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Now there's no funding.
Most of the organizations
aren't hiring. What do
we do with the [HIV]
knowledge and skills?

After-Crisis: Redundancies and Continuities in HIV-Related Skills, Knowledge, and Structures in Nairobi, Kenya¹

Emmy Kageha Igonya, Eileen Moyer, and Frederick Murunga Wekesah

In the early 2000s, massive economic and technical resources accompanied the framing of HIV as a humanitarian and global health crisis in much of the Global South. These resources and framing combined to produce and enhance a wide range of HIV-related structures, skills, and knowledge with afterlives that have exceeded the crisis period in Kenya and elsewhere. Drawing on ethnographic fieldwork among HIV support groups in Nairobi, Kenya, conducted in the decade that followed the declared crisis period, we examine how local providers of HIV care and services understood the crisis and crisis narratives and practices. We highlight the consequences of after-crisis financial cutbacks, including anxiety, redundancy, financial hardship, and the devaluation and underutilization of expertise and care infrastructures. We argue that the structures, knowledge, and skills developed through engagements with international aid have complex afterlives, often concealed for lack of funding and forced dormancy. Our research examines strategies deployed by actors on the ground to continue offering services and support in the wake of crisis.

Introduction

Early in the morning on March 9, 2017, Emmy Igonya, the first author, received a phone call from a secretary at one of Kenya's public universities telling her of the impending closure of the university's Centre for HIV Prevention and Research. The center's work focused on most-at-risk

populations, including men who have sex with men (MSM), sex workers, and people who inject drugs. The secretary asked Emmy if she had funding to save the center from closure. Emmy had first collaborated with the center as a research consultant in 2015. Just before her work there began, the director—the founder, leader, and sole fundraiser of the center for ten years—had died. During the call, the secretary said the center had repeatedly lost out on funding to other organizations since then. Its predicament was not unusual: international funding for HIV-related organizations in Kenya is often awarded based on the director or founder's reputation, existing networks, and relationships with (Western) donor organizations. Comparing it to similar occurrences at other organizations, the secretary said they were suffering the consequences of leadership syndrome.

The phrases *leadership syndrome* and *founder effect* have been used in Kenya to describe the personalized character of donor-leader relationships. Organizational development literature relating to the founder effect often points to internal mechanisms that prevent employees and organizations from flourishing at the expense of autocratic leaders, but our research suggests that international funding agencies often underscore the power of autocratic founders, and that such mechanisms can have devastating consequences for organizations and employees if the founder departs or dies. Many involved in HIV-related civil-society work in Kenya told us that donors preferred to fund organizations that had founders or directors already personally known to them and that when a founder or director died or moved on, funding was rarely renewed. Several pointed to internal organizational challenges. Founders or directors regularly failed to mentor people to take on leadership roles in their absence. This made it difficult for organizations to thrive or attract funding despite organizational strengths related to knowledge, skills, and infrastructure. This interpretation suggests that trust within and between organizations is heavily influenced by personal relationships, perhaps driven by a fear of corruption, as well as the desire to deliver results in the increasingly data-driven world of global health.

Donors, it is believed, focus on making deals with individuals who can deliver results, paying little attention to the internal organizational politics related to the founder effect. The result is that organizations like the HIV Centre are unlikely to be re-funded when their founder dies or departs, regardless of the skills and knowledge acquired under the founder's leadership or the quality of the work they helped to deliver. While such findings are not specific to HIV-related service organizations, or even to the world of international development, the accelerated pace of the HIV crisis response in Kenya, combined with the vulnerable health of many civil-society organizational founders, many of whom are HIV positive, has exacerbated the founder effect. The negative consequences of the founder effect became increasingly visible within Kenyan organizations involved in HIV-related work after 2010, once the worst of the HIV/AIDS crisis had passed and funding opportunities, especially for community-based organizations, had become scarce.

In the early 2000s, international donors began providing mass technical and material support to fight HIV in Kenya (Igonya 2017; MSF 2017). The proliferation of global health and humanitarian response structures, knowledge, and skills went hand in hand with a massive financial apparatus. By 2010, however, the field was shifting, and the HIV crisis was being reconceived as an epidemic that could be managed through targeted, evidence-based interventions. This shift was motivated at least in part by another crisis, the global financial crisis of 2008, and the logics of efficiency and funding reduction that followed (Igonya 2017). The story of the center's threatened closure provides a lens through which to examine the impact of the shift in framing and funding that accompanied the postcrisis in Kenya. We are particularly interested in the afterlives of skills, HIV knowledge, and structures that had been developed during the crisis. What became of the organizations, institutions, and individuals that benefitted and even flourished in the crisis? How have humanitarian norms and practices been shaped by this experience?

Global health and humanitarian responses to crises generally come to an end when the funding does, even when the responses have not met goals to end the conditions of the crisis. Postcrisis contexts, therefore, reflect specific continuities and discontinuities and how these are (de)valued. Local providers and receivers of assistance grapple with challenges in the postcrisis, including shifting needs of organizations and clients and the sustainability of programs and institutions (Dlamini-Simelane 2017; Moyer 2015). When a health crisis is declared to be under control, a discourse of normalization often accompanies the scaling down of interventions and funding. Especially in resource-poor settings, this can mean that people confront the challenges of living with a chronic condition in a context where basic needs may be hard to meet (Moyer and Hardon 2014; Russell and Seeley 2010), contributing to the "chronicity of crisis" (Vigh 2008).

In addition to saving lives, the humanitarian response mandate includes the prevention of human suffering and emancipatory possibilities intended to make life better (Bennett, Foley, and Pantuliano 2016; Harrell-Bond 1986; Goldstone and Obarrio 2017; Redfield 2005, 2013, 2017). Yet responses are characterized by urgency, practical strategies, and an experience of temporary abnormality (Vigh 2008), linked to the magnitude of the crisis, responses, and temporal orientations (Redfield 2005). By design, humanitarian missions are meant to conclude when the emergency is averted. International response structures then disengage, leaving the chronic management of open-ended crises to others, ideally local organizations, both state and nongovernmental (Redfield 2013; Vaughan 2007; Vigh 2008). Within the context of the crisis, the humanitarian frame establishes intentionally temporary local structures or labor markets to implement the transnational actors' agenda (Davey 2012; Pacitto and Fiddian-Qasmiyeh 2013). Simultaneously, the involvement and expansion of existing local structures and communities in delivering aid to target populations is commonplace (De Waal 1989; Drabek 1987). Local organizations play a key role in facilitating community dialogues, helping

international players embed interventions in existing infrastructures, and ensuring collaboration with specific individuals.

Despite the importance of these local structures and individuals, the international humanitarian response apparatus routinely undervalues them (Challand 2008; Redfield 2013). The task of mediating between humanitarian response structures and target communities is extremely complex, requiring formal and informal negotiation skills, many of which may remain invisible to outside organizations (Beckett 2017; Redfield 2013). Local mediators, often organizational founders or leaders, commonly serve as stand-ins for affected communities, speaking on their behalf and representing them to international responders—a practice that may reinforce hegemonic notions of victimhood embedded in international humanitarian responses while diminishing empowerment possibilities and an eventual return to normalcy (Beckett 2017; Harrell-Bond 1986).

HIV as a Humanitarian Crisis

In the 1990s and 2000s, HIV/AIDS ravaged many parts of Africa (Amuyunzu-Nyamongo 2001; De Waal 1993, 1997; De Waal and Whiteside 2003; World Food Programme 2009). The framing of HIV/AIDS as a crisis facilitated emergency responses across the continent, mobilizing funding and human resources on a massive scale to enable antiretroviral treatment (ART) success (Nguyen 2005; World Food Programme 2009). The crisis framing of HIV was justified, though it was a consequence of highly orchestrated political maneuvering meant to trigger a specific international emergency response. As efforts to scale up ART access got underway across hard-hit countries in the Global South, it became apparent that providing pharmaceutical treatment alone—ART, Septrin, and drugs for opportunistic infections—would not be enough (Prince 2012). Other forms of aid, including food parcels, psychosocial support, HIV counseling, and treatment-adherence training were needed to get drugs into bodies and save lives (Igonya 2017; Kalofonos 2010; Le Marcis 2012). The forms of aid that accompanied ART programs often sought to target HIV-infected people in their communities, relying on existing humanitarian structures while encouraging the development of new organizations, some of which would be led by people living with HIV (PLHIV).

A vast research apparatus accompanied the rollout and scaling up of HIV pharmaceutical treatment, including community-based social science and state-of-the-art clinical trials. This apparatus trained fieldworkers, clinicians, epidemiologists, and other experts to provide health services and assist in gathering data (Aellah and Geissler 2016; Moyo Okwaro and Geissler 2015; Prince 2012, 2013a). PLHIV increasingly came to be involved at all levels of treatment delivery and support as so-called experience experts, undertaking mundane activities such as updating medical records, providing ongoing supportive counseling to clients, and tracking and tracing those

needing treatment to ensure they would not be “lost to follow-up” (Dlamini-Simelane and Moyer 2017; Moyer 2014).

Local structures, including NGOs, community-based organizations (CBOs), and HIV support groups, served to channel assistance in the form of direct funding, psychosocial support, HIV counseling, income-generating activities, and job opportunities (Heyer et al. 2010; Kyakuwa 2009; Moyer 2015; Nguyen et al. 2009; Oosterhoff 2008; Oosterhoff et al. 2008). Organizations often received funding to carry out so-called demonstration projects, with the (misguided) presumption that local funding would materialize or temporary laborers would be regularized if positive effects were demonstrated. Some, perhaps blinded by neoliberal notions of charity, assumed that those involved in the work would continue indefinitely to work as volunteers (Prince and Brown 2016). In practice, many programmatic and work-related opportunities faded away at the end of the funding period, regardless of how successful they had been (Oosterhoff 2008).

Although AIDS had been a reality for two decades in Kenya, the crisis response that unfolded in the early 2000s resembled disaster-relief efforts in temporality, a suspension of ethics, and the triage-like character of the response (Nguyen 2010). In 2004, following a shift in global policy that would make life-saving pharmaceutical treatments widely available in African countries heavily affected by HIV and the establishment of global funding mechanisms, including the Global Fund and the US President’s Emergency Plan for AIDS Relief (PEPFAR), the global response to HIV in Kenya gained momentum. International NGOs partnered with and promoted the growth of local civil-society organizations to expand HIV-related social services while targeting the most vulnerable and supporting the enrollment of people in treatment programs (Brugha et al. 2004). This period, marking the NGO-ization of HIV service provision in Kenya, resulted in a rapid proliferation of structures, skills, and knowledge among a wide variety of actors beyond the existing public healthcare system. Critics have cast this undertaking in a negative light because it produced AIDS exceptionalism and parallel health structures, often at the expense of the public-health system; however, it achieved intended effects, including the strengthening of civil-society and patient activism, as well as shifting care-related tasks away from an overburdened biomedical system through the support of community-based care and support mechanisms. These forms of health sociality and labor were largely unsustainable because they relied almost exclusively on the donor sector for financial support.

After Crisis

By 2010, only six years after AIDS was recognized as a global health and humanitarian crisis, many international players were proclaiming that the end of AIDS was in sight, to be achieved primarily through expanding access to pharmaceutical treatment, the widespread use of which promised

to reduce new infections drastically. HIV had come to be seen as a logistical challenge, to be solved by getting pills into bodies and tracking those bodies to establish evidence of success. In Kenya, as elsewhere, this shift in framing resulted in a sharp decline in humanitarian funding and the remedicalizing of HIV (Nguyen et al. 2011). In this article, we conceptualize this shift through the frame of after-crisis, an extended period of institutional and labor transition shaped by global health and humanitarian policies deployed from distant locations, often operating under financial and political logics of efficiency, population-level health effects, and the desire to encourage local and national ownership of internationally defined health and humanitarian concerns.

In Nairobi, these logics of withdrawal seldom made sense to those who had invested time and effort to transform themselves and their organizations to address HIV and related matters, often at the behest of international organizations that championed ideals such as patient advocacy, treatment literacy, and community-driven responses as part of a larger aim, to empower people and promote specific imaginaries of democracy. In places like Kibera, the postcrisis framing meant that funding shifted away from community-based care and support initiatives that had understood HIV as a psychosocial problem and toward organizations, public and private, that prioritized biomedical and pharmaceutical interventions. The community-based structures, skills, and knowledge that had flourished faced future uncertainty; PLHIV and others who had taken training courses to learn how to provide community-outreach services faced unanticipated precarity. It was as if a massive job-training program had swept through Nairobi but concluded that such jobs were not required after all.

Our research has let us observe how local NGOs and CBOs responded to the remedicalizing of HIV in Kenya and consequent shifts in funding (Igonya 2017; Igonya and Moyer 2013). Research conducted in roughly the same period in other African sites has questioned the relationship between training-related empowerment narratives in the HIV crisis and those in the postcrisis. Ruth Prince (2012, 2013b) and Gemma Aellah and P. Wenzel Geissler (2016) have examined disjunctures between the HIV economy and its claims of empowerment and the aspirations and opportunities afforded to economically precarious individuals and communities. Thandeka Dlamini-Simelane (2017), working in Eswatini, and Lyson Tenthani and colleagues (2012), working in Malawi, documented the undervalued and precarious labor of expert patients, also called peer mentors and peer educators, who were engaged via temporary contracts in diverse settings across Africa to fill gaps in HIV care (see also Moyer 2015). Building on the work of these scholars, we consider the afterlives of the HIV-related structures, knowledge, and skills that proliferated during the HIV crisis, critically questioning the ideas of volunteerism, temporary employment, task shifting, treatment literacy, and patient or client empowerment that were inherent to the crisis response. We particularly question how the postcrisis shift affected local responses to HIV, income opportunities for Kenyans engaged in the HIV sector, and the ways that PLHIV came to be targeted as distinct risk groups, rather than a biosocial collective.

Study Site

This study was conducted mainly in Nairobi, in the neighborhood of Kibera and at Kenyatta National Referral and Teaching Hospital (KNH). KNH and Kibera were chosen because of the number of HIV support groups and HIV interventions linked to the sites at the time. For decades, KNH has borne the highest HIV clinical care burden in Kenya (Arthur et al. 2000) and has played an important role in shaping HIV interventions in Kenya and beyond. It was among the first sites in Africa to develop models for peer-led HIV support groups and peer mentoring in public hospital settings. Located within easy walking distance of KNH and other key medical research facilities in Nairobi, Kibera is an exceptionally convenient site for health interventions and research, not least because of the structures, knowledge, and skills harbored by local residents and organizations. It is the largest and most populous informal settlement in Kenya (Kenya National Bureau of Statistics 2010). The prevalence of HIV there, together with high rates of morbidity, mortality, and poverty, has made it an attractive site for national and international players involved in the HIV response.

Data-Collection Approaches

Our analysis benefits from long-term ethnographic engagement with key sites and players involved in the HIV response in Kibera and at KNH. Our first ethnographic study was conducted in 2008, at the height of the HIV crisis-response period. We worked with two PLHIV-led CBOs tasked with educating communities about HIV treatment through a lens of patient empowerment supported by the International Treatment Preparedness Coalition, an organization of HIV-treatment activists. Then, between 2010 and 2013, we conducted intensive fieldwork on HIV-support groups just as funding for support groups was disappearing. Through 2019, we conducted periodic follow-up research with selected organizations and participants.

In 2010, we mapped thirteen active support groups at KNH and selected six for in-depth study. These included groups focused on youth, men's sex therapy, mixed adults, healthcare workers, discordant couples, and antenatal issues. Selection was based on achieving a diverse sample informed by attendee makeup, issues addressed, group activities, and meeting days. Of twenty-one groups registered with Kibera Post Test Club, the umbrella organization, only eight were active in 2010; the rest had become dormant because of funding cuts. From these eight, we selected three using criteria of type of activities, gender, and meeting days. In addition to our research with these organizations, we conducted interviews with representatives from international NGOs, local NGOs, and CBOs with activities in Kibera. Research participants included informants from various organizations, peer educators or mentors, and other PLHIV and community members who

participated in support-group activities in group meetings or community-outreach activities.

Methods included a review of media coverage related to HIV in Kenya's three leading newspapers, the *Daily Nation*, *Standard*, and *Star*, between May of 1990 and 2013; more than four hundred participant-observations accompanied by conversations and informal discussions; thirty-eight key-informant interviews with government and civil-society organizations; sixty-eight in-depth interviews with PLHIV from ten support groups and other HIV interventions; thirty-eight informal walking-group discussion sessions; eight focus-group discussions; and sixteen case studies with individuals and representatives of structures involved in providing or receiving community-based HIV services.

Participant-observation involved attending and participating in support-group sessions and other group-related activities, including visiting hospitals and members who had babies, attending weddings, walking to and from bus stands with participants, participating in street-advocacy activities, and hanging out in participants' social worlds. The range of sources and materials collected has let us develop a comprehensive picture of a highly fragmented field, which was being dismantled and reassembled at the time of research.

Most interviews and discussions were tape-recorded and transcribed verbatim. Handwritten notes were taken during support-group sessions and informal discussions, in accordance with prearranged agreements. Ethical approval for this study was granted by the Kenyatta National Hospital / University of Nairobi ethical review committee. All participants were above eighteen years old and consented to participate. We use pseudonyms throughout to help ensure confidentiality.

Emergent Local HIV Humanitarian Response: Structures, Skills, and Knowledge

During our first field encounters, we found a well-funded and highly active community-driven response to HIV, one that was focused on destigmatizing HIV, educating the public about the disease and treatment opportunities, and encouraging PLHIV to cocreate and colead the response to HIV. By 2010, when we returned to the field intent on documenting the ways that support groups, peer workers, and HIV counselors were addressing the psychological and social needs of PLHIV, we found that the structures and organizations that had facilitated this work were being dismantled and reassembled in a response to shifting funding priorities.

"You're too late," was a statement often made by the support-group members and facilitators and the founders and staff of organizations when we approached them in 2010. They suggested that the time of large-scale funding for community-based responses to HIV had ended. Community-based HIV response structures were under threat, and the people with the

skills and knowledge needed to provide support were finding themselves redundant. Everyone we spoke to said the same thing: the golden days for a community-based response, especially support groups, had been between 2003 and 2009. That was when HIV had been considered a crisis by global players and the response had largely been driven by humanitarian organizations that preferred to work through civil-society organizations, rather than rely on government structures characterized as overburdened and unreliable.

When humanitarian organizations began intensively focusing on HIV in Kenya, they found a small community of PLHIV who were already seeking skills and knowledge while putting in place rudimentary structures and institutions to respond to HIV. In the late 1980s and 1990s, faced with a life-threatening condition and no treatment, high levels of stigma, and a slow national response, people with HIV and AIDS organized themselves. Their efforts focused on providing essential services to those most in need and served as an advocacy platform for people to demand a national response.

The first union of people with HIV and AIDS in Nairobi established a buddy group that focused on compassionate support and sharing available HIV information. The UN agencies that were just beginning to address AIDS in Kenya noticed the group. They provided training and invited its members to participate in HIV awareness-raising activities, for which they were paid. The training they received included skills related to giving public testimonials and disclosing their status, as well as basic information about living with HIV. Members of the group were sponsored to attend international meetings, where they gained further skills in advocacy and activism and for which they received generous allowances.

Such opportunities were an eye-opener, demonstrating that people with HIV could provide a service and get paid in return. One buddy-group member noted, "We got very excited when we realized we could educate pupils or students in schools, educate people in churches, and even in communities. We only talked about our own experiences of living with HIV." Recognizing the income-earning potential of the work, some buddy-group members founded their own NGOs and CBOs, positioning their organizations to receive international funding while serving in lucrative advisory roles to international organizations.

By the early 2000s, when AIDS in Kenya was finally framed as a crisis worthy of a coordinated response, many people had already died, and many others were very sick. Support systems, formal and informal, were fragile and overburdened. From 2003, technical and material aid was funneled primarily through international NGOs tasked with scaling up ART, but these organizations needed on-the-ground partners to reach target groups. HIV treatment at the time, in part shaped by activist discourses, was considered to exceed medicines and home-based care services, which were extremely intensive in physical and emotional care work. Motivated by concerns related to adherence and possible viral mutations, funding was made available for psychosocial support in the form of counseling, peer-support groups, and treatment-literacy training workshops, often facilitated by CBOs. Many

CBO and support-group leaders, as well as those involved in peer mentoring work, had been among the first to receive treatment when it became locally available. They had benefitted greatly from HBC services and treatment-literacy trainings.

Most of our interlocutors were keenly aware that those who had been saved by ART would need to figure out how to generate income. Many had lost work because of physical illness or stigma and discrimination, and those on treatment needed good food, shelter, and social support to thrive. The World Bank (2000) saw PLHIV-led support groups as important sites for addressing the economic challenges associated with living with HIV and provided funding to further their development, encouraging groups to develop income-generating strategies, such as table banking, small-craft production, gardening, and small businesses. The involvement of PLHIV in the community-based humanitarian responses met an important political goal: the Greater Involvement of People with AIDS principles, woven into the HIV-response policies of UNAIDS, The Global Fund, and PEPFAR.

As the money started rolling in, the government created the National AIDS Control Council (NACC) to coordinate a multisectoral HIV response. Funds were pooled for Kenyan civil-society responses to HIV that were to be managed by the NACC. To improve their visibility and chances of receiving support, some local NGOs and CBOs formed umbrella groups, through which aid, HIV knowledge, and psychosocial support were delivered. Community-oriented organizations emerged within state institutions, including medical facilities at KNH and at the HIV Center at the University of Nairobi. These unusual partnerships were important sites for training PLHIV and other nonmedical experts involved in the HIV response and became clearinghouses for disseminating HIV knowledge and skills related to counseling and testing, facilitating psychosocial support and peer education, and raising community awareness and patient advocacy. Later, these institutions would play a key role in (re)training community representatives to undertake the track patients lost to follow up and link them to care.

In 2000, KNH, in partnership with Family Health International, initiated post-test clubs (later changed to support groups) as a platform for HIV knowledge and psychosocial support for HIV testers, regardless of one's HIV status. Support groups were cofacilitated by health providers and PLHIV peer educators, most of whom had already received extensive treatment-literacy training through the MSF (*Médecins Sans Frontières*) program. These were some of the first peer educators in Kenya. Some remained at KNH after being trained, but others were encouraged to set up support groups in their communities, and the wages at KNH motivated some to seek better-paying jobs or set up NGOs and CBOs.

As awareness of HIV-related income-earning opportunities grew among PLHIV, community structures were affected. Many groups splintered and competed for resources. This process was intensified by beliefs related to founder syndrome. We found that men were especially interested in earning an income for community work. This gendered effect was observed in

support-group leadership and participation in Kibera, where leaders and participants were rarely compensated. Organizations like MSF, concerned about the sustainability of community-based support mechanisms, encouraged volunteerism and did not pay allowances. Men were often quick to abandon unpaid volunteer work for paid peer-education work elsewhere or other non-HIV-related economic opportunities. Women took over the founding and leadership of HIV support groups, feminizing the humanitarian community-based response in Kibera and other communities.

By 2008, when the global financial crisis hit, an extensive infrastructure of community-based care had been established in Nairobi. International humanitarian organizations and other NGOs were facilitating the training of a generation of PLHIV who would go on to establish a network of NGOs, CBOs, and support groups, as well as engage in a variety of jobs as peer mentors, educators, and counselors. They were not at all prepared for the change in policies and funding priorities that would accompany the fiscal crisis and the shift in politics in Washington, DC.

Disrupted Engagements: Post-Crisis Vulnerabilities, Tensions, and Continuities

Shortly before 14:00, Emmy arrives early for a group session at KNH, where she is joined first by Martha, a peer educator, and five minutes later by the nurse-counselor in charge of support groups. While waiting for participants to arrive, Martha engages the nurse, asking, *"Do support groups really empower members?"* Countering the nurse's response of *"Very much,"* Martha asks, *"How can you say support groups empower people, and all we do is give information? A woman comes to the support group and shares that her husband has beaten her after disclosure, and we just offer her advice without solving the real problem. She's going back to the same man, who might beat her and chase her away. Did we empower this woman? Others come to the group and share about lack of food and job, and they have children. All we do is empathize with them as they go back home hungry, with no food for the children, yet we provide them with information on treatment adherence, nutrition, emphasizing a balanced diet and positive living, including condom use. We even caution them about their CD4 not doing well, like 'reduce stress, eat well.' In that case, have we really empowered them? Many people come with various challenges, and we empathize telling them 'tumesimama na wewe' (we stand/support with you) or 'tuko pamoja' (we're together in this), take tea and snacks, and they go away just as they came, perhaps more miserable*

because their expectations aren't met." (Fieldnotes, December 10, 2013)

Martha's words highlight the frustrations, uncertainties, and anxieties that constituted living with HIV in the after-crisis, as well as the awareness by peer workers that little could be done to address these concerns. The days of allowances, skills, and knowledge were in the past, replaced by a medicalized HIV response, frustrating individuals who felt increasingly pressured to care for themselves without the benefit of social or economic support.

PLHIVs like Martha, who could claim expert HIV knowledge and skills, lost their income when the programs paying their salaries were defunded. Because the whole sector was suffering from cuts and their status was widely known in their communities where HIV stigma had hardly diminished, peer workers could not easily find work elsewhere, forcing many to stay on as volunteers in hopes that programs would eventually be reestablished. At KNH, peer educators saw their contracted working days reduced from five to two, even as the demands for their labor continued and, in some cases, increased. The number of patients on the clinic rolls were expanding, and the peer workers were needed to provide supportive counseling, follow-ups on missed clinic appointments, and health talks to clients—work that could not be done by already overworked nurses or other hospital staff. That they were urgently needed in the clinics where they worked, combined with difficulty finding work elsewhere, meant that throughout the period of our research at KNH (2010–13), most peer workers continued to be employed marginally at the hospital, even though their allowances were often delayed, sometimes for months, and they were rarely fully compensated for their work. For most, peer education was their primary source of income, and some reported not having enough to eat, being evicted from or locked out of their rented houses, and having to walk long distances to work because they could not afford bus fare.

By the end of our formal study period at KNH, of the peer workers employed at KNH, only Martha had managed to find another job where she could use her skills. During follow-up research in 2014, however, we found that the fortunes of KNH peer workers had changed. The hospital's comprehensive care clinic for HIV had secured funding for an unironically named hospital-based community-based care under ACTS (AIDS, Care, Treatment, Support) project. The project allowed the hospital to give peer workers long-term, full-time contracts with better remuneration. During an informal discussion, one peer worker noted:

Our patience and determination have paid off. I had nowhere to go. You know you have knowledge and skills that could help people, and even yourself, but it becomes useless when you cannot apply it. This [peer education] is the only work I've done, the only thing I can do. Now I'm delighted with the hospital for giving us another chance. . . . I have a better

salary, can pay rent and bus fare, buy food, and pay school fees for my children.

In their new roles, peer mentors were to encourage “uptake and retention in HIV treatment and care” across the hospital, helping link hospital patients in other wards and clinics to HIV care and treatment. Linkage to care programs that employ PLHIV experts has been put in place in other clinics in Kenya, but such opportunities remain rare and the job security found by peer workers at KNH is exceptional, despite the ongoing essential work they do. As the country’s top research hospital, KNH continues to attract considerable funding for its HIV programs, but most health facilities that expect to supply more HIV positive people with treatment for less money do not. In such contexts, scarce resources are put into procuring medicines, while funds for social and psychological support are cut.

What Do We Do with the Knowledge and Skills?

As at KNH, PLHIV in Kibera struggled with the question of what to do with a surplus of HIV knowledge and skills in the after-crisis. The reduction in funding for a community-based HIV response had a range of negative effects on Kibera-based organizations and PLHIV involved in community work. Some organizations ceased to exist, and the people who worked for them were made redundant. Organizations that were less intimately entangled with the international humanitarian response became dormant—meaning that individuals and networks could still be located by a determined anthropologist, but care infrastructures had been dismantled or put on hold. People affiliated with these organizations could be activated if funding or opportunities emerged. Some organizations were able to restructure and transition to tackle new areas of concern. For example, most of the remaining HIV support groups shifted their mandate to focus on economic ventures, such as informal credit unions and providing early childhood care. Some Kibera-based NGOs expanded their geographical coverage and began offering health services, including clinical care services for HIV.

When we interviewed the chair of a dormant Kibera-based NGO, it had been ten years since he had lost his job as a police officer because of AIDS-related illnesses. When he became bedridden, he had been abandoned by his wife. That’s when home-based care interventions reached and resurrected him, motivating him to join those who had saved him. HIV-related work became his only source of income. Sharing his frustrations regarding the shift in funding practices, he said:

Our network was formed by MSF to coordinate HIV support-group activities. Groups paid subscription fees of KSH 1000. In addition, we as an organization were funded by NACC and other donors. Now there’s no funding, and most of the organizations

aren't hiring. What do we do with the knowledge and skills?
What should we do when an organization isn't hiring us?

The chair was one of many PLHIV in Kibera who had been trained by MSF, allowing him to develop knowledge and skills related to treatment literacy, as well as support-group formation and facilitation. Without funding, the network he had founded had come to depend on unincientized volunteerism. He had sought work at a new clinic, five hundred meters from his office, that had opened while many of the internationally backed HIV initiatives were closing down. Despite his training and experience, he did not secure a job.

Like the chair, forty-seven-year-old Joseph Jalang'o had participated in HIV humanitarian responses since precrisis times. When Joseph learned he was HIV positive, he had already lost his job because of recurrent illnesses and hospitalizations. Seeking help, he joined a support group where he accessed HIV information and psychosocial support, with income-earning opportunities related to HIV advocacy and awareness raising. An NGO ran the next support group he joined and sponsored his attendance at international HIV and AIDS conferences, increasing his knowledge and advocacy skills. This opportunity ended in the after-crisis, prompting him to volunteer at a local NGO that was running support groups. With a wealth of knowledge and skills, he hoped to get hired as a paid staff member, but with funding dwindling, the NGO had limited employment possibilities. As a single parent of four children, he could not meet his economic needs. After eighteen years with HIV work as his main source of income, he told us, "Support groups can be disappointing. . . . I think I got involved in HIV activities by mistake. . . . I've been used and dumped like toilet paper!"

In 1987, when Jemima, a mother of seven, found out she was HIV positive, she was thrown out of her matrimonial home by her husband. In 2011, she remarried an HIV-positive man and was living with him, two adult sons, and a seven-year-old grandson when we met her. Formally jobless, at sixty-seven years of age, she was the primary breadwinner for her family, since her sons were unemployed, and her husband was bedridden and unable to work his security-guard job. Disillusioned with volunteer work and low, unstable allowances, she had founded Tumaini Support Group in Kibera, where she occasionally secured community-based care subcontracts. When we interviewed her, she was full of energy and ideas for projects that could improve her community. Tumaini had obtained some income-earning opportunities: it had been subcontracted to offer home-based care services, but this came to an end with the reduction in HIV funding, rendering Jemima and her fellow group members jobless. They had tried table banking, but some members could not raise the agreed amount of money, and others defaulted on repayments of loans secured from the group, exacerbating internal group conflicts.

For years, Jemima, like Jalang'o and the chairman, had committed herself to learning everything she could about HIV to expand her expertise and qualify for community-based work in the HIV sector. Despite being highly empowered to advocate for themselves and their communities, the

defunding of community-based interventions resulted in making them feel disempowered, unable to achieve the degree of self-care they knew they required to thrive, and unable to assist other PLHIV to meet the ongoing economic and other challenges of the disease. She struggled to make a living, while the knowledge and skills that once promised hope and empowerment became economically unviable. She and others like her were left economically exposed, but so too were their families and communities. Many were demoralized, as the skills and knowledge that had once been highly valued could no longer be parlayed into even a basic income.

Frustrations, Uncertainties, and Resilience

We met thirty-eight-year-old John in 2008, when he was working for an international NGO that supported PLHIV-run community-based treatment-literacy projects. Previously, he had worked as an HIV peer educator for a local NGO, after being trained by MSF. Among the first generation of HIV peer workers, he gained a position in the world of international AIDS activism, where he came into contact with donors and gained knowledge and skills that would eventually earn him his job at the international NGO. He received a good salary, plus hefty allowances when attending conferences abroad—which allowed him to move from a lower-middle class residence to a middle-class one, buy a nice car, and enroll his children in private school—significant signs of upward economic mobility. Elsewhere, we have argued that people like him, who made up the first generation of Kenyan HIV activists to succeed on the global stage, might be understood through a lens of the African big man (or woman); they turned HIV activism into a lucrative, cutthroat enterprise, operating like business moguls to position themselves as international spokespeople for Kenyans with HIV (Igonya 2017).

When John lost his job at the international NGO in 2012, unlike many who struggled with the defunding of community-based work, he quickly established a CBO for men living with HIV, taking advantage of international concern with the comparatively low uptake of treatment by men. He appointed himself chief executive officer and secured sufficient funding via his international contacts to set up a three-roomed office in a respectable neighborhood and hired three employees to facilitate support groups for men. By 2018, when we met him again, however, things had taken a turn for the worse.

“Times are hard. I couldn’t get more funding, and I closed the office. Life has been tough,” he explained. Only a year after opening, John had folded his men’s organization. Despite a wealth of skills, knowledge, and expertise, including managerial skills, like many others, he found no work in the HIV field and sometimes volunteered at a friend’s CBO. To earn a living, he was working as a fishmonger, but did not have money to invest in the business. He had been barely scraping by for the previous five years, had given up his middle-income house, and was living in an informal, low-income settlement. He had sold his car and moved his children to public schools.

As researchers, we considered it a sign of just how bad things had become for community-oriented HIV workers when someone as skilled and well-connected as John could not make a living in the field, yet a year later, in early 2019, when we met John again, he informed us he had secured a job at an NGO shortly after we had last spoken and had already bought a car and had moved again to a middle-income residence. His story is important because it demonstrates the unpredictability of the career trajectories of HIV experts who specialize in community care. Because most people are employed through temporarily funded intervention projects, they can easily find themselves out of work between projects, even when they head their own organization. For some, however, determination and contacts can pay off, especially if they can read the signs of upcoming funding calls and be flexible enough to position themselves to take advantage of new trends. In this way, we assert our prior argument: people like John operate like business moguls, responding to an unstable market and bankruptcy by reinventing themselves to capitalize on emerging opportunities.

As with John, we met Zakaria, one of the first to declare his HIV status in public in Kenya, during our 2008 treatment literacy research. He was a founding member of a national network of PLHIV and served on its board. In 2008, he was also chief executive officer of the CBO he founded, drawing on connections and funding from his national-level work. The CBO specialized in raising HIV/AIDS awareness and improving treatment literacy to encourage people to access HIV testing and treatment. When we spoke to him in 2011, he told us he had built a house, but was concerned that funding streams were drying up and worried that he would be unable to pay for his children's education. By 2013, his concerns proved prescient. For lack of funding, he was forced to close the office of his CBO and join his wife's business, a merchandise shop.

As with John, we had assumed that was the end of Zakaria's work in the HIV field, but when we reached out in 2019 to catch up with him, he invited us to meet him at a county public hospital, where he was working as a peer educator. Looking smart in a white lab coat, the ubiquitous uniform of health-facility-based peer educators in Kenya, he met us at the gate and took us to the hospital's peer-education office. We met his colleagues there, one of whom had worked at the CBO with him before. When we asked what had become of his community work, he told us:

This is where I am working now. There's no funding, no work. I couldn't afford an office; it has been tough and complicated. You get stressed because you don't have an income, you have a family to care for, and for us on HIV treatment, we need money to buy food. . . . Food is part of treatment. I was offered this job and am happy to spend my time here and make some money. There's no money in HIV for small organizations like mine. I'm glad to be here.

Zakaria's good fortune was tenuous. It was a step down from the life he had had when he was involved in national- and international-level AIDS activism, and he was no longer in charge of his own CBO. His work as a peer educator allowed him to make the most of his HIV skills, but the project that hired him was dependent on funding from an international NGO that was supporting treatment expansion in Kenya. In many ways, he and his colleagues were overqualified for the work they were doing, which mainly involved encouraging those who had recently tested positive for HIV. He seemed dismayed by this:

Many of us have lost jobs and funding. You call or meet someone, and they tell you they don't have a job, or their funding was cut off. I've done so much work in HIV, but when there's no funding, what can we do? And some of us are now old. I lost my job when I was sickly in 1993, and I spent many years in the HIV field. We went into HIV work because we were [HIV] positive. It was easy. Not anymore. I'm lucky to have this peer-education slot. My former CBO peer educator, he got the job first, and when they asked for another person to work with him, he came for me.

Following the ups and downs of John's and Zakaria's careers in the world of HIV for more than a decade provides insight into the challenges people like them have faced. Both were pioneers in leading their communities' responses to HIV, among the first to acknowledge their HIV status publicly, among the first to work internationally as PLHIV representatives and activists, and among the first to establish PLHIV-led community-based organizations to educate and empower other PLHIV so that they would seek out testing, treatment, and support. They became the big men of the PLHIV-led response in Kenya, establishing careers for themselves in an emerging field when they had no other way to earn a living. They were particularly challenged when international funding for community-based response work was cut. Their impressive skill sets and extensive knowledge and networks, however, have meant that they still manage to earn a living from HIV work, even if that work is no longer focused on political action or empowering PLHIV to demand high-quality care and treatment. Contemporary HIV-related work is generally depoliticized. Peer workers are expected to support the biomedical treatment process, and the precarity of their work contracts diminishes the likelihood that they will challenge the status quo.

"I'm Not Going to Live on AIDS Alone": Staying or Moving On

Not everyone who had taken on PLHIV leadership roles during the HIV crisis remained in HIV work. In June 2017, Emmy ran into Jackeline while waiting to board a plane at the Jomo Kenyatta International Airport in

Nairobi. Jackeline was a founding member and the former chief executive officer of a national HIV network organization in Kenya. Responding to a question about what she had been up to since leaving the network, she said:

I'm not going to live on HIV alone for the rest of my life. We can do other things to earn a living. Those who eat AIDS alone have no alternative sources of income. When I was in HIV interventions, I invested in education and went to university I'm using the education and the skills I acquired as the network leader to do other things. I've set up a women's group in my home, and we focus on agricultural activities. Some people don't have anything else to do, other than living on HIV. I've made my mark on HIV in Kenya and moved on. . . . You cannot live on AIDS alone.

Like John and Zakaria, Jackeline was among the first in Kenya to disclose her HIV-positive status publicly, and her public testimonials played a major role in putting a human face to HIV in Kenya and globally. While still at the network, she entered national politics and unsuccessfully vied for a parliamentary seat. Wisely, she had used some of the money she was making at the network to continue her education and had completed a master's degree by the time she lost her job there. She had been unemployed for some time, but eventually found her footing running an NGO to support rural women's agricultural activities. Though she was no longer using her HIV-related knowledge, no doubt the managerial and fundraising skills developed at the network, along with the university education paid for through her work there, combined to put her in a good position to launch her own NGO when HIV funding diminished.

Jonathan's story resembled Jackeline's. He had been active early in the Kenyan humanitarian response to HIV, also well-known for publicly disclosing his HIV status. His position in this field helped him land a lucrative international job, and he was a founder and director of a CBO. He had invested heavily in a college. His HIV-related work had translated into comfortable upper-class income and status. When he lost his international job in 2008, he was not too worried because he knew he could fall back on his work at the CBO and the college, yet by 2010, the CBO had folded for lack of funding, and the college had gone bust. When we met up with Jonathan in 2011, he told us, "I've moved on. [pause] It has been hard to get a job in HIV field." He had worked for years in the HIV humanitarian sector but could not find HIV-related work. Eventually, he decided to move to the environmental-conservation field, where his skills were appreciated, even if the focus was not HIV. He liked his new job, but it did not pay nearly as well as had his work on HIV. Reflecting on his previous career, he said, "I did my part, and I'm proud of it; others have taken over."

Postcrisis Innovation and Continuity

A reduction in funding for community-based initiatives did not mean there was no funding at all for HIV in the postcrisis: rather, funding was redirected in line with cost-effective strategies that were to be both evidence based and targeted, so that ART thresholds established globally could be met. Within Kenya, such initiatives included promoting HIV treatment adherence with a focus on so-called key populations and retaining people in treatment programs. Key populations, including MSM, sex workers, adolescent girls and women, injecting drug users, and prisoners, had been identified through incidence studies as being among those most likely to be infected with HIV. They were referred to as most-at-risk and drivers of the epidemic, making them key to any effective attempt to eliminate HIV.

In the postcrisis, though many international humanitarian organizations halted their HIV work, others refocused their HIV work to compete for funding. Similarly, Kenyan NGOs repackaged themselves to be attractive to donors. Three of the NGOs we worked with constructed health facilities and positioned themselves as HIV-treatment providers. The Kenya Network of Women with AIDS and the Kibera Community Self-Help Programme (KICOSHEP) established health centers that provided care to PLHIV in accordance with the humanitarian principles of home-based care they had learned during the crisis period. Rather than visiting critical PLHIV patients in their homes to compensate for failing family-support systems, patients were treated in in-patient facilities. Similarly, Women Fighting AIDS in Kenya (WOFAK) and KICOSHEP established health facilities in Kayole and Kibera that offered full-fledged laboratory and curative services, as well as psychosocial support through a conglomeration of HIV support groups:

We have PLHIV who still need home-based care in the community. They may not be many, but they are there. . . . When funding reduced, I wrote a proposal and got funded to set up a home-based care facility.

A WOFAK staff member similarly said:

I feel really empowered. I joined as a support group member, and I've grown with the organization to this level. I know many PLHIV who lost their jobs when funding reduced, but I'm lucky I still have a job.

Other organizations repositioned themselves in the new market by offering expertise in particular areas. For example, the Movement of Men against AIDS in Kenya took advantage of growing international funding aimed at promoting so-called positive masculinity and funding for HIV interventions targeting MSM.

Continuities were also observed in support-group settings. All larger PLHIV-led Kenyan NGOs we worked with continued support-group activities in the post-crisis, despite limited funding. The Association of People with AIDS in Kenya (TAPWAK) and the Foundation of PLHIV/AIDS in Kenya (FOPHAK), for example, maintained community-based support groups for people on treatment, sometimes providing food packages to members. Responding to a question on support groups, a TAPWAK staff member noted:

There are challenges with treatment adherence, stigma, disclosure, and people are still testing HIV positive. We still need psychosocial support, food, and home-based care. As an organization, we need support groups to provide psychosocial support and supply food to improve treatment adherence. Some people are on HIV treatment and do not have food. Therefore, we seek funding and reach out to PLHIV through support groups. We've sustained staff at the head office and continued to support group facilitators and members with food. We also support them on income-generation activities to encourage self-reliance.

Likewise, FOPHAK worked to meet the continued demand for services among their still growing membership, even expanding their focus to include orphans and vulnerable children:

The reduction of funding didn't mean the fight against HIV was over. We still have issues. We still use support groups in delivering HIV response. We realized PLHIV still needs support groups. Being on treatment for life isn't easy; they need support and information on new developments. Groups that focused on the distribution of material support during the crisis period have closed. We followed the MSF strategy. . . . With limited funding, we still offer support groups as an activity but only pay allowances to facilitators. We also have programs on orphans and vulnerable children that still attract donor funding.

Smaller CBOs found it more difficult to reinvent themselves in the post-crisis, but some managed. Ahmed, after completing treatment literacy and support-group formation and facilitation training at MSF, founded a support group that grew to become a community-based organization called HAKI (rights) in Kibera. HAKI received enough HIV funding to flourish during the early years of treatment scale-up (2004–9) when donors favored CBOs with generous grants. In the after-crisis, HAKI diversified its activities to include treatment-literacy training, legal aid, orphan care, a school program, food-aid distribution, and gender-based violence. HAKI transformed HIV support groups into income-generating groups and created a network for

group savings and loans. In 2012, it mobilized more than fifty savings-and-loan groups through which more than four million Kenya shillings (about €40,000) circulated among its members in Kibera.

Conclusion

Using the frame of a “moral economy of survival,” Prince (2012) argues that even as international aid works to empower people to realize self-care through access to ART, it furthers the medicalization of HIV. Volunteerism in HIV care work, in this context, intersects with desires to access training, capacity building, and the objectives of improving health and generating income (Prince 2013b, 587). Our research has allowed us to study the ways that humanitarian and global-health framings of the AIDS pandemic have shaped social and economic opportunities within communities and institutions while fostering new forms of biosociality, modes of volunteerism, and ideologies of empowerment and patient rights. When AIDS was declared a humanitarian crisis in Kenya, an apparatus for delivering care to the community was needed, as were community representatives. The first generation of people saved by ART were called on to assist in the cause; some played an important role in their communities, providing home-based care and other forms of psychosocial support, nurturing support groups and generating income, while others got involved in advocacy and activism, putting a face on AIDS, raising awareness about the disease, and shaping the national and international response to HIV. Some were compensated enough for their services that they could assemble careers in HIV-related work. When the crisis was declared over, however, most of them were no longer able to make a living.

In the scramble for income, some PLHIV who had gained knowledge and skills through trainings offered by NGOs sought work in clinical settings as peer workers, many of whom shifted from community-based work to work in public-health facilities and received temporary employment contracts, once again subsidized by international donors. Despite stated desires to advocate for PLHIV in health facilities, their contracts put them in a precarious position, forcing them to worry about the irregularity of compensation schemes tied to international funding, job insecurity, and the future availability of ART. Treated as temporary for more than a decade, they have promoted HIV treatment and positive living, helping public hospitals and their international partners achieve their targets. The after-crisis has often resulted in ambivalence among them. So-called experience experts, whose expertise far exceeded their experience of living with HIV, wanted to realize the greater involvement of PLHIV in biomedical spaces, as had been promoted in the crisis era, but instead often reported feeling disempowered and demoralized, undervalued, underutilized, and underpaid (Dlamini-Simelane 2017; Tenthani et al. 2012).

Conceptualizing empowerment as tied to aspiration and the desire to move forward with life projects, Prince (2012, 2013b) offers a lens to examine dimensions of vulnerability, uncertainty, and tension that arise in the face of redundancies, organizational dormancy, and meager wage allowances associated with the postcrisis HIV response. If we understand empowerment as meaningful to the extent to which it fosters resilience or helps people and communities move forward to achieve aspirational goals, we can critically examine the link between HIV humanitarian responses and the aims and objectives of (inter)national development. Our findings show that the declaration of HIV/AIDS as a crisis resulted in the emergence of a local economy of HIV and the NGO-ization of the HIV response, with a proliferation of structures, skills, knowledge, and opportunities, interwoven with expectations of income-earning opportunities and access to care, as well as notions of democracy, civic duty, and patient rights. These expectations were fostered and held not only by people directly involved with the HIV response, but also by their families and communities. The withdrawal of international aid for community responses to HIV in the after-crisis laid bare the ways in which income-earning opportunities and access to material aid had come to be understood as essential aspects of empowerment. In fact, for many involved in community-based work, empowerment and development are synonymous with income and access to material aid.

Our research draws attention to the ways that the community response to HIV in Kenya was dismantled and reassembled in the after-crisis, resulting in tensions around redundancies, dormancy, and sustainability of community programs. In line with the humanitarian mandate of saving lives and the promise of a return to normalcy, the international humanitarian response exited the HIV-response scene after the disease had been refigured as biomedically manageable (Bennett, Foley, and Pantuliano 2016; Goldstone and Obarrio 2017; Redfield 2005, 2013, 2017), leaving behind a community-based response obsessed with economic survival and providing support for people with a lifelong chronic condition that complicated any promise of a return to normalcy.

Over the last decade, Kenya has witnessed a near collapse of the once thriving NGO HIV support-group structure, as once well-funded community-based initiatives have become dormant in the wake of a global economic crisis and the near complete medicalization of HIV. Though this collapse has had particular effects on PLHIV who work in the HIV sector, it has resulted in diminished treatment-literacy levels among younger PLHIV and fewer public debates on patient rights while depoliticizing the HIV response more broadly.

The unfinishedness of the HIV pandemic continues to attract limited funding for community and PLHIV-led responses. Our research suggests that only organizations or groups that can reinvent themselves by changing their objectives and activities have survived. Similarly, only individuals with higher education levels can transfer skills and knowledge acquired during the crisis to the after-crisis milieu. It seems paradoxical that those with the most

need—people with low educational levels, particularly PLHIV—suffer the most when funding is cut for community-based responses. The very people who made the success of treatment programs possible cannot find work in public-sector health provision and NGOs because they are undereducated or unable to speak English sufficiently to satisfy the monitoring and evaluation requirements of donors increasingly interested in metrics.

There is a second paradox: as treatment becomes routinized and more people find their way into treatment programs, demands on the public-health sector are increasing. Much of the work required to maintain the success of HIV treatment is time intensive and low skilled—work like that which community-based peer workers did at the height of the crisis, work that many of them would be happy to do again, but only if they can earn a decent living while doing it. In 2020–21, we witnessed peer workers reinventing themselves in the face of a new pandemic: COVID-19. The skills they had honed working in HIV made them uniquely suitable for largely social community-based interventions, such as hand washing, social distancing, and mask wearing. Expertise in tracking PLHIV has translated to contact tracing. Though persistently undervalued in contemporary public health practices, community care workers in Kenya, many of them PLHIV, continue to play an integral role in patching together a public-health response to infectious disease.

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