the person who cared for him was a woman and not unusual that she was somewhat knowledgeable about HIV and HIV care. As a resident of Kibera, chances are she had been personally touched by the disease, perhaps had provided care to someone in the past and felt it was her moral duty to care for Jacob when his family failed him. In addition to this neighbourly support, Jacob received regular visits from HAKI's HBC team, which provided emotional and material support in the form of food, and he received treatment from MSF. When his family failed him, these members of the Kibera community stepped in, linking him to the nearby MSF facility where he could get treatment and providing sufficient emotional and material support for him to regain his health.

### The 'right' to care

The moral outrage Jacob expressed in his story about his family's failure to care was similar to stories heard in many support groups in Nairobi; underlying such stories is the assumption that the burden of care and support for the sick should fall on immediate family and extended kin networks. Such stories work to perpetuate societal norms regarding the expectation of family care, while providing a means through which people with HIV can reassert their humanity and their right to be cared for by kin.

Anthropological research in many African settings has demonstrated that despite the commonality of such norms, families often do fall short, particularly when it comes to providing care for people with HIV.<sup>2</sup> Such failures are often moralized; before the era of treatment in Tanzania, family members in rural areas often defended themselves against claims that they did not care enough for those dying of AIDS by blaming their kin, especially urban migrants and women, for their sickness (Setel 1999; Dilger 2006, 2008). Even after treatment became the norm, Mattes's (2012) research showed that moralizing blame continued to be used to justify poor care within families.

Whereas invoking morality to justify the failure to care has been well documented in the case of HIV in Africa and beyond, much less attention has been paid to the ways that people with HIV make moral claims upon the family to provide care. Both Moyer (2012) in Zanzibar, and De Klerk (2013) in Kagera, have demonstrated how failing to care and stigmatizing those with HIV has been figured as uncivilized and immoral in Tanzania.

Moyer has also demonstrated how HIV-positive activists can ‘flip’ the discourse of blame to demand better care and challenge discrimination from family and community members. Although one might argue such claims can be traced to the emergence of activist identities, the commonness of such claims among participants in this study suggests that the phenomenon extends beyond the biosocial space of HIV activism and points to shifts in the ways that HIV is being re-moralized within family contexts in Kenya in the age of treatment.

Writing prior to the emergence of HIV, Vaughan (1983) questioned anthropological and historical constructs of the family in Africa. The ‘African family,’ often idealized and moralized in informants’ normative accounts of everyday life, is easily reified by research that fails to attend to the ways that family relationships and transactions shift over time and across place. To understand the ways kinship and kinship expectations are defined in context, Vaughan suggests that researchers approach the subject ‘sideways’ and examine non-familiar relations. By examining the failure of family-based HIV-care relations and the ways that community-based organizations have become entangled in family relations, this paper attempts to provide some insight into the ways that care is being redefined and re-moralized in the context of HIV treatment, as well as the ways that kinship is being redefined in the context of HIV care.

### **Methodology**

This paper draws on 20 months of ethnographic research on HIV care and support groups in Nairobi, Kenya, conducted between January 2011 and August 2012. Although research was conducted in diverse localities within the city, this paper focuses on data collected at Kenyatta National Hospital (henceforth Kenyatta) and in the neighbourhoods of Kibera. The research utilized ethnographic methods, including participant observation in support groups, interviewing, informal conversations, focus group discussions (FGDs) and ‘walking sessions’. Walking sessions were an organic continuation of the Kenyatta support group sessions, taking place when the second author walked with group members from the hospital to downtown Nairobi where they boarded their buses home. These sessions lasted approximately 45 minutes and focused on what had transpired in the support group; they provided insight into members’ perceptions of the groups and background information about members, including their relations with family members. Follow-up interviews and observations were conducted with some group members in their homes, and numerous informal conversations were held with support group members on the telephone.

Twenty-nine formal interviews were held with participants purposively sampled from support groups (18 from Kenyatta, 11 from Kibera). Six FGDs were conducted: two with support group members from Kenyatta, two with HIV-positive support group members in Kibera, and two with Kibera community members whose HIV status was either negative or unknown and who had lived in Kibera prior to 1984, when the first HIV case was announced in Kenya. Interviews were conducted in Kiswahili or English.

### **Shifting configurations of care**

The responses of families, as well as community and health facility-based support groups, to HIV have been shaped by historically shifting conditions in Kenya, including new medical technologies, international aid, the national response to HIV and the extent to which rights and dignity have been ascribed to HIV-positive individuals. Whereas

antiretroviral treatment has dramatically reduced the care burden on the one hand and helped to conceal it on the other, social technologies such as support groups, treatment literacy training and HIV activism have heightened the expectations of people living with HIV and AIDS for care from the state, their communities and, importantly, their families.

In Nairobi, shifting expectations for care have also taken place within a broader context of steady urbanization, growing inequality, the increasing nuclearization of families and a growing number of women in the workplace. Whereas this broader context has limited the extent to which urban households – particularly women struggling to balance work and family obligations on tight domestic budgets – can provide care for chronically ill family members, shifts in the way HIV has been framed by national, international and local responses have contributed to the way that care in the home has been valued, both economically and morally.

In the early part of this century, when the Kenyan government began taking HIV seriously, the state, as well as international donors, recognized the need to strengthen care and social support for those infected with HIV. In the absence of reliable kin-based care in the cities, a move was made to reorganize support away from families to community-based programmes in the form of HBC and HIV support groups. Institutionalized social support, organized through NGOs and health facilities, became the norm in the era of treatment. As the positive effects of treatment began to be seen, the need for palliative care reduced drastically, and peer-to-peer support groups began filling gaps in social support (Brashers, Neidig, and Goldsmith 2004; Heyer et al. 2010).

Kibera, where most of the research for the paper was conducted, is an ‘informal’ neighbourhood and does not officially exist in the policy world. As such, the Kenyan state does not provide public services, including health services, to the approximately one million people living there. Residents, however, have fairly easy access to some of the best public health care in Kenya because Kibera is only five kilometres from Nairobi’s centre and both Kenyatta and the Mbagathi district hospital are only a short walk away. Although the hospitals are run by the state, they rely heavily on funding from international donors. Kibera’s health needs are further served by a complex network of NGOs, the best of which – including MSF and HAKI – are physically based in Kibera. The ‘NGO-ization’ of Kenya has affected all health services (Hearn 1998), but the effect has been most visible in the context of HIV-related health issues. Even by Kenyan standards, Kibera offers an extreme case of NGO-ization, in part due to the lack of formal public services in the area, but also because of its location and the ease with which it is reached by the donor community.

### **Provisional responses in precarious contexts**

Following Geissler’s (2014) imagination of public health landscapes in Africa, Kibera should be considered the ‘big island’ in Nairobi’s public health archipelago. With a few exceptions, the HIV services in Kibera have been offered in a patchwork and time-limited manner. For Kibera residents, the provisional and precarious nature of HIV services mimic the provisionality and precarity of daily existence. In such environments it is common to witness ‘flexible configurations’ of what Simone (2004, 5) has called ‘deterritorialized frameworks of social reproduction and political identity’.

The CBO HAKI is one such configuration in that its flexibility has allowed it to survive despite precarious and provisional funding. Founded in 2002 as a self-help, micro-finance group of 25 individuals Kibera to gain financing from the Kenya Rural Enterprise Program for petty business, HAKI has evolved over its 12-year history to meet the needs

of its steadily growing membership, all the while depending minimally on donor support. Under the business-like leadership of Charles Ogutu, HAKI officially became a CBO in 2005 with the explicit aim of fostering economic empowerment among the group's HIV-positive membership, as well as seeking ways to finance the organization's home-based care, legal aid and orphan care programmes.

Research for this paper was conducted in multiple care-oriented organizations in Kibera, but HAKI stood out for its success. At a time when many other organizations were collapsing due to a lack of donor funding, HAKI remained a strong community presence. Like many other HIV-related organizations in Kibera, HAKI had blossomed during the early years of the treatment era (2004–2009) when donors favoured CBOs with generous grants intended to fill gaps in what was seen as an overburdened health care system. But unlike most CBOs, HAKI continues to address the needs of its membership. This is mainly because the leadership is continually seeking ways to become self-sustaining through investment in small businesses and even property in Kibera. They recognize that it is not enough to generate income for their membership; the organization must have sufficient income to operate as well. Although donations and occasional project money do sometimes swell HAKI's coffers, the business model for the organization does not rely on precarious aid.

The remaining three sections of this paper examine configurations of HIV care in Kibera in three eras using HAKI as a lens: pre-treatment, treatment expansion ('scale-up'), and what the authors refer to as 'the wake of the crisis'. This periodization approach provides insight into the ways that care needs, expectations of who should provide care, and ideas about how those providing care should be compensated have shifted over time.

### Care and support in the city prior to antiretroviral treatment

In FGDs on care before and during the early years of HIV, most agreed that family and kin had been responsible for caring for the sick, and that families usually managed to meet their obligations. Although such sentiments were most likely shaped by an idealization of the past and conflation with rural norms, there were enough detailed examples of good care that had been provided by kin in Nairobi to argue that it was the coming of AIDS that made it difficult for families to fulfil care obligations for a range of material, moral and emotional reasons.

Even before HIV, however, prolonged care for the sick in urban homes was expensive and presented challenges, putting a strain on kin networks (Iliffe 2006). In urban homes, most family members worked or were seeking work, meaning outside help was needed for care tasks, such as feeding patients, ensuring medicines were taken and accompanying patients on follow-up hospital visits. Unlike family-based care, which was presumed to be obligatory, even if mutually so, outside care incurred a debt (Seeley 2014). Some neighbours helped one another with the expectation of later reciprocity; others expected to be paid. Outside help also had its limits. People the authors interviewed agreed that there were some intimate tasks you could not ask neighbours to perform and, further, that neighbours were to be called upon only for temporary crises such as funerals and acute illnesses, but not long-term care.

Given the limited extent to which urban residents could offer or expect family-based care, it was not uncommon for people to rely on rural-based health facilities and extended families for care and support in times of prolonged illnesses. Even in the present day, urban dwellers state that maintaining links with rural relatives is important because of the care they may be able to provide in the event of prolonged illnesses. Interviewees also

reported that rural hospitals are cheaper and using them makes it more convenient to involve rural kin in long-term care, allowing urban dwellers to provide monetary and emotional support. Relatives also routinely sent urban kin to rural areas when they were suspected to be suffering from a condition best treated by traditional medicines, or to save the cost of transporting a body home for burial when death seemed imminent.

Caring for any sick relative with a prolonged illness is difficult in Nairobi, but caring for relatives with HIV presents additional challenges. If left untreated, HIV leads to a painful, messy death, and requires around-the-clock nursing. In the pre-treatment era, people in Kibera abandoned bedridden relatives in their homes or at health facilities like Kenyatta. While the breakdown in family care and support can be explained partly by the care burden the disease brought, many participants also observed that faltering social support was due to ignorance and fear about HIV:

Before they knew what the cause of the disease was, they were very concerned and would look after the person and try to find out what was the problem. But when it was discovered you were HIV positive, they knew you were dying, no treatment, they just abandoned you or took you to a rural home to die there. (FGD, HIV-positive woman)

The truth is there was a time when people were very sick; they had prolonged diarrhoea till they were finished. People were very scared of them, feared them; family members would abandon them and neighbours just came to look at them from afar, they would not touch them. It took a Good Samaritan to tend them; sometimes they used to die in the houses. (FGD, HIV-negative woman)

As the burden of HIV grew and more families failed to cope, care and support began to be offered to the bedridden through HBC services provided by local churches, NGOs and CBOs:

There were those [sick people] who were alone in the houses . . . . We had some people from the Catholic Church who used to come to bathe them, clean their houses and wash their clothes, cook for and feed them, even cook for the children, and give them medicines. (FGD, HIV-positive woman)

Similar to what Simbaya and Moyer (2013) have argued with regard to Zambia, community-based responses during the pre-treatment era in Kenya were often motivated by pragmatism, a sense of charity and moral obligation. In Kenya, most of those who provided care and support through HBC programmes in the pre-treatment days did so for little or no remuneration and received little training. It was only in the era of HIV treatment scale-up – and the accompanying influx of international aid – that community-based care and support began to receive considerable sponsorship from international donors (Wringe et al. 2010).

### **Care and support in the age antiretroviral treatment and *msaada***

Similar to other countries in Africa, free antiretroviral treatment first began to be provided in public health facilities in 2003 in Kenya. By 2004, programmes were expanding rapidly, and those most in need found it relatively easy to access treatment in Kibera. At the time, public health experts were concerned about adherence, worrying that without proper support, people would fail to take their medicines as prescribed, inviting treatment failure and viral mutations that would defeat the available medications. Defining and delivering

adequate social support to those on treatment became a key objective of both state-coordinated treatment programmes and the donors investing in treatment.

There was agreement among state hospitals and donors that patients should receive adherence counselling and that those from lower socioeconomic backgrounds would require material support to ensure adequate nutrition. Whereas the upper and middle classes of Nairobi, who typically accessed treatment through private health facilities, received basic and usually one-off adherence counselling, those who attended public facilities such as Kenyatta were subjected to multiple rounds of adherence counselling and strongly encouraged to join one of the hospital's health-worker facilitated support groups (cf. Mattes 2011). Those who sought treatment at the Kibera-based MSF programme benefited from a week-long training course in treatment literacy, based on models developed by treatment activists living in Western countries, that provided participants with extensive information about their disease, treatment and what was called, 'living positively', a package of lifestyle advice designed to deliver optimal health through eating well, exercising, avoiding alcohol, tobacco and other intoxicants, and practising safe sex. As with Kenyatta, MSF clients were also encouraged to join support groups.

Following the MSF model, many CBOs in Kibera began sponsoring support groups for the people living in their immediate environs.<sup>3</sup> In this way, small NGOs and CBOs in Kibera emerged as key players in the era of treatment scale-up, offering spaces where those beginning treatment could gather to share their experiences and garner emotional support; importantly, they also became a means through which much-needed material support could be delivered to what is commonly referred to as 'the largest slum in Africa'. The relationship between international aid organizations and Kibera-based NGOs and CBOs benefited both sides: donors were in need of a public to help and suitable partners to deliver the aid, and the NGOs and CBOs needed capital to operate and expand.

According to study participants from Kibera, the coinciding of free treatment with material support reinforced beliefs that CBOs and health facilities, rather than families, should serve as the most important source of social support. In many ways, the very word 'support' came to be equated with material rather than emotional support during this period in Kibera, and most often was translated in Kiswahili as '*msaada*', literally meaning help or assistance, usually of the material kind. One HIV-positive woman in a FGD recalled, 'People came to help us in Kibera. They brought *msaada* . . . food, school uniforms, school fees, money for shopping and rent . . . [T]his *msaada* really helped people who were bedridden to recover.'

People who were sick with HIV and their families looked to NGOs and CBOs for care and practical needs. When HBC helpers arrived in homes, family members would show them to their bedridden relative, often with the phrase: 'Here is *your* person'. One HIV positive woman who worked as a home-based caregiver during that period recalled:

Those bedridden were locked up while family members went to work, or they just refused to offer them nursing care . . . I went to some houses and found the bedridden patient was locked in from the outside . . . had not been washed, had soiled his beddings and vomited on the floor . . . Houses used to stink . . . We used to wash them and clean them. Some NGOs came and would pay us, but we also felt it was our responsibility to do that because most of us had recently been resurrected because of the care we received from other people infected with HIV. Our own family members feared touching us, so if no one came to your assistance you would stay in soiled linen.

People who survived long enough to receive treatment when it became widely available in 2004 commonly used words such as 'resurrected' or 'revived', but they were just

as likely to attribute their salvation to the care given to them by fellow people living with HIV who were working for CBOs as they were to antiretroviral medicines. John, who lived in Kibera at the time, insisted that HBC services revived him. He had been a police officer living with his wife and children, but when his health began to fail, he lost his job, and his wife left him. Some people who were living with HIV and who were working as HBC providers found him, took him for treatment and then visited him daily, washing him, cooking for and feeding him, all the while encouraging him until he 'revived,' at which point he felt morally compelled to join the HBC providers.

There is no doubt that the coming of antiretroviral treatment saved the lives of many in Kibera, and that it reduced the need for palliative care. It did not, however, erase people's need for care and material support as they recovered, nor did it compel relatives to assist HIV-positive people with basic needs while they struggled to regain their health. Especially for the urban poor, HBC and other activities sponsored by CBOs such as HAKI were a vital component of early treatment initiatives, addressing gaping holes in kin-based care networks.

### **Care and support needs in the wake of the crisis**

Around 2009, the crisis mentality that surrounded HIV began to level off in Kenya, as well as among international donors, many of which reduced their expenditures following the 2008 economic crisis. Elsewhere, the authors have argued that the economic crisis in donor countries predicated a shift in discourse regarding the framing of HIV as a crisis (Simbaya and Moyer 2013). Treatment certainly alleviated the worst effects of HIV on individuals, communities and states in Africa, but it hardly brought an end to the HIV crisis. Although treatment was available in public health facilities, and HIV-related morbidity and mortality rates had fallen drastically, people were still dying and public hospitals continued to struggle to adjust to the chronic care needs of people on treatment.

Despite widespread divestment, money for medicines generally continued in the wake of the global economic crisis. Much of the money that had been available for HBC and support groups was linked to international funding initiatives that came to an end. This meant that NGOs and CBOs, which had flourished during the treatment scale-up era because they were able to provide services and goods, had to re-invent themselves in order to appeal to their clients. Unable to offer direct material support, groups that survived redirected their energies to economic empowerment through various income-generating schemes. Many community-based support groups in Kibera stopped meeting during this period, in part because there was no financial incentive for participants, but also because as people got healthier, they needed to look for work. There were still support groups in Kibera that offered psychological support, but they tended to be tied to income-generating activities, or were only open to people who had recently started treatment or were bedridden. The 'crises' – both the advent of HIV and the global economic crash – might have been over, but there were still people in Kibera like Jacob who had been abandoned by their families and in need of care, even if HBC was no longer funded. Nutrition also remained important for the economically marginal residents of Kibera, and NGOs and CBOs continued their work to get available food to those who were most in need.

In May 2012, after a HAKI support group session, Mathews, a newly recruited support group facilitator, received a telephone call from an MSF-Belgium social worker concerning the deteriorating condition of a bedridden HIV patient named Ken. Mathews seemed disturbed as he hung up, saying that the caller had suggested that it would not be

long before Ken's demise. Mathews decided to visit Ken at home, inviting the second author and a social worker to join. An excerpt from the authors' field notes describes what was learned:

We found Ken in his humble six-by-six foot room in Gatwekera Village, a ten-minute walk from HAKI's offices. Mathews opened the closed door when we arrived, calling Ken's name and welcoming us inside. The room was like most in Kibera, with a cement floor, and walls and a roof made from corrugated iron sheets. The space was divided in two by an old, torn bed sheet. In what served as the living room stood a stool, one chair, a coffee table and a *jua kali* wheelchair,<sup>4</sup> upon which Ken had piled his medicines. Just beyond the curtain was Ken's bed. As we entered Ken responded in a feeble voice to Mathews; we could just hear him over a radio tuned to BBC Africa. Ken wanted to sit, but Mathews and the social worker could not get him up. Defeated, he laid on his bed, shaking our hands as Mathews made introductions. When the social worker asked Ken if his brothers had shown up, he shook his head no.

Prior to 2011, Ken worked as a radio journalist in Southern Sudan. He was flown back to Nairobi when he got sick. Ken's brother, who was also a journalist and sports anchor for one of Kenya's leading media houses, brought Ken to his home in Dohnholm Estate. He took him to Gertrude's Hospital, a private, for-profit health facility that caters to the middle classes. At Gertrude's, Ken tested positive for HIV and began antiretroviral treatment. For eight months Ken lived with his brother and family, but did not improve. Eventually his brother kicked Ken out, saying that Ken's illness was interfering with his (married) family's priorities. Although Ken had two unmarried brothers living in Nairobi, they did not have steady jobs and refused to take him in.

His sister – a housewife with two young children, living in a one-room house in Kibera – came to his aid. She convinced her husband to find a room for Ken and began washing his clothes, cooking for him and feeding him when he was unable. Ken's brother-in-law helped out when he could, but as a casual worker in Nairobi's industrial area, he left early morning to queue for jobs and returned home late. Ken was taken to one of MSF-Belgium's clinics in Kibera for treatment. Almost 10 months after Ken had been brought to Kibera, none of his Nairobi-based brothers had visited or offered any support despite his sister's repeated requests. Neither had other relatives in the city offered to help.

Apart from asking Ken to sit up and enquiring whether his brothers had visited him, the HAKI staff did not offer any physical care or support to Ken during our visit. According to them, it was the family's responsibility to care for the sick. After visiting Ken, they moved on to his sister's house to ask if she had reached the brother who was a journalist. When she replied that he was avoiding her calls, the HAKI staff advised her to keep trying and to inform them of her progress. The HAKI HBC programme had limited resources, and because Ken's relatives were financially able to care for him, he did not qualify for their shrinking HBC programme; they saw Ken's case as one of negligence. HAKI also had a team of paralegals, however, and they were considering taking legal action to compel Ken's relatives to support him.

Ken's story shows that in the era of treatment, there is still a need for long-term care for people living with HIV. Not everyone thrives on treatment and there are fewer care-based NGOs and CBOs to patch the kin-based safety net. This leads to organizations such as HAKI redirecting their energies to compel families to provide care through legal means but also leads to a shift in the moral discourse that blames families for failing to care. In this moral framework, people with HIV are positioned as having the 'right' to receive care from their families, and failure to care is seen as both discriminatory and a shirking of social norms.

## Conclusion

Treatment scale-up has brought about a longing for normalization among policy makers and donors, whereby the need for psychological, social and economic support, to say nothing of home-based nursing care, is downplayed, while support groups based in health facilities become increasingly medicalized to promote drug compliance and reduce risk behaviour (Russell and Seeley 2010; Mattes 2011; Simbaya and Moyer 2013; Moyer and Hardon 2014). Yet, our research indicates a continued demand for both community-based care and material support in the age of treatment, particularly in economically marginalized urban locales such as Kibera where family care is sparse and unreliable.

The effectiveness of treatment in diminishing HIV morbidity has meant that funding for HBC activities has also diminished, creating a loss of much-needed income for those people living with HIV who had worked as care providers, as well as a decrease in the care and support that community-based support groups are able to offer. HBC providers, who were both the backbone and public face of community-based support groups only five years ago, have been forced to disengage from support group outreach activities because of economic need. This context has led to resentment and disillusionment within many support groups, but especially those serving low-income areas of the city. Ongoing economic uncertainty affects people living with HIV and, ironically, the institutions that were established to support them, creating much uncertainty about the sustainability of the support group model as a site for treatment literacy training, psychosocial support, the reduction of self- and community-based stigma, and the alleviation of economic insecurity.

Writing about Tanzania, Green (2012, 310) has argued that the majority of CBOs are not directly involved in development, but are better understood as ‘development agents in waiting’. Such a description certainly fits many of the HIV-related CBOs in Kibera, most of which have gone dormant, as HIV community-based funding has declined over the last few years. HAKI, however, has been much more proactive in securing its financial health by investing in various economic schemes to benefit the organization as well as individual members. This was made evident in early 2011 when HAKI’s offices burned to the ground in a fire that began in a nearby charcoal maker’s hut. Like a phoenix, HAKI rose up from the ashes in a matter of weeks, with new office facilities built with organizational funds and minimal support from a few benefactors. They even managed to ‘buy’ the land the offices are situated on.<sup>5</sup>

CBOs like HAKI, however, are rare. HAKI means ‘rights’ in Kiswahili and the organization, perhaps more than most the authors have worked with, is actively involved in making rights-based legal claims on behalf of HIV-positive people. The arguments made in this paper intentionally do not take up the growing literature on the ‘therapeutic citizenship’, because the rights-based claims made by HAKI and others are not about access to treatment. While HIV *treatment* is readily available to the residents of Kibera, good *care*, however, is not. CBOs such as HAKI and people living with HIV do not position themselves as citizens in order to demand care from donors, the state, or the state’s health facilities. Rather they articulate a conception of rights that is concerned with economic justice and humane care for people living with HIV, and is directed at the families of people living with HIV. HAKI enacts this moral demand through home visits, counselling and, occasionally, legal cases.

In the wake of the crisis and donor divestment, the authors find that sites that once trained people with HIV to position themselves as citizens (or ‘clients’— see Whyte et al.

2013) are today more likely to serve as sites where people with HIV gather to ‘reinvent tradition’ and re-moralize family care. Meinert (2014, 130) has conceptualized this shift in care responsibilities to the domestic domain as ‘homework’, arguing that its success relies on moralizing the patient–healthcare provider relationship, resulting in ‘feelings of obligation and responsibility’. She further suggests that questions about patient health and treatment obligations and responsibilities must be reworked when donor projects inevitably come to an end (Meinert 2014, 131). The findings presented in this paper demonstrate that both responsibility for and expectations regarding care and social support in Kibera have been in constant flux since the emergence of HIV, a result of the shifting availability of treatment technologies – including antiretroviral medications, home-based care and support groups – as well as changing priorities in donor funding and the ever-precarious social landscape of Kibera.

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### Notes

1. MSF has worked in Kibera since 1998 and has been offering antiretroviral treatment and support since 2002. In April 2005, MSF launched a HIV comprehensive care centre, jointly run with the Ministry of Health, and they currently operate several other facilities in Kibera. A paper about MSF in Kenya states: ‘In 2012 . . . MSF provided anti-retroviral treatment to 4100 HIV patients in Kibera. Over the years, the organization has pioneered several innovative models of care, such as developing HIV patient support groups to boost adherence and empower patients.’ (<http://www.msf.org/article/kenya-new-clinic-brings-comprehensive-care-most-vulnerable>, accessed 14 January 2014).
2. For an excellent recent review of this literature, see Seeley (2014).
3. Initially, MSF offered treatment literacy training and support group services to anyone on treatment, but now their groups are only open to people receiving treatment in their own facilities.
4. *Jua kali* refers to the informal economy in Kenya and often to objects made from recycled materials. Ken’s wheelchair had been cobbled together from a white plastic chair and old bicycle wheels.
5. Since Kibera is an informal settlement, one cannot technically own the land, but common law dictates property rights; since ‘buying’ the land from the previous ‘owner’, HAKI no longer pays rent.

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