

## Peer mentors, mobile phone and pills: collective monitoring and adherence in Kenyatta National Hospital's HIV treatment programme

Eileen Moyer\*

*Department of Anthropology, University of Amsterdam, Amsterdam, 1012 DK, the Netherlands*

*(Received 7 May 2014; final version received 13 May 2014)*

In 2006, the Kenyan state joined the international commitment to make antiretroviral treatment free in public health institutions to people infected with HIV. Less than a decade later, treatment has reached over 60% of those who need it in Kenya. This paper, which is based on an in-depth ethnographic case study of the HIV treatment programme at Kenyatta National Hospital, conducted intermittently between 2008 and 2014, examines how HIV-positive peer mentors encourage and track adherence to treatment regimens within and beyond the clinic walls using mobile phones and computer technology. This research into the everyday practices of patient monitoring demonstrates that both surveillance and adherence are collective activities. Peer mentors provide counselling services, follow up people who stray from treatment regimens, and perform a range of other tasks related to patient management and treatment adherence. Despite peer mentors' involvement in many tasks key to encouraging optimal adherence, their role is rarely acknowledged by co-workers, hospital administrators, or public health officials. Following a biomedical paradigm, adherence at Kenyatta and in Kenya is framed by programme administrators as something individual clients must do and for which they must be held accountable. This framing simultaneously conceals the sociality of adherence and undervalues the work of peer mentors in treatment programmes.

**Keywords:** peer mentors; HIV; adherence; surveillance; mobile phones

### Collective monitoring, collective adherence

We are expected in the peer mentors' room at Kenyatta National Hospital at 11 a.m., following the daily rush at the HIV treatment centre. With an hour to spare, we grab a cup of Kenya's finest coffee. Fifteen minutes later, my colleague, Emmy Igonya, gets a text from Charles, the head peer mentor at the hospital saying he is waiting for us, and we should come as soon as possible. We down our coffees and grab a cab, assuming there must be some miscommunication. As we are only 10 minutes away and anxious to get started on what is sure to be a busy day, we don't respond to Charles. We just go. After haggling with the driver over what is less than a dollar, we are driven quickly to the hospital over roads that are being resurfaced: a sign someone is investing in the city and hospital infrastructure?

Arriving at the peer mentors' room, we are welcomed warmly by Charles and four colleagues who are uncharacteristically crammed into the tiny two-by-two meter space. We are offered the two seats behind the desk and, once sitting, we see a young woman, perhaps in her early twenties, standing in the midst of the mentors, and looking expectantly at us.

Without pause, Charles incorporates us into what we slowly realize is some sort of group counselling/intervention session. With a big, knowing smile, he instructs me in Kiswahili:

---

\*Email: [E.M.Moyer@uva.nl](mailto:E.M.Moyer@uva.nl) or [eileenmoyer@hotmail.com](mailto:eileenmoyer@hotmail.com)

© 2014 The Author(s). Published by Taylor & Francis.

This is an Open Access article. Non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly attributed, cited, and is not altered, transformed, or built upon in any way, is permitted. The moral rights of the named author(s) have been asserted.

‘Tell her how you know me.’ A bit confused, I start to tell her how I had met Charles and a bit about my research. He stops me, ‘No, I mean *why* we know each other.’ Emmy, a bit quicker than me, figures out what he wants and replies, ‘We know you as a peer mentor; we know you because you are HIV positive.’ ‘You see!’ Charles shouts triumphantly, ‘You know I did not tell them what to say. Now do you believe us?’ Looking around at the other mentors, then to me, she asks in English: ‘What about them?’ ‘Yes’, I answer, ‘them too.’ Looking a bit shaky to me, she says to the room: ‘Okay, maybe I can accept they are HIV, but me, I am young. Is there someone young I can see?’

Amidst relieved laughter, several mentors suggest calling Paul, the youngest of the mentors, presumably busy somewhere else in the hospital. A text message is sent, and within a few minutes Paul arrives. At first, he assumes he has been summoned to greet me. As we are exchanging news, the girl breaks in, still speaking English: ‘Is it him? How do I ask him? What do I say?’ ‘Say *HIV*’, Charles tells her, as if it’s obvious. Looking at Paul, she hesitates and then asks, ‘Are you – HIV?’ Laughing, he says, ‘Yes, I was born with HIV’, and shakes her hand. ‘Kumbe! It’s true, it’s possible’. (Field journal, Nairobi, January 2014)

Mission accomplished. The woman has accepted the possibility that she could be HIV positive, despite being young and looking and feeling healthy. Having taken an HIV test earlier that morning at the hospital’s Voluntary Counselling and Testing (VCT) centre, she had been shocked by her results. The counsellors there, thinking she might need a bit more time to make sense of the positive diagnosis, had called Charles to ask him to give the woman extra attention. About 18 months earlier, the VCT had initiated a new policy to be followed when someone tested positive: a text message is sent to a designated peer mentor, who comes to the VCT centre and escorts the often disoriented client to the HIV Comprehensive Care Centre (CCC), where a file is established and the client is informed about further laboratory tests and treatment options. Prior to using the mentors as escorts, it was common for people to disappear from the hospital – and the hospital system – after testing positive. Seeing the issue as a logistical one, the head of HIV counselling, Dr David Bukusi, had solved the problem by having the mentors take people by the hand, sometimes quite literally, and walk them through both the bureaucracy and the sprawling grounds of the hospital.

The mentors were ideal for this task because they were inexpensive and their work duties were flexible by definition; they were expected to fill in when and where needed. Quickly, however, the counselling staff realized that peer mentors were effective at helping people to ‘accept their HIV status’ and convincing them to enter medical care, tasks that had previously been left to the counsellors. When Kenya revised its national HIV testing and treatment guidelines in 2008 to encourage more people to get tested, it was widely assumed, both in Kenya and globally, that once tested, those needing treatment would seek it out (Moyer et al. 2013). It has become increasingly apparent, however, that that follow up routinely does not occur after people test HIV positive (lost to follow-up), especially in contexts where counselling services and referral systems are weak (Rosen and Fox 2011). Among those who were working with HIV-positive people at the hospital, almost everyone interviewed agreed that ‘accepting’ the test result and the consequent shift in identity to being ‘a person with HIV’ were *the* critical first steps to treatment success, a consensus that suggested that increased psychosocial support around testing and treatment initiation could improve the likelihood that HIV-positive people receive the recommended care. Many of the new rapid testing initiatives, which target people in their homes, the workplace, at schools, and other community locales, provide limited counselling services, expecting those who test positive to report to a health facility for follow-up, which they often fail to do. Those involved in patient support who were interviewed at

Kenyatta and elsewhere in Kenya strongly believed that people who were tested without proper counseling were also among those who had the most difficulty accepting their HIV status and were most likely to struggle with adherence when they began treatment. Nurses, counsellors, peer mentors, and even patients pointed to the failure to accept one's HIV status as an explanation for clients being lost to follow-up, as well as for poor adherence and the failure to embrace a healthier lifestyle, all factors that shape treatment efficacy. By escorting clients, peer mentors pragmatically tackled the problem of HIV-positive people falling out of care through a practice that was simultaneously logistical and social, reducing the likelihood that clients would leave the hospital between testing positive for HIV and entering the treatment programme.

This paper investigates the logistical-social nexus of the tracking and monitoring of HIV-positive people at Kenyatta National Hospital and specifically examines the critical position of peer mentors within this nexus. Tracking and monitoring HIV-positive patients is a key component of any successful HIV treatment programme. Whereas much has been written about the way treatment programmes attempt to 'responsibilize' clients through medical counselling and advice giving (e.g., Nguyen 2010; Mattes 2011; Moyer, Burchardt, and van Dijk 2013), most of these arguments reinforce the notion of the client as an individual agent whose subjectivity is shaped through engagements with biopower. Medical surveillance is presumed to be both dehumanizing – turning people into numbers – and depoliticizing – concealing the political and economic factors that shape the who, what, where, and when of counting. Often conceived of as an abstract, blunt object, medical surveillance is rarely examined as an everyday practice entangled in social relations. Using Kenyatta as a case study, this paper argues that the tracking and monitoring of clients is a complex, collective, social task that is neither easily reduced to technocratic measures nor easily confined within the clinic's walls. A close examination of the daily practices of peer mentors demonstrates that both monitoring and adherence are collective, rather than individualized practices.

### **The 'success' of HIV treatment in Africa**

Antiretroviral treatment for HIV is a complex, life-saving medical technology that loses its efficacy if the prescribed drugs are not consumed in the directed manner. For antiretroviral treatment to succeed in medical terms, it must prevent the virus from mutating so that the medicines continue to work for the patient; halting such mutations is of benefit as well for the wider public, both now and in the future. The efficacy of antiretroviral treatment on a population level is measured by the number of lives saved/improved and the extent to which viral mutation has been avoided, both of which are best achieved when antiretroviral medication is taken as prescribed.

The fear of low adherence, viral mutation, and the possible emergence of untreatable HIV strains made scientists and global health policy makers hesitant to 'transfer' this technology to Africa and other low-resource settings in the late 1990s, when it was available in most Western countries (Farmer et al. 2001). In Kenya, the effectiveness of this technology was known in the late 1990s, and some were able to access treatment.<sup>1</sup> However, until 2003 it was considered 'inappropriate' for use in low-income settings by global health policy makers because it was too complex and too expensive. A combination of activism, a simplified antiretroviral pill regimen, and reduced medicine prices led to a global paradigm shift in the early part of the twenty-first century (Wilson and Blower 2006). These factors led to the expansion of antiretroviral treatment to countries such as Kenya that were hardest hit by the epidemic, setting the stage for a massive global health

initiative, the goal of which was the transfer of a complex medical technology to non-Western countries.

At the time, many naysayers expected ‘treatment scale-up’, as it has come to be known, to fail completely.<sup>2</sup> Public health care systems in much of Africa had been gutted by more than a decade of structural adjustment programmes and were already overburdened by nearly two decades of trying to treat people with AIDS. The few antiretroviral treatment trials that had been run in Africa had taken place in idealized, near laboratory-like settings with little resemblance to existing public health services (MSF 2002). Even those who desperately hoped treatment scale-up would succeed (the author included) could not see how this complex medical technology was going to work in the multiple and diverse settings that make up Africa. Yet, by most accounts treatment scale-up has succeeded. Over the last decade, antiretroviral treatment has become widely available in public health settings across Africa; millions of people are receiving treatment, millions of lives have been saved, and millions of HIV infections have been prevented. Despite the fears of the naysayers, treatment adherence has been high in Africa and viral mutation has been minimal. Research in diverse settings suggests that adherence rates in Africa average about 90%, exceeding adherence levels in North America and dispelling concerns that adherence would be inadequate in resource-poor settings (Ware et al. 2009). Ware et al. (2009), searching for an explanation for this unexpected success, suggest that the high levels of social support that people on treatment are likely to receive in Africa have a profound impact. This social support may come from family and friends, but it is also likely to come from health workers, support group members, and other treatment helpers who collectively encourage adherence by making their expectations known to the person on treatment and thereby increasing the person’s sense of responsibility. From this perspective, it is possible to conceive of both adherence and the monitoring of people on treatment as collective actions that combine social and logistical support.

From an anthropological perspective antiretroviral treatment is more than a combination of medicines: it is an assemblage of pharmaceuticals, services, and surveillance tools that travel to specific institutional settings around the world (Nguyen 2004). This treatment is accompanied by a set of medical ‘best practices’, guidelines that attempt to ensure that patients everywhere are subject to the same treatment regimen, and that those patients can be similarly counted and tracked. It also travels with social technologies, including support groups, counselling practices, and peer mentoring programmes (Robins 2009; Nguyen 2010; Kyakuwa, Hardon, and Goldstein 2011; Kielmann and Cataldo 2010; Moyer, Burchardt, and van Dijk 2013; Simbaya and Moyer 2013). These social technologies help to produce the success of antiretroviral treatment programmes by encouraging treatment adherence through the promotion of medical and social norms among people on treatment.

### **Research setting and context**

The arguments presented in this paper draw on an ethnographic study of the HIV Comprehensive Care and Treatment Centre (CCC) at Kenyatta National Hospital carried out between 2011 and 2014. The author has been conducting research on HIV in eastern Africa for more than 15 years and at Kenyatta for about six years;<sup>3</sup> the focused ethnography on peer mentors is one facet of this broader work. As part of her wider research, the author has also completed case studies among expert clients<sup>4</sup> in Mombasa, Kenya; Lusaka, Zambia; and Zanzibar, Tanzania. About six weeks in total were spent interviewing the 10 peer mentors working at Kenyatta and observing them during their daily duties

as they engaged with clients, one another, and other hospital employees. Additional staff working in the CCC were also interviewed, including nurses, social workers, administrators, and doctors. All interviews were conducted in English or Swahili by the author, who is fluent in both languages. Interviews with peer mentors provided important knowledge about their work and private lives, but observing them at work provided the most insight into the various and inventive ways they encouraged treatment adherence through informal conversations, counselling sessions, telephone calls, and participation in hospital-based support groups.<sup>5</sup>

Kenyatta is a teaching hospital and the top referral hospital in Kenya, and is considered among the best public hospitals in Africa. It receives complicated cases from all over the country and the greater east African region on a daily basis, while also providing emergency and long-term care to Nairobi's residents. HIV continues to require significant attention: in 2013, patients with HIV still occupied about one-third of hospital beds. While some of these were already on treatment, it was still relatively common for patients with advanced AIDS to arrive at the hospital having never been tested for HIV. As the hospital is located at the edge of Kibera, an area of the city often referred to in the development literature and media as 'the biggest slum in Africa', a great many, but certainly not all, of the hospital's patients are poor and working class.

Toward the back of the sprawling complex of buildings that make up the hospital, one finds the CCC. The CCC is housed in and is administered by the hospital, but receives a great deal of financial support from various international funding agencies. As in other African health care settings, AIDS care is better funded and is housed in better facilities than is care for other diseases. Most notably, the CCC has been a Partnership for Advanced Care and Treatment (PACT) Centre of Excellence since 2010. PACT is the lead partner on a five-year CDC/PEPFAR<sup>6</sup> grant to develop centres for HIV treatment and care excellence in some of Kenya's top public hospitals, including Kenyatta National Hospital. The CCC is better staffed than most other hospital departments, and the PACT project supplements the salaries of some nurses and counsellors, as well as a small group of HIV-positive people who work as peer mentors in the hospital. The peer mentors are nominally paid by PACT, but they are considered part of the regular HIV counselling staff of the hospital and are supervised accordingly. It is unclear who will pay the salaries of the peer mentors once the PACT project is complete. Several peer mentors began working in the hospital prior to the arrival of PACT and have been paid successively (although intermittently) by several different projects. There is talk among the hospital administration about regularizing the peer mentors and making them permanent staff, but some peer mentors are against this as they do not trust the hospital's bureaucracy to recognize their experience-based expertise and fear they will be replaced by people with academic training.

The work the peer mentors do is varied and challenging and requires them to perform a difficult balancing act as they strive for recognition as equals among hospital staff while simultaneously advocating for better care and treatment for patients who have been institutionally defined as their peers. The peer mentors work throughout the hospital, filling various gaps in care and improving linkages between departments. After a series of institutional struggles, they were assigned their own office, a two-by-two metre room in the CCC formerly serving as the 'broken objects room'. The irony was not lost on the peer mentors, most of whom passed through the office several times a day to check in and share stories with their fellow workers or to counsel clients. The peer mentors occupied a decidedly liminal space in the CCC, both physically and semiotically, seen as health workers by clients and as people living with HIV by other health workers.

### Everyday practices of care between clients and expert clients

It is not uncommon in many African settings, where landlines and Internet communications are spotty, for people to ask employees working in institutional settings for their private mobile numbers. People might, for example, have the private numbers of police officers, taxi drivers, airline employees, and so on, stored in their phones. Some might read this as the first step toward corruption, using private affective relations to gain preferred access to public services. It may also be read as a refusal of the institutionalization of power – an act of everyday resistance to power. Perhaps. But, just as likely, this can be understood as an act of everyday logic, a sensible, pragmatic response to the fact that institutions rarely work as promised. Horst and Miller (2006), who conducted research on mobile phone use in Jamaica, noted that phones were instrumental for creating social networks, in addition to the micro-coordination of activities ‘on the go’. Horst and Miller (2006) did not specifically examine the way phones were used to create social networks between those working in public service and their clients; the ‘link-up’ practices they describe for Jamaica, however, are similar to those we observed in Kenya, where mobile phones were the key communication technology used to create links between people with HIV and their peers working in the health sector.

During research among expert clients in Nairobi and Mombasa, Kenya, in January 2011, it was observed that people living with HIV who worked in health care delivery frequently exchanged telephone numbers with clients and their families. When people recently diagnosed with HIV asked expert clients for their phone numbers, it was often the first step to accepting a new HIV-positive identity and a way of actively creating a new social network around that identity that could provide support. The exchange of telephone numbers also gave expert clients a way to follow up with the newly diagnosed patients, providing a means of monitoring their health, their entry into medical care, and their adherence. Having the mobile number of a trusted expert client at the treatment centre allowed HIV-positive clients to coordinate the logistical details of hospital visits and drug pick-ups, as well as elicit information and advice about the daily challenges of living with HIV, which spared them additional trips to the clinic. Whereas some clients routinely reached out to expert clients, others simply stored the numbers in case of a crisis yet to come. When an HIV-positive individual seemed to be in crisis – physical, social, economic, or psychological – expert clients would usually make it their business to follow up with the individual, organizing care on their behalf, intervening with family if necessary, and sometimes even visiting them at home.

Despite the common practice of getting numbers from people working in institutions, HIV-positive clients in Kenya rarely asked doctors or nurses working in public hospitals for private numbers, nor did doctors or nurses offer to give them out. (An exception to this pattern was found among patients who knew the doctors or nurses before their diagnosis.) Although clients often did not know that the term ‘peer’ indicated an HIV-positive status, they usually seemed more at ease with peer mentors than with doctors or nurses, reporting that peers ‘had more time’; were more open to discussing issues related to sexuality, dating, disclosure, and family without being overly judgemental; and often had greater practical knowledge about living with HIV, as well as tips for taking medicines as prescribed and minimizing side effects (Kielmann and Cataldo 2010; Kyakuwa 2010; Dapaah and Moyer 2013). Although peer mentors were perfectly willing to disclose their HIV status to clients, they rarely did.<sup>7</sup> Despite this, clients tended to associate more easily with peers than they did with other medical personnel; they imagined them as people desirable to ‘link up’ with, that is, to incorporate into their social networks for

instrumental purposes related to their disease that might emerge at a later date, beyond the clinic.

Similar practices were observed elsewhere in Kenya, Tanzania, Zambia, Ghana, and Swaziland where we have also conducted research into expert client programmes.<sup>8</sup> The sharing of phone numbers seems to be even more common among expert clients who work in the same communities where they live and where they are known amongst their neighbours as HIV experts who are able to offer a wide range of information about the complexities of living with HIV in an open, supportive, and non-judgemental manner.

It seems that much of the care work that expert clients do in both health facilities and in the community is facilitated by mobile telephony. Expert clients can be reached at any time to address questions related to HIV care and management, a fact that led several to comment that they were never free from work. One noted that she had to force herself to turn her phone off in the evening and on Sundays because she had come close to burning out in the past, spending all her time attending to clients in crisis. Because the phones that are used are usually privately owned, expert clients generally absorb the expense of such communications. Clients will 'flash' them, or send them a text message requesting a call, or will pay for a call just long enough to request help. Similar to what Horst and Miller (2006) observed, the matter of who paid for a call indicated assumptions related to material hierarchies, expertise, and expectations of responsibility. Expert clients were expected to pay for the calls because they were connected to institutions and were presumed to receive a reasonable salary, or even to be reimbursed for calls. In fact, most peer mentors receive very low pay (if they are paid at all) and do not receive any phone credit, unless they are participating in a specific intervention project.

Interviewing expert clients about the relationship between mobile telephone use and care usually resulted in rather mundane answers, perhaps a reflection on the fact that mobile telephones have quickly become a rather mundane technology in Africa (de Bruijn et al. 2009). Despite numerous invitations by the researcher to get expert clients to expand on the ways that mobile phones shaped care, those interviewed would generally stick to basic descriptions, such as: 'Well, they allow us to follow-up more easily.' By contrast, observing what expert clients did with their phones, specifically the peer mentors working at Kenyatta, yielded much more insight. Similar to what we observed elsewhere, peer mentors at Kenyatta went to extraordinary lengths to make themselves available to their clients, including giving out their private phone numbers to clients they met at the hospital and when visiting patients in their homes.

The Kenyatta CCC is also expanding the formal use of mobile telephony as a means of promoting treatment adherence. Over the last several years, mobile phones have come to be increasingly used for patient surveillance and to encourage adherence across Africa. A few examples: in Uganda and elsewhere, phones have been used to spread health information in the form of text-based quizzes where winners receive phone credits. In Zambia, Kenya, Tanzania, and several other African countries, PEPFAR-funded 'mentor mothers', HIV-positive women who have already given birth to an HIV-negative child, have been enlisted to 'buddy-up' with HIV-positive pregnant women, and were given phones and weekly phone credits to facilitate their tasks; and a programme run by the Elizabeth Glazer Pediatric AIDS Foundation in Tanzania sent out weekly text messages to rural mothers with detailed accounts of how their foetuses were developing, with the aim of improving prenatal care and lowering infant and maternal mortality rates.<sup>9</sup>

The Kenyatta CCC gives peer mentors the task of making follow-up calls to patients who fail to appear for scheduled appointments. The mentors normally use their own phone, inserting a SIM card belonging to the clinic and loading it with prepaid phone

credit bought from vendors working on the hospital grounds when money is available for the purpose. In the language of HIV intervention, those unruly subjects who fail to attend appointments or collect drug refills are known as 'treatment defaulters'. Peer mentors are routinely employed to 'trace treatment defaulters' by telephoning them when they miss appointments, or, when that fails, visiting them at their homes.

In 2012, the peer mentors at Kenyatta kept ledger books with patients' names, ages, genders, treatment regimens, and phone numbers. When patients failed to show up for an appointment, they received a follow-up call within three days. If they were unreachable and funds were available, someone would be sent to track them. This was a full-time task, and a peer mentor was almost always on the phone in the peer mentors' office.

Paul, in his early twenties and the youngest of the peer mentors, seemed to spend the most time on the phone, calling clients who had missed appointments from the cramped office. As the office was hardly private, and was the place the researcher was invited to sit while waiting to conduct interviews, there was ample time for observation. Even within the context of a project-funded programme (the 'defaulter tracing' programme was funded by PACT), the availability of calling credit was never a given. It seemed Paul spent a great deal of time waiting for money to buy credit. When the green and red Safaricom phone credit cards were finally obtained, he would scratch the back to reveal the code, enter it into his phone and begin making calls. Generally he just went down the list, calling people who had missed recent appointments using the phone numbers noted in the ledger. Normally, a few of the numbers would be out of service. Paul said that this was because the nurses who saw the clients sometimes wrote the number down wrong or failed to update the numbers when clients changed them. People also sometimes gave a wrong number, hoping to avoid surveillance or to maintain their privacy. Paul said that numbers could be easily checked by 'flashing' the client at the moment that he or she provided the number to make sure it was correct. As this was a common social practice beyond the clinic, it seemed a reasonable means of checking.

When Paul did reach someone, he was always exceedingly polite and circumspect. He tried his best to get the actual client on the phone without raising suspicion, trying to keep the client's confidentiality. He would say he was calling from the hospital, but make no mention of the clinic or what the call was about. Even when speaking directly to the client he would be vague, saying simply that he was calling to reschedule the hospital appointment they had missed, making no mention of the CCC or HIV. Usually, people were happy to hear from him, informed him that they had simply forgotten the appointment, and agreed to reschedule.<sup>10</sup> If the client was being treated with antiretroviral medicines, Paul would ask if the client had enough pills to last until he or she came to the clinic and remind him or her of the importance of not missing a dose. Most days he reached a few clients who informed him that, indeed, they had not missed their appointment and that they had been at the clinic the day before and picked up their medicines. This would happen when the nurse on duty forgot to update the ledger. Some clients might also report that they had come to the clinic but had been refused service because their file could not be found. This, again, was a mistake that Paul was ready to blame on the nursing staff.

The phone calls, it seemed, not only tracked patients who defaulted, but also provided a window into the logistical difficulties of tracking patients within the clinic, even one that was considered a centre of excellence. The phone calls also highlighted tensions between the peer mentors and the nursing staff: Paul was not the only mentor to assign blame to nurses when clients did not receive quality care. Nurses working at the CCC who were interviewed for this project seemed to appreciate the work the peer mentors did, but also complained that the peer mentors occasionally overstepped their duties.



Similar tensions between nurses and expert patients have been observed in Ghana (Dapaah and Moyer 2013), and can be partially explained by the fact that the duties of peer mentors are rarely concretely defined and are constantly shifting depending on external projects.

### **The social-logistical nexus of surveillance**

Much has been made of the way public health surveillance works as a form of 'governmentality', controlling the subjects it tracks and shaping subjectivities (Hacking 1986; Strathern 2000; Sangaramoorthy 2012); less attention has been paid to the way that surveillance shapes relations between those tasked with tracking, and between trackers and those being tracked. A focus on numbers may conceal subjects as it produces new subjectivities among those being counted, but it also conceals the subjects who do the counting. Observing the peer mentors at work reveals that surveillance is not a blunt object; the practice of tracking is an art requiring cleverness, patience, respect, and confidentiality.

Although the staff at the Kenyatta CCC still worry about patient adherence, they have come to understand that clients may 'fall out of care' as a result of gaps in the system, including logistical issues such as failing to update phone numbers, documenting patient attendance, or keeping track of a client's file. Clients may also get 'lost' between their diagnosis at one of the hospital's VCT centres or wards and their enrolment at the CCC. They may also be labelled as 'lost to follow-up' after enrolling at the CCC if they fail to return for laboratory test results, routine monitoring, or medicines. Providing logistical support by managing client files, calling clients who have missed appointments, and accompanying clients from the VCT and hospital wards to the CCC are some of the key ways that peer mentors track clients through interpersonal contact.

Much of what PACT has done at the Kenyatta CCC since 2010 to make it a centre of excellence relates to efforts to iron out logistical issues, specifically through the use of computer and mobile phone technologies and the employment of peer mentors to keep track of clients receiving care. Key to this process has been the gradual replacing of hand-written records (patient ledgers, files, lab reports) with a computerized record system known as IQCare, and the training of staff, including peer mentors, to use this system. A state-of-the-art laboratory facility was also built with project funding, meaning that CD4 counts, viral loads, and tuberculosis testing can now be done within the CCC,<sup>11</sup> and test results can be immediately uploaded into the IQCare database. These changes are meant to make tracking clients within the hospital and between visits much easier – as long as the records are kept up to date. By late 2013, the ledger used by peer mentors to track clients had been replaced by a computerized database. In January 2014, the peer mentors had begun updating clients' contact information in preparation of an initiative to send reminder text messages to all clients before their appointments. A similar programme had been instituted in the second half of 2013 for the Prevention of Mother to Child Transmission (PMTCT) programme; in October 2013, 100% of PMTCT clients returned for scheduled clinic visits, a stunning success.

The VCT centre had also standardized the utilization of peer mentors to improve linkages between testing and treatment. Since 2012, clients who test HIV positive at a VCT centre are escorted by a peer mentor to the CCC. The peer mentor, who is informed when a client tests positive via a text message or quick call from one of the counsellors at the VCT, makes sure new clients know where the CCC is, explains the various tests they will have to undergo, provides additional peer counselling if needed, and reassures clients of

the possibility of living a long and healthy life with HIV, using their own story as an example when necessary.

Kenyatta National Hospital plays an important role in the nation's public health response to HIV. Interventions that prove successful there often become policy and are exported to public health facilities nationwide. Although most of the peer mentors at Kenyatta are currently remunerated through external project funding, the hospital is discussing formalizing their employment and making them part of the civil service. Similarly, it is hoped that the computerized patient tracking system currently in use at the CCC will begin to be used throughout the hospital, and eventually nationwide. Questions remain as to the extent to which such peer mentoring and patient tracking might suffer from being formalized: are peer mentors better positioned to advocate for clients from the margins of the health system? What happens when mobile telephony and computers are formally used by health facilities to track patients in place of or in conjunction with peer mentors?

The formal use of telephones to track patients at Kenyatta differs from the informal use of telephones by peer mentors and other expert clients in several key ways. First, in the formal system, communication is unidirectional: peers can call or send text messages to clients, but not the other way around. This differs from the more socially embedded practice, whereby clients and peers exchange numbers. Second, communication is more anonymous in the formal system: the client may not even know the peer making the call, or may get a generic text message without a signature. Third, the calls and texts that are initiated via the formal system are more medicalized: specific information relating to HIV treatment is conveyed, with little opportunity for questioning or situating treatment challenges within a wider social frame. Finally, in the formal system, the responsibility for the call (as indicated by who is paying for it) is shifted to the hospital or the funded project, altering the politics of 'linking up'.

All of this suggests that patient monitoring and tracking is becoming more anonymous at Kenyatta. Will this diminish peer mentors' motivation to go the extra mile to encourage adherence? Will it discourage the formation of personal bonds between peer mentors and individual clients? Will adherence rates suffer as a result? Only time will tell.

## **Conclusion**

The desire to promote adherence in Africa has given impetus to the development of HIV treatment initiatives that exist parallel to national health-care programmes. These parallel initiatives routinely incorporate a range of social services to encourage adherence over time and across space. These social services are usually conceived in an ad hoc manner and are performed by an underpaid and semi-volunteer workforce of (often) HIV-positive people. They have commonly taken the form of peer mentor programmes, support groups, and home- or community-based outreach and care programmes, and have usually been funded by short-lived external projects with the presumption that they were both temporary and necessary to get treatment programmes up and running.

While the care delivered by peer mentors to clients is highly valued by the clients, it is barely recognized by treatment programme administrators. When interviewed, most admitted they did not really know exactly what peer mentors did, nor how they did it. This may explain why peer mentors are normally paid through external project funding, but it may also be that hospital administrators do not value the work peer mentors do precisely because they are paid through external project funding. Because most expert client programmes in Africa have been instigated by external projects,

African public health policy makers and medical administrators have been slow to acknowledge their importance in promoting adherence, tracking clients, and increasing the overall success of treatment. Framed by donors and public health experts as people who ‘fill gaps’ in health systems by taking over nursing, counselling, and clerical tasks as needed, expert clients are usually understood as an inexpensive and temporary solution to overburdened national health programmes rather than as integral to programmatic success.

Expert clients are not commonly employed to track and monitor client adherence outside of Africa. Rather, clients are tracked elsewhere via technologically complex computer systems, and adherence is monitored via viral load testing. The absence of these technologies in most African health care settings to date has meant that many clients have been ‘lost to follow up’, but it has also meant that those who have enrolled in treatment programmes have been embedded in a system of social support through which adherence is collectively encouraged and monitored.

The peer mentor programme at Kenyatta is just one of the important social technologies that form the social-logistical nexus that has contributed to high adherence rates in Africa. Antiretroviral treatment ‘works’ at Kenyatta and elsewhere in Africa largely because of the collective monitoring of clients by those working in the clinics where care is provided. Such work requires an understanding of the complex challenges that shape the everyday lives of HIV-positive people on treatment, a quality that defines the peer mentors.

### Acknowledgements

Special thanks to Emmy Kageha Igonya, David Bukusi, Charles Obangi, and Charles Oguto for allowing the author to ‘put them on speed dial’ on her Kenyan phone. A preliminary version of this paper was presented at the 2012 American Anthropological Association on a panel organized by Rossio Motta and Rima Praspaliauskiene. Thanks to them and to Marianne de Laet for her thought-provoking discussion of the author’s paper at the AAA. Thanks as well to Josien de Klerk, Anouk de Koning, Jenna Grant, and Vinh-Kim Nguyen for their close reading of prior drafts of the paper and to Erin Martineau for her careful editing. Research for this paper was funded by the Netherlands Organization for Scientific Research (NWO) as part of the Integrated Program ‘Filling the Gap: Social institutions and AIDS in Kenya, Tanzania, and Zambia’. Ethical approval for this study was granted by the Kenyan Ministry of Education, Science and Technology, and Kenyatta National Hospital/Nairobi University.

Conflict of interest: none.

### Notes

1. Interviews with Kenyan HIV activists indicate that it was possible to obtain antiretroviral treatment through international activists or through other connections in Western countries, but that such opportunities were both rare and unreliable. Sources paint a picture similar to what Nguyen (2010) described for Abidjan around the same time, where treatment was available to those few who could afford it or who had the right international connections.
2. Writing in 2001, Farmer and colleagues described the refusal to expand treatment to poor countries as the ‘unmentioned elephant in the conference rooms of many scientific meetings’ (Farmer et al. 2001, 404).
3. The author has been the lead research coordinator on three HIV-related anthropological studies conducted at Kenyatta National Hospital since 2008. See, for example, Moyer and Igonya in this issue; Igonya and Moyer (2013); Moyer et al (2013).
4. ‘Expert client’ is a term used to refer to HIV-positive people who are employed in HIV care and treatment programmes. At Kenyatta they are referred to as ‘peer mentors’, but elsewhere

- they may be called ‘expert clients’, ‘expert patients’, ‘peer counsellors’, etc. For an excellent review of expert client programmes, see Kielman and Cataldo (2010).
5. Peer mentors attended various support groups as both facilitators and as participants. Although support groups are generally considered separate from peer mentoring, in practice there was much overlap between these two social technologies at Kenyatta.
  6. United States Centers for Disease Control/President’s Emergency Plan for AIDS Relief.
  7. As one peer mentor explained, ‘Being HIV positive is not a profession.’ Peer mentors normally only disclosed their status as a means to convince clients who were experiencing a psychological or existential crisis following diagnosis or who were refusing to take treatment as advised.
  8. Dapaah and Moyer (2014). See also Kyakuwa, Hardon and Goldstein (2012).
  9. All of these projects have been observed by the author. For more examples, see Chi and Stringer (2010) and Lester (2013).
  10. A notable exception, and a story the peer mentors liked to tell, occurred when a mentor unknowingly called a hospital doctor who was on treatment. The doctor reportedly felt that her privacy had been violated and tried to bring an end to the entire programme. The mentors told this story with much amusement, pointing out that stigma was often highest among those in power.
  11. CD4 cell counts and viral load testing are done to measure the stage of the disease and the extent to which treatment is working. A high CD4 count and a low viral load are desirable.

### Notes on contributor

**Eileen Moyer** is associate professor of cultural and medical anthropology at the University of Amsterdam. Her research focuses on HIV, youth cultures, and urban health in eastern Africa, particularly Tanzania and Kenya.

### References

- Chi, Benjamin H., and Jeffries S. A. Stringer. 2010. “Mobile Phones to Improve HIV Treatment Adherence.” *The Lancet* 376 (9755): 1807–1808.
- Dapaah, Jonathan Mensah, and Eileen Moyer. 2013. “Dilemmas of Patient Expertise: People Living with HIV as Peer Educators in a Ghanaian Hospital.” *Ghana Studies* 14–15: 195–222.
- De Bruijn, Mirjam, Francis Nyamnjoh, and Inge Brinkman, eds. 2009. *Mobile Phones: The New Talking Drums of Everyday Africa*. Leiden: African Studies Centre.
- Farmer, Paul, Fernet Léandre, Joia S. Mukherjee, Marie Sidonise Claude, Patrice Nevil, Mary C. Smith-Fawzi, Serena P. Koenig, et al. 2001. “Community-based Approaches to HIV Treatment in Resource-poor Settings.” *The Lancet* 358 (9279): 404–409.
- Hacking, Ian. 1986. “Making up People.” In *Reconstructing Individualism*, edited by T. C. Hellner, M. Sosna, and E. Wellbery, 222–236. Stanford, CA: Stanford University Press.
- Horst, Heather A., and Daniel Miller. 2006. *The Cell Phone: An Anthropology of Communication*. Oxford: Berg.
- Igonya, Emmy Kageha and Eileen Moyer. 2013. “Putting Sex on the Table: sex, sexuality and masculinity among HIV-positive men in Nairobi, Kenya.” *Culture, Health & Sexuality* 15 (sup 4): S567–S580. doi: 10.1080/13691058.2013.815367
- Kielmann, Karina, and Fabian Cataldo. 2010. “Tracking the Rise of the ‘Expert Patient’ in Evolving Paradigms of HIV Care.” *AIDS Care* 22 (S1): 21–28. <http://dx.doi.org/10.1080/09540121003721000>
- Kyakuwa, Margaret. 2010. “More Hands in Complex ART Delivery? Experiences from the Expert Clients Initiative in Rural Uganda.” *African Sociological Review* 13 (1): 143–167.
- Kyakuwa, Margaret, Anita Hardon, and Zoe Goldstein. 2012. “The Adopted Children of ART: Expert Clients and Role Tensions in ART Provision in Uganda.” *Medical Anthropology* 31 (2): 149–161.
- Lester, Richard D. 2013. “Ask, Don’t Tell: Mobile Phones to Improve HIV Care.” *New England Journal of Medicine* 369 (19): 1867–1868.
- Mattes, Dominick. 2011. “We Are Just Supposed to Be Quiet: The Production of Adherence to Antiretroviral Treatment in Urban Tanzania.” *Medical Anthropology* 30 (2): 158–182.

- Moyer Eileen, Rijk van Dijk, and Marian Burchardt. 2013. "Editorial Introduction: Sexuality, Intimacy and Counselling: Perspectives from Africa." *Culture, Health & Sexuality* 15 (supp 4): S431–S439. doi: 10.1080/13691058.2013.829977
- Moyer, Eileen, Emmy Kageha Igonya, Roselijin Both, and Peter Cherutitch. 2013. "The Duty to Disclose HIV status in Kenyan Health Facilities: Three Models of Disclosure from Everyday Practice." *SAHARA-J* 10 (S1): S60–S72.
- Nguyen, Vinh-Kim. 2004. "Antiretroviral Globalism, Biopolitics, and Therapeutic Citizenship." In *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*, edited by A. Ong and S. J. Collier, 124–144. London: Wiley-Blackwell.
- Nguyen, Vinh-Kim. 2010. *The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS*. Durham, NC: Duke.
- Robins, Steven. 2009. "Foot Soldiers of Global Health: Teaching and Preaching. AIDS Science and Modern Medicine on the Frontline." *Medical Anthropology* 28 (1): 81–107.
- Rosen, Sidney and Matthew P. Fox. 2011. "Retention in HIV Care between Testing and Treatment in Sub-Saharan Africa: A Systematic Review." *PLoS Medicine* 8 (7): 1–16.
- Sangaramoorthy, Thurka. 2012. "Treating the Numbers: HIV/AIDS Surveillance, Subjectivity, and Risk." *Medical Anthropology* 31 (4): 292–309.
- Simbaya, Joseph and Eileen Moyer. 2013. "The emergence and evolution of HIV counselling in Zambia: a 25-year history." *Culture, Health & Sexuality* 15 (sup4): S453–S466. doi:10.1080/13691058.2013.794477
- Strathern, Marilyn. 2000. *Audit Cultures: Anthropological Studies in Accountability, Ethics and the Academy*. London: Routledge.
- Ware, Norma C., John Idoko, Sylvia Kaaya, Irene Andia Biraro, Monique Wyatt, et al. 2009. "Explaining Adherence Success in Sub-Saharan Africa: An Ethnographic Study." *PLoS Medicine* 6 (1): e1000011. doi:10.1371/journal.pmed.1000011
- Wilson, David P., and Sally M. Blower. 2006. "Rational Choices for Allocating Antiretrovirals in Africa: Treatment Equity, Epidemiological Efficiency, and Feasibility." *PLoS Medicine* 3 (3): e160. doi:10.1371/journal.pmed.0030160