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Routines, hope, and antiretroviral treatment among men and women in Uganda

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Abstract

Antiretroviral treatment programs, despite biomedical emphases, require social understanding and transformations to be successful. In this paper, we draw from a qualitative study of HIV treatment seeking to examine the drug taking routines and health-related subjectivities of men and women on antiretroviral treatment (ART) at two sites in Uganda. We show that while not all participants in ART programs understand clinical protocols in biomedical terms, they adopt treatment taking strategies to integrate medication into daily practices and social spaces. In turn, these embedded practices and understandings, shape long term hopes and fears for living with HIV, including the possibility of a cure. More significant than new forms of citizenship or sociality, the authors suggest that quotidian dimensions of treatment normalization shape the long term experience of medication and outlook for the future.

Keywords

Uganda; HIV; antiretroviral; routine; treatment literacy; hope

Introduction

The reality of life-saving and health-restoring treatment for HIV infection is now common in many regions. However, rollout of antiretroviral treatment (ART) has been uneven, disproportionate, and frequently troubled (David 2014; Høg 2014; Kenworthy and Parker 2014). For those on medication, the process of taking treatment is embedded in social processes and concerns, and thus becomes part of the so-called new “normal” of living with HIV over a long period of time (Hardon and Moyer 2014a; McGrath et al, 2014; Moyer and

Hardon 2014; Russell, Seeley, and Whiteside 2010). Accessing medication, however, involves understanding and knowledge of treatment protocols as imparted by clinicians, counselors, and pharmacists (Dowse, Barford, and Browne 2014). The experience of taking medication is also impacted by the understanding and perception of how the medication acts in the body, and the hope or fear of how treatment will impact long-term disease management. In sum, the experience of being HIV infected and on medication is fundamentally social in nature (Doyal and Doyal 2013). As anthropologists, we respond to Hardon and Dilger's call to "emphasize not the biomedical norms governing ART programs but the sociocultural and economic ambiguities that occur in practice... [to] show how patients negotiate ongoing challenges to adherence in everyday life" (2011:149).

In this paper, we examine medication-taking routines and health-related subjectivities of men and women on antiretroviral treatment (ART) at two sites in Uganda, as they relate to the hope derived from drug taking. Drawing from a qualitative study of HIV treatment seeking, we examine how participants both develop treatment routines to maintain ART adherence and interpret how medication works. In turn, these embedded practices and understandings, woven into the daily fabric of living with the disease in Uganda, shape long term hopes and fears for living with HIV, including the possibility of a cure. As clinics impart the rules and regulations that accompany treatment, they aim to produce compliant patients through practices and understanding (Hardon and Moyer 2014b; Nguyen 2005, 2009; Niehaus 2014; Prince 2012; Rasmussen 2013). However, while many patients develop treatment routines and integrate the practices into their daily lives, this does not always link to understanding of how treatment works in the body. Instead, men and women base these practices on hope that treatment will heal them, despite ongoing fears and uncertainty about the future. These narratives and experiences echo what Whyte et al. refer to as the "intensely social character of accessing treatment and staying alive" (2014:17).

Normalization: Everyday life on ART

Recently, there has been an emphasis on the normalization of HIV and a move away from exceptionalism (Hardon and Moyer 2014a; Russell et al 2007). Normalization in this context has two dimensions: incorporation of HIV into daily life of individuals and integration of HIV into the "normal" life of communities. The primary emphases of this literature have been on ways in which treatment, self-care, stigma reduction, and integrated clinical care contribute to the process of normalization (Hardon and Moyer 2014a; Mattes 2012; McGrath et al 2014). Alongside this is development of routines and daily practices surrounding HIV medication. At the same time as treatment becomes normal for patients and a part of their social lives, some treatment programs themselves are becoming more narrowly biomedical, removing social and personal concerns from the scope of treatment access (Kalofonos 2014; Marsland 2012; Moyer and Igonya 2014; Prince 2012).

Treatment routines are inextricable from long-term experience of the disease. While social barriers to treatment access have been examined across contexts and found to be significant (Nyanzi-Wakholi et al 2012), less attention has been paid to home life and practices of pill-taking in ART. Talam et al (2008) found key factors affecting adherence among a cohort in Kenya to be patients' busyness, being away from home, and forgetting. Recent changes in

drug regimens have reduced the number of pills patients need to take to as few as one pill per day, instead of multiple pills multiple times per day. This change recognizes the burden of trying to incorporate medication into daily life (Tweya et al 2014). In Uganda, Martin et al (2013) examined the dimensions of “self-management” required for ongoing adherence to ART. They found patients were attuned to the multiple responsibilities of obtaining and taking medication, managing illness-related identities, and monitoring their health. We argue that these practices are embedded in daily routines of patients on HIV treatment and are based on faith in treatment efficacy and hope for future health. The normalization of medication is negotiated on a daily basis at the individual and household level, not only at the clinic, and contributes to construction of pharmaceutical selves and treatment-related practices within a patient’s “local moral world” (Mattes 2012), or what Le Marcis refers to as “mundane transformations” (2012:490). A strength of qualitative and anthropological approaches to studying HIV has been to contextualize the experience of the illness within social lives, relationships, and communities, making life with HIV the object, rather than HIV itself (Biehl 2007; Hardon and Dilger 2011; Hirsch et al 2009; Le Marcis 2012; Prince 2012). To fully understand how patients construct experiences of HIV and long term survival, we argue, it is necessary to examine how treatment-related routines develop as a particular set of practices.

Hope and treatment outlook

Hope in the context of HIV is defined variably and can range from hope for a cure to hope that medication continues working (McGrath et al 2014; Russell et al 2007). Hope is shaped by an individual’s illness history, understanding of treatment, and broader life circumstances (Bernays et al. 2014). Recently, hope has emerged as a focus due to the increasing ability to treat and live with HIV over many years (Dilger and Luig 2010). With this backdrop of uncertainty, hope is variable and heavily context-dependent (Le Marcis 2012).

The rollout of ARVs has induced cautious optimism in many places. Johnson (2012) reports in Malawi that for those on ARVs hope intertwines with feelings of stigma. Those on treatment who are able to overcome stigma have the possibility of future planning and livelihood restoration. Similarly, self-stigmatization decreased and hope increased with time spent on ARVs in Uganda (Bedingfield et al 2014; Tsai et al 2013). Tsai et al (2013) attribute this to decreased symptom burdens and improvements in physical and psychological well-being. However, another study also found that the “financial and social struggles introduced by AIDS” were not reduced by ongoing treatment (Bedingfield et al 2014:75). The decrease in fear of an AIDS-related death was the greatest change or “revelation” of treatment. Relatedly, Mutabazi-Mwesigire et al (2014) found that even with restoration of hope, individuals at the central referral hospital in Kampala faced challenges of poverty and other factors negatively influencing their quality of life. Le Marcis (2012), likewise, questions the narratives of individual transformation within clinical settings, given the intense biosocial transformations that must be undergone in all realms of an individual’s life, particularly the domestic sphere.

While hope for the future marks some experiences on medication, uncertainty has marked long-term expectations since the early days of HIV (McGrath et al 2014; Moyer and Hardon

2014). Unanticipated effects of treatment rollout can shift experiences between hope and uncertainty, particularly in settings with treatment stockouts (David 2014). Curran et al (2014) found that initiation of treatment for couples, even with counseling, can lead to fears of early death from treatment complications, worries about side effects, and what treatment can mean for someone who otherwise appears healthy. Faith in the efficacy of treatment and management of these fears, then, is crucial to an individual's sense of hope (or lack thereof) and desire to adhere to ART, regardless of technical understanding of how the medication works.

Treatment baggage

For a patient, the initiation of ART comes with rights and responsibilities of adherence that may require new forms of understanding about the medication and how it acts on the body (Hardon and Moyer 2014b; Nguyen 2005, 2009; Niehaus 2014; Prince 2012). As Hardon and Dilger write, protocols and guidelines of treatment act as “baggage” in the distribution of medication (2011:149) but are inseparable from clinical interactions. Clinical instructions and clinical encounters can act in ways that reshape notions of self, citizenship, and health (Hardon and Moyer 2014b; Nguyen 2005, 2009; Prince 2012; Russell et al 2015). Those on medication are given information about HIV, medications, and related tests in clinical encounters that may or may not include individual counseling and follow-up questions, giving primacy to “biological identity” (Marsland 2012:475). Despite a clinic's best efforts, the interpretation of how medication acts on the body and patient self-efficacy can vary widely by individual (Nozaki et al 2013). Similarly, individual subjectivity and physiological responses to treatment shape perceptions of medications and understandings of how they act on the body (Nachega et al 2005; Nozaki et al. 2013).

The clinical encounter remains a significant space for imparting treatment guidelines and consequent understanding and practices (Russell et al 2015). Rasmussen (2013) shows that in Uganda, there is a persistent disconnect between what counselors explain to patients and the ‘rules’ that patients understand regarding treatment. In contrast to many prevention campaigns, treatment programs are still heavily biomedical, despite the social nature of adherence, support, and nutrition (Marsland 2012; Meinert et al 2009; Prince 2012). The need to build scaffolding in support of patients is reflected in the extensive testing and monitoring that patients undergo prior to going on ARTs and across their course of treatment. These systems of monitoring and testing are fundamental to what Whyte and colleagues (2014) refer to as a patron-client system in which patients are “enrolled” in treatment at a particular provider. They receive a range of supportive services in exchange for patients submitting to monitoring to ensure they are following the “rules” of ART and becoming “clients” of the healthcare system. The terms “client” and “patient” are generally used interchangeably in the Ugandan clinical context (Kyakuwa, Hardon, and Goldstein 2012).

Patient education regarding ART and the obligations and expectations of treatment are key to the patron-client relationship, solidified through paperwork as a symbolic contract. Despite being in a largely resource-limited setting, Ugandan providers can sometimes create spaces for collective identity development and sharing of information on self-care (Russell et

al 2015). The quotidian dimensions of treatment and long term illness identity management, despite being initiated in a clinical setting, are largely enacted in the home and through daily habits of medication taking. These are manifest in broader terms than therapeutic citizenship and biosociality, such as friendship, kinship, clientship (Meinert et al. 2009), and routines. An international study by Nachege et al (2012) reports substantial gaps in patient knowledge of HIV and comprehension of the importance of adherence. Although the most common reason for nonadherence was forgetfulness, not misinformation, they suggest that understanding the need to adhere to medication increases compliance to clinical protocols. The role of routine and treatment practices, then, is key to decreasing forgetfulness and maintaining adherence.

Treatment landscape in Uganda

The dramatic reductions in HIV prevalence in Uganda have been lauded as an international model for prevention, focusing on behavior change and multi-sectoral responses (Ibembe 2009; Whyte et al 2014). Today, despite previous reduction in rates and significant progress in treatment rollout, countrywide prevalence rates hover around 7%, a level the Uganda AIDS Commission describes as “unacceptably high” (2012:2, 2013). However, as the global emphasis in managing HIV transitions toward biomedical models of prevention and treatment rollout (including treatment as prevention) (Moyer and Igonya 2014), Uganda faces similar challenges as many other developing countries. Funding for AIDS responses is pieced together through a combination of government, bilateral and multilateral sources (Uganda AIDS Commission 2014). These sources work toward similar goals in sometimes fragmented ways, relying largely on the national healthcare infrastructure (Hardon and Dilger 2011). National healthcare is free in Uganda, but public health centers face challenges in having sufficient staffing, medicines and supplies to treat patients (Chen et al 2004; Winchester 2015). Despite this, treatment rollout has accelerated in the past eight years, reaching an estimated 70% of those in need (using eligibility of CD4<350) (Uganda AIDS Commission 2014:23).

Antiretroviral treatment routines and understandings are inextricably tied to the history of HIV in Uganda. As Whyte et al. note, HIV prevention messages permeated all aspects of daily life in Uganda, from early in the epidemic (2014:12). Optimism infuses current treatment campaigns across the country through billboards, television campaigns, and radio adverts. Images of healthy-looking families promote the availability and effectiveness of antiretroviral treatment, including one sponsored by the Joint Clinical Research Centre in Kampala featuring a young couple with the text, “Thanks to antiretroviral therapy we can face life. We support each other. We tested positive together. We take AIDS treatment together everyday. We are healthy, strong and productive.” As rollout accelerates, clinics manage potential stockouts by strategically shifting donor funding and occasionally shortening times between refill visits for patients.

An important feature of HIV/AIDS treatment and care in Uganda is reliance on multiple providers and sources of care resulting in what Whyte and colleagues refer to as the “projectified” landscape of HIV/AIDS care (Whyte et al 2013, 2014). Whyte et al (2013) identify several factors that underlie development of this care structure. Most prominent are

two factors: the dominance of donor-based programs and the complexity of HIV/AIDS care. The first ensured that multiple programs, with different services, sprang up across the country. Because these programs are not part of the country's health system, they are not well coordinated and heterogeneity in services is notable. To address the second factor, the complexity of HIV/AIDS care, programs closely monitor patients for adherence to medication. This means frequent clinical assessments, behavioral assessments, and careful apportioning of drugs at intervals intended to protect drug supplies and to get patients to return to the clinic. To maintain funding and programs, projects compete for patients, offering a range of services, including drugs and treatment, but also food, job assistance, or other supportive programs.

Study setting

The social landscape of urban Uganda is rapidly changing. The capital, Kampala, has approximately 3.5 million residents and continues to grow, attracting international businesses, shopping and entertainment districts. With this backdrop, those living with HIV must navigate areas of dense urban population to attend a clinic. Many choose nearby facilities for convenience, but others may go further to settings with better reputations or more privacy. The possibility of privacy and maintaining a non-illness-based identity are challenged in this setting.

Mbarara in Southwestern Uganda is a peri-urban district capital. The town is located along transportation routes to Rwanda and the Democratic Republic of Congo, making it a hotspot for transmission early in the epidemic. The clinic where we recruited participants is in the busy setting of the regional referral hospital. The majority of patients, however, come from surrounding rural areas and many rely on subsistence farming. Despite being over 250 kilometers from the capital, AIDS programming has reached Mbarara and the surrounding region. The signs of this are visible, highlighting the ways in which those with HIV in the Mbarara region face a similar interface with HIV messages and programs.

Methods and Sample

This paper reports data from a qualitative study of treatment experiences at two sites in Uganda, as a component of a longitudinal study of the social context of treatment seeking in Uganda, conducted between September 2008 and March 2011 (see Winchester et al 2013, McGrath et al 2014). Participants were recruited from two major clinical centers, one in the capital city of Kampala and the other in the town of Mbarara in the southwestern region, in order to compare urban and peri-urban experiences in two areas with historically high rates of HIV and early treatment rollout programs. Ethical approval was granted for the study by Institutional Review Boards at Case Western Reserve University, the Joint Clinical Research Centre, Mbarara University, and the Uganda National Council for Science and Technology.

Forty participants were recruited for participation in a sub-study designed to examine treatment experiences in depth. All participants were chosen purposively from the larger longitudinal study sample with the objective of creating a heterogeneous representation of the study population. Twenty participants at each of the two sites were enrolled based on representing a range of age, sex, marital status, education status, and treatment experience.

Participants were evenly divided between women (n=10) and men (n=10) in Mbarara, and nearly the same in Kampala, with 11 males and nine females. Six research assistants conducted observations and interviews in the home, workplace, and clinic. These trained research assistants were also responsible for clinic-based interviewing in the longitudinal study and thus developed a rapport with and were familiar to all participants prior to follow up. Interviews were done using a loose structure, allowing comparability across individuals, while also allowing for the interview to potentially include topics of the participants' choosing, a method used in other comparative ethnographic projects (Hirsch et al 2009). The domains covered included illness histories, structured pill taking observations, clinic visit route tracing, social support networks, and social and economic costs of treatment. Not all participants completed all sections of the interviews, which were conducted over one to three visits at the participants' home, work, or place of their choosing.

The research team took detailed fieldnotes during visits, which were later transcribed and combined with transcribed audio recordings of the interviews. Complete notes and transcripts from each participant were coded for a priori themes of treatment seeking, social support, and costs of treatment. These were further broken into more detailed codes, including emergent themes of hopes and fears surrounding long term illness. Treatment routines and hope for a cure were specifically solicited in the interviews, but treatment understanding emerged from these conversations and was coded later.

Findings

Our forty participants had roughly comparable demographic characteristics at the two sites. They were on average 39.4 years old at the beginning of the study; approximately half of the sample in both sites report being currently married, with the rest divided between those who are divorced, widowed, or single. Participants were equally split between those with less than a completed primary education and those having completed secondary school or above. The only significant demographic difference between sites ($p<.05$) was the household size, with those in Kampala reporting larger households, on average, than those in Mbarara. Approximately half in each site also reported being currently employed, though slightly more in Kampala (54.8%) than Mbarara (45.2%). Using employment as a proxy for difficult to measure socioeconomic status, we further asked what type of work people do and sources of support they access. Only one quarter of participants in the study report any sort of formal employment, such as being a security guard, teacher, or staff in a clinic. More commonly, they rely on a variety of sources to get by, whether through individual small business initiatives or subsistence farming. This informal work is frequently seasonal and done in concert with other income-generating activities, such as driving a motorcycle taxi, selling handicrafts, or renting out rooms.

At both clinics, patients received both individual counseling and group education sessions, run by nurses, counselors, or expert clients (patients living with HIV who have publicly disclosed their status and conduct HIV community outreach, frequently as unpaid clinic volunteers) (Kyakuwa, Hardon, and Goldstein 2012). Group sessions were repeated each visit, after nurses triaged those requiring individual counseling. Sessions covered many aspects of HIV treatment and "positive living," including information about medication

adherence, treatment failure, and CD4/viral load tests, as well as PMTCT, reinfection, opportunistic infections, the need for routine medical visits, condom use, sleeping under mosquito nets, and nutrition. Additional advice encouraged avoiding smoking or drinking, planning income generation, and writing a will. Once enrolled in treatment, patients were expected to attend clinic every two to eight weeks, depending on medication availability at clinic. Patients were, therefore, regularly exposed to information about HIV, ART, and life with HIV.

“Relieving the virus from damaging the body”: Treatment understanding

Knowledge about how antiretroviral medication works is gleaned from many sources. While clinical encounters focus on protocols and maintaining patient adherence, they also give broader information as to why medication is important. Patients then integrate this information into other understandings of health and general worldviews. We found a range of possible explanations and understandings related to how antiretroviral medication acted on the body.

First are those who have processed biomedical explanations for the action of the medication and can explain it. These participants articulated the long-term nature of medication taking and goal of viral suppression. This category includes both men and women at both sites, in Kampala and Mbarara. An older woman explained, “the medicine is for the virus. The virus is HIV/AIDS; it [the medicine] helps me to make it dormant though it doesn’t die but makes it inactive. That’s why I no longer fall sick frequently like before” (female, 42, Kampala). Similarly, a man in Kampala said, “[the medication] is for relieving the virus from damaging the body” (male, 31, Kampala). Further, in Mbarara a participant echoed that ARVs are “for reducing HIV in the body... when you take it, you get energy and become well” (female, 35, Mbarara).

Biomedical means of explanation are frequently expressed colloquially, with CD4 cells referred to as “soldiers” and the virus put to “sleep” through treatment. The use of expert clients to promote treatment and adherence at clinics facilitate these sorts of translations and understandings. For example, Betty¹ lives in Mbarara; she is 60 years old and works as an expert client and peer educator at the clinic where she gets her medicine. She spoke at length about what the medicine does to her body, and further, how others should view medication. “The drugs I’m taking are keeping the virus dormant. It does not cure the HIV virus but stops it from multiplying... The HIV does not kill, what kills is lack of information, lack of knowledge, self-stigma, because the moment you accept that you are HIV positive and then get information that you are not going to die and then how you are going to take your drugs, how you are going to look after yourself, how you are going to make life to continue.”

Along with high levels of understanding exists some confusion in explaining how the medicine works, and ongoing concerns about long-term treatment. A woman in Kampala struggles to tell an interviewer what the medicine does, but she knows that it makes her feel better and gives her hope: “It helps me to live longer, it’s for... I don’t know...I know what it is but explaining it is a problem. It reduces the strength of the virus...It gives me strength.

¹Names of participants have been changed to protect their privacy.

It also gives me hope because after taking it I feel okay and I have no problem” (female, 29, Kampala). Several others, like her, could not name their drugs or say what they did, but maintained that their adherence was high. Some were confused about potential side effects, such as believing the medication “burns the liver” (male, 38, Mbarara) or “spoils our kidneys” (female, 53, Kampala). During the study period a well-known Tanzanian traditional healer was featured on the radio. He claimed to be able to heal HIV through use of herbal medication. His claims and alternate understandings on HIV medications featured prominently in interviews, though only three participants felt that their infections were possibly caused by witchcraft.

“Being cured is being alive”: Long-term outlook

Hope in treatment efficacy and long-term health outlook is crucial to maintaining adherence and the motivation to continue taking treatment, regardless of treatment understanding. We asked participants if they believed that they would be cured, intentionally using a broad question to encompass different interpretations of being cured or healed. Approximately half of the participants (21 out of 40) indicated that they believed a cure for HIV is possible; there were no major differences in beliefs between the two sites. The definition of a cure, however, varied widely. Some believed that being on treatment meant that they were cured already, and that their dramatic return to health showed evidence of a cure. A middle-aged man in Mbarara poignantly explained, “being cured means looking good, like the way I am now. Can someone differentiate between me and you?” (male, 39, Mbarara). Another woman in Mbarara felt the same, “I think I am already cured” (female, 40, Mbarara).

Others said that they would only know they have been cured if they test negative and that though they have hope, the current medication is not truly a cure. As one man in Mbarara explained, “To be cured is to find that on another checkup, you don’t possess any signs of the illness that was disturbing your health. It had been treated thoroughly and your body has been totally cleansed of the illness. That’s when you are cured, but the medicine we are taking is not a cure” (male, 57, Mbarara). Another man in Mbarara said first that he was cured, but then clarified to say he was not sure if there was a *true* cure, “Being cured is being alive...When you’re still on Earth, eating, drinking, alive, is what it means by being cured. Only God knows if there is cure” (male, 65, Mbarara).

Uncertain responses ranged from a simple “I don’t know” to more detailed expressions of the tension between health and treatment: “While taking this medication, I can’t be specific that I can get healed or not because for the many years I have taken ARVs I have not had any problems...even diseases like flu or colds rarely affect me, though on the other hand I also can’t say that I have healed and stopped taking my treatment unless the doctors tell me so” (male, 56, Kampala). Another man in Mbarara says, “recovering from HIV, I think I will recover from it after getting another drug but not this one.” (male, 24, Mbarara). They have guarded hope, but understand that the current treatment is not a cure. Even those who said they did not believe their medication was a cure qualified this with optimism over their improved health status. One older woman (she appeared to be in her sixties, but reported herself as being in her forties) said that she knew she would never test negative, but described her physical transformation on medication, “even my CD4s have increased. I

remember I started when they were 98 but now they are 1025 and every day I see myself becoming more beautiful. Yet before I used to look like an old woman even though am old, now I am 44 years old but I used to look older” (female, 44, Kampala).

Despite the hope for a cure, many participants still recounted fears of living with the disease over the long term and what treatment might do to their bodies. A woman who works in the health sector explained, “I know it [the virus] cannot totally go but it [the medicine] sustains me... I would like to know, is there an end to the virus? Are there not some side effects to these medicines, because we have been swallowing this medicine since long ago and I keep wondering when it will all end” (female, 31, Mbarara). She, like others, doesn’t know what the future of treatment will be. Their responses highlight the ambivalence of knowing from clinical encounters that they will never stop taking their medication, yet feeling healthy on a day-to-day basis. This liminal state between sickness and health, between positive and negative status is one of prolonged yet managed uncertainty.

An older participant, Joseph, is a 57-year-old school teacher in Mbarara. He is soft-spoken and loves to talk. His wife passed away and he remarried a younger woman, but his favorite topics of conversation are conspiracies and his health. He shared his knowledge of his current medication and adherence to protocol, despite worries over the origins of HIV; as he commented, “what keeps my mind bubbling all the time is the information we get about the originality of the virus, was it manufactured?” He knows the pills are not a cure and continues to put his faith in them for long-term health. Recently he has begun to think about the possibility that they may not always work or that he could be given fake drugs for his condition. “Then of recent, we have heard that, this is also another kind of worry...[the] fake manufacturing [of] these drugs in the same kind of look and appearance like these ones we get and they are threatening to break through our country’s border to come to us. Then we really feel very frightened.”

Other fears centered around the ability to continue accessing drugs and the dependency on foreign money. One woman shares her worries, explaining that “based on the current situation I am really worried because previously when we used to go for sensitizations, we were told all drugs are free but now they are no longer recruiting people for free drug, and all who were joining had to buy their own ARVs. I think the donors were experiencing some problems” (female, 50, Kampala). These vague concerns were echoed several times, highlighting international financial concerns and dependency on foreign aid, “I have not heard about [stockouts] as such but I have heard about credit crunch in America where our help comes from for the drugs I started getting worried thinking that they may reduce on the donation and fail to get the drugs, that was my worry” (male, 46, Kampala). Fears and uncertainty are not unexpected among this group, despite their ongoing interactions with clinics and counselors. Hope and fear are tenuously balanced with the reality of appearing healthy and knowing that they depend on ARVs for survival.

“I don’t hide them”: Treatment routines

We explored a literal dimension of treatment practice by asking about how antiretroviral treatment is brought into the physical and social space of the home, including where the pills are kept, and pill-taking routines. Participants frequently state that medication was kept in

plain sight, an indication of being open with their status and having nothing to hide. Their detailed routines show a familiarity with the medication and understanding of clinical protocols. As the following examples show, participants developed routines related to the storage of medications that allowed them to manage needed medication adherence even in challenging settings.

In both Kampala and Mbarara, the type of home that a person lives in influenced their decisions regarding how to handle and store treatment and how to deal with it on a daily basis. Smaller homes are frequently crowded and concealing treatment comes with logistical concerns. These living spaces may also influence people to disclose to their families so as not to need such secrecy. In Mbarara, an interviewer wrote of an older women's living space: "The house is owned by her and it has two bedrooms and a sitting room. There was no kitchen seen, though the three stones on which they prepare food were seen outside in front of the house." A family of three or four people (depending on the night) shared the living quarters. While not the smallest home, the woman responded by carrying treatment everywhere with her. She said, "I am now used [to the treatment] and I can't forget because now it's a part of my daily activities that I have to perform. I go with my drugs in the bag to my shop such that in case it's time to take my medicine in the evening before I come back, I take them from there. I keep my drugs in the bag that I carry everywhere I want to go. These drugs are packed in their containers. I hang my bag on a nail up on the wall in the bedroom. I even carry my bag to the shop when I am going to work. I just put the bag in the shelves" (female, 52, Mbarara). While she does not attend to the temperature control guidelines for the medication, she understands the significance of adherence and has embedded the medication-taking practices into her daily routines and spaces.

Some keep their cases of medication locked or under the bed, in order to keep the drugs safe from possible intruders and for reasons of secrecy. Most leave medication at home, only bringing it with them if they will be away for longer than their daily routine. Regardless of the specifics, each participant had a routine surrounding medication storage and taking and emphasized the care with which they regard their treatment. As Simon in Kampala described, "I have a big box that once had radio batteries and that's where I keep the drugs, I then put a polythene paper on top. I only remove the ones I will be taking for a week and I place it on a table in the bedroom and I know it's safe" (male, 41, Kampala). He works in a maize mill and religiously takes his medication and travels with it daily. Previously, he took herbal medications but fell ill repeatedly. After switching to antiretroviral medication, six years after diagnosis, he did not have a regular routine and missed more than a week of pills while fasting. The clinicians advised he not miss more doses and his health returned. Since that time, he said that he has faith in the doctors and the medicine and has been fastidious with his routine, explaining: "I can't derail and get back to the reckless person I was some years back."

Another man shared, "I always keep my drugs in the drawer of the bed and I make sure after swallowing my drugs at the right time I put them back in their container and put them back in the drawer of the bed and I make sure that I drink a lot of water before taking the drugs" (male, 50, Mbarara). These routines, like Simon's, are woven into daily practices. One woman shifts her sleeping schedule around the possibility of having side effects from

medication, “At first I was scared of it [taking the pills] but I got an idea that let me take it [the first pill] at 6 am, then sleep for 30 minutes, then wake and start my daily work” (female, 42, Kampala).

Despite some reported openness in treatment practices, many still felt the need for secrecy. Michael is 31 years old and works as a motorcycle taxi driver (*boda boda*) in Kampala, a group known for being high risk (Nyanzi et al. 2004, 2005). He invited an interviewer to his home for a study visit, after sharing with her that he was open with his status and felt comfortable telling others about his condition. Upon her arrival, the interviewer was asked to pose as a person interested in buying real estate. Michael held up the pretense and then escorted her toward the local chairman’s home. On the way, he revealed that he had not told his wife his status. In fact, he went to great lengths to lock his medication in a suitcase so that his wife could not find them. Several months later, he asked the interviewer to visit again, this time inviting her inside and opening up, albeit reluctantly. He said that he was beginning to disclose his status, but only if it was not going to be shared widely, “My friends and relatives are okay and I do not have any problem telling them if they are not going to publish my status in newspapers.” During yet another visit, Michael shared that he told his wife about his status. His growing comfort with disclosing and with his relationship was demonstrated in the shift of his drugs from a locked suitcase to “I put it in a cool place, in a drawer.” Further, their relationship was strengthened, as he commented, “I keep it in a bag if I am going to a place out of town, but it’s rare that I spend nights out.”

Significantly, knowledge of treatment protocols and medication taking routines is not always paired with broader understanding of what the treatment does to the body. In Mbarara, one man reports keeping his drugs on a cement floor to control the temperature, even though he doesn’t know the names of the medication and is uncertain how to explain what the drugs do to his body and sickness. “I don’t know them [the names of his medications] because for me I see drugs, but I don’t know their names... Their use is to fight HIV” (male 24, Mbarara). As seen above, most participants have strict treatment routines and strong faith in instructions from physicians, whether or not this is paired with broader understanding. As one woman in Mbarara describes, “I take what the doctors tell me as Bible truth” (female, 53, Mbarara).

Similarly, knowing treatment routines and having high adherence does not always lead to acceptance of the situation or optimism about the long term. One participant in Mbarara participates in a study which uses electronic pill caps to ensure patients are adherent. If he misses a dose, he receives a phone call reminding him to take the medication. Although he knows this will help his adherence, he said “It’s for my lifetime; it’s like being given a lifetime sentence in the prison” (male, 39, Mbarara).

It is important to note, however, that participants may over-report the degree to which they have routinized ART out of a desire to be a “good patient,” thus creating some bias in our findings. Indeed, Whyte and colleagues (2014) clearly describe the importance of living up to the expectations and obligations of being a good “client” so as to maintain access to ART. Since our sample was selected purposively, the positive attitude to ART treatment and high levels of knowledge may not be universal, and their willingness to participate in research is

likely to skew findings towards those with positive experiences of care. That said, however, we note that the detailed descriptions of their daily activities point to a well-thought routine for taking daily medication and their ongoing visits to the treatment centers for check-ups and refills, demonstrates the degree to which these patients are engaged in ongoing care. So although this group may not be representative of all HIV positive clinic attendees in Uganda, their experiences show a growing cadre of motivated patients invested in their care.

Discussion and Conclusion

Social lives of medication

These data highlight the range of treatment practices and consequent understandings for HIV in Uganda, as a part of the social transformations for people living with the illness. As Meinert et al (2009) suggest, there is more to HIV treatment than therapeutic citizenship or biosociality, both of which are constructed in clinical spaces. Rather, home life, relationships, and the ability to integrate illness identity into daily practices is at the heart of what HIV means on a daily basis. Patients have developed specific routines and practices to manage HIV in response to clinical instructions and education. This element of self-care shows management of the disease within the physical spaces of the home, as has been emerging in Uganda with treatment rollout (Martin et al 2013). Our respondents knew their medication routines and embedded the medication into daily practices, surrounding work and movements around the home. This is part of daily self-care and integral to long-term illness management (Martin et al. 2013). Additionally, as Michael the boda boda driver demonstrated, these practices have symbolic significance. His use of medication and managing of space and privacy related to his comfort level with the disease and disclosure of status in the household. He and others symbolize the “mundane transformations” that operate on a daily basis for those living with HIV (Le Marcis 2012:490; Biehl 2007).

In contrast to approaches that focus on the clinic, our study by following PLWHA into their homes expands perspectives of sociality of men and women on ART. When framed as treatment routines and protocols, treatment understanding is high. Knowledge of treatment protocols and medication taking routines, however, is not always paired with broader understanding of what the treatment does to the body. Some participants showed fluency in biomedical understandings of disease and the action of medication on the body. Others used language from the clinic and translated it into local metaphors to grasp the action of the medication, as happens in other settings (Whyte et al 2002). Despite its popularity in other parts of sub-Saharan Africa, witchcraft explanations of HIV in Uganda are not pervasive (Ashforth 2002) and most participants used a biomedical or closely modified model of disease explanation. The long history and visibility of HIV in Uganda, as well as the biomedical emphasis of treatment programs make these understandings logical and part of the social fabric (Whyte et al 2014), particularly for our clinic-based sample of participants.

As others have shown, literacy and understanding of HIV medication can have broad impacts, but is difficult to define operationally (Kalichman et al 2008; Kickbush 2001). From the mixed types of treatment understanding shown in our study, we advocate for an expanded definition of clinically-assessed literacy to consider the “social lives of medication” and how clinical instructions play out in the world of competing demands,

work, and crowded homes (Niehaus 2014). This allows for the possibility of developing treatment practices that lead to high adherence, regardless of technical understanding. Using the framework of “praxis,” (Singer 1995) our advocated expansion of treatment literacy would include the practical, embodied, and socially-constructed routines that make up much of life with HIV. This could be potentially important for juxtaposing the social routines of medicine as alternative forms of knowledge against the biomedical, largely proscriptive forms of information conveyed in the clinical setting.

Hope despite ongoing uncertainty

Despite high adherence potentiated by their daily routines of drug taking, participants expressed a range of understandings about the possibility of a cure for HIV. The Ugandan context shows the complex tension between hope and normalization from treatment on the one hand, and ongoing fears and uncertainty for the future on the other. Mixed understandings of how medication acts led to mixed understandings of what a cure or being healed would look like. Half of our participants believe either that a cure for HIV is possible or that they have been cured. Their narratives are infused with hope and the potential for a future. This type of outlook allows for the resumption of a ‘normal life’ after the initial crisis of diagnosis or illness (McGrath et al 2014; Russell et al 2010). The other half of our participants either felt that they would not be cured or were uncertain as to what that would mean. Even in Uganda where stockouts have been infrequent, uncertainty and dependence enters the minds of those on treatment (Taylor and Harper 2014). As several of our participants showed, fear of fake drugs or fears of running out of treatment plague them. While medication has improved health, it has not always allayed fears or future uncertainty. The translation of clinical practice into daily routine allows individuals to focus on the mundane dimensions of illness management rather than more abstracted fears. Ultimately, what the overall optimism and adoption of daily treatment practices demonstrate is the persistence of hope despite uncertainty. Our research advances anthropological approaches to HIV (Hardon and Dilger 2011; Whyte et al 2014) by taking the object of study to be daily practices and the subjectivity of infected individuals rather than the disease itself or clinical experience. We show how clinical practices are transformed into routines and taken into the domestic sphere. This dimension of self-care is inextricable from hope and understanding and crucial to developing long-term, locally-relevant programs for antiretroviral distribution.

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