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Challenging the Paradigm: Anthropological Perspectives on HIV as a Chronic Disease

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Abstract

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Recently HIV has been framed as a ‘manageable’ chronic disease in contexts in which access to effective care is reliable. The chronic disease paradigm emphasizes self-care, biomedical disease management, social normalization, and uncertainty. Data from a longitudinal study of patients (N = 949) in HIV care at two sites in Uganda, collected through semistructured interviews and ethnographic data, permit examination of the salience of this model in a high burden, low resource context struggling to achieve the promise of a manageable HIV epidemic. Our data highlight the complexity of the emerging social reality of long-term survival with HIV. Participants struggle to manage stigma as well as to meet the costs involved in care seeking. In these settings, economic vulnerability leads to daily struggles for food and basic services. Reconceptualizing the chronic disease model to accommodate a ‘social space,’ recognizing this new social reality will better capture the experience of long-term survival with HIV.

Keywords

antiretroviral treatment; chronic disease; HIV/AIDS; identity work; Uganda

By the late 1980s, discourse about HIV began to frame HIV/AIDS as a ‘manageable’ chronic disease akin to other contemporary health concerns. This was noted prominently in reports from the Fifth Annual International AIDS Conference in 1989. For example, Lawrence Altman reported in the *New York Times*:

The 5,000 reports at the international AIDS meeting here focused on how AIDS has become a chronic disease.... In jammed lectures and in discussions in thronged hallways, many experts spoke of managing AIDS like cancer and other chronic diseases with ‘cocktails’ of several new and existing drugs. (1989:C3)

Although cautious about the limitations of current treatments, Altman highlighted scientific optimism. Subsequently, the public perception of HIV began to shift, as described by Fee and Fox (1992) and Beaudin and Chambre (1996). As infection rates soared, especially in the developing world, this characterization of HIV, made possible by advances in treatment, deemphasized urgent, acute aspects of the disease in favor of a model of long-term survival. Even skeptics noted the importance of clinical management in the shifting nature of the disease process (e.g., Bayer 1992).

This “emergence from the plague model” (Beaudin and Chambre 1996:684) signaled the ‘normalization’ of HIV, recasting it as a chronic disease of contemporary life. However, just as was true for the epidemiological transition from infectious to chronic diseases in the twentieth century, the transition to a manageable chronic disease has not unfolded at the same rate or in the same way in all populations (Heuveline, Guillot, and Gwatkin 2002; Sankar and Luborsky 2003). Indeed, the actual and perceptual shift to a chronic disease is concentrated in settings with reliable access to appropriate care. Scientific optimism aside, populations hard hit by HIV/AIDS, such as those in Sub-Saharan Africa, continue to struggle to achieve the promise of a manageable HIV epidemic.

With access to HIV/AIDS medications continuing to expand, the applicability of the chronic disease paradigm has been re-examined (e.g., Colvin 2011; Swendeman, Ingram, and Rotheram-Borus 2009). In this article, we first describe the ‘chronic disease paradigm.’

Second, we examine its applicability to HIV in a global context, specifically considering how experiences of long-term illness and treatment are affected by the context of daily life. Subsequently, we employ data from Uganda to demonstrate that HIV in resource-poor settings differs from other chronic diseases, because the economic burden of treatment compounds daily struggles and treatment regimens challenge people's ability to maintain privacy and manage stigma. We suggest the need for a new paradigm of chronicity and 'normalization' that considers the reality of daily life for HIV-infected persons.

BACKGROUND

To understand the experiences of HIV infected persons, it is important to examine three elements of the chronic disease paradigm: the long course of disease, the role of the medical care system in disease management, and the effort to recapture 'a normal life.'

The Chronic Disease Paradigm

A hallmark of chronic disease is that it occurs over a long period of time, often the lifetime of the individual. A person may die with the disease but not from the disease. A characteristic of the disease process is uncertainty, because the disease may be 'managed' or 'controlled' but not cured (Brashers et al. 1998; Scandlyn 2000; Swendeman et al. 2009). A primary goal of chronic disease management is to manage this uncertainty. HIV/AIDS is chronic in this sense because, although people can now 'live with HIV' for years, uncertainty regarding disease progression remains.

The literature on chronic disease management emphasizes self-care combined with biomedical disease management, as occurs, for example, with cardiovascular diseases or diabetes. Kitahata and colleagues (2002) propose the World Health Organization framework for chronic disease care in the developing world as a model for HIV care, noting, however, that expertise in delivering HIV care can stress already overburdened health care systems.

A goal of disease management is to maintain 'a normal life.' Russell, Seeley, and Whiteside (2010) described the process as a 'quest' to regain control, create order, reduce dependence on others, and feel 'normal' again. Hence, disease management extends well beyond biomedical management of symptoms and viral advance.

Some argue that constructing HIV as a chronic disease decreases stigma (Siegel and Lekas 2002; Swendeman et al. 2009). This de-stigmatization is predicated on the availability of treatment because successful treatment allows individuals to resume normal activities and to live without physical markers of illness (Siegel and Lekas 2002). Paradoxically, being on antiretroviral treatment (ART) may actually generate stigma, as noted by Kendall and Hill (2010) and Russell and colleagues (2007), due to noticeably improved health, clinic visits, daily medication use, and changes in breastfeeding or sexual habits. In other words, reduction of stigma is the premise of much of the discussion regarding treatment, but it is not necessarily the reality of experience.

Another element of the quest for normality touches on psychological and social implications of living with a chronic disease, including the 'identity work' needed to be a person with a

chronic disease (Russell et al. 2007; Siegel and Lekas 2002). Unlike the ‘sick role’ characterized by relief from some social responsibilities during treatment seeking, there is an expectation of a return to normality—albeit one punctuated by episodes of acute disease. The chronic disease paradigm requires patients to actively manage disease through self-monitoring and ongoing engagement with biomedical care. Therefore, the chronic disease management model explicitly includes the responsibility to self-manage. This requires transition to a role in which one simultaneously has both a ‘normal’ life and an ongoing disease.

Perhaps the most important difference between HIV and other chronic diseases is that HIV is infectious. HIV-infected persons who adhere to ART decrease their viral loads to a level that significantly reduces the probability of transmission (Forsyth and Valdiserri 2012). However, a ‘normal’ life includes a sexual life and for many, pregnancy and childbearing. The possibility of transmission as people regain ‘normality’ draws attention to the need for ongoing, reliable access to treatment, and the care needed to manage risky behavior. Second, HIV differs from other chronic diseases in the degree to which HIV/AIDS remains stigmatized. The notion that an HIV-infected person can live a ‘normal life’ assumes the ability to control stigma. ARTs make it possible to look healthy—thereby concealing the diagnosis from others. In this way, reliable access to ARTs constitutes an important means to decrease and control stigma.

The goal of disease management is to manage both symptoms and the uncertainty of the experience. The model rests on patients’ self-care to maintain their health, including taking medications, eating properly, and monitoring symptoms and side effects. HIV disease progression is monitored through measuring CD4 counts and viral loads at a biomedical facility. There is no means to monitor disease progression at home (Swendeman et al. 2009).

Together, the long-term nature of chronic disease, the uncertainty, and the need to regularly access medical care require mobilization of resources. Mobilizing a social network to provide resources, however, may require disclosure of HIV status, a complex and messy process (Winchester et al. 2013). The need to disclose remains an ongoing challenge for many HIV-infected persons, with implications for their ability to access needed resources. In addition, although successful disease management hinges on access to medications, HIV medicines are available to a fraction of those needing them (World Health Organization, Joint United Nations Programme on HIV/AIDS, and UNICEF 2011). Populations hardest hit by HIV also lack reliable access to biomedical care generally, including HIV medications and monitoring facilities. Therefore, many people have neither home management nor ongoing access to clinical care.

RESEARCH BACKGROUND AND METHODS

In 2010 an estimated 1.2 million Ugandans were infected with HIV (Uganda AIDS Commission 2012). Countrywide prevalence was reported to be 6.7%, with differences in prevalence by gender, region, and age: Women had a nationwide prevalence rate of 7.7% versus 6.7% for men; prevalence was highest in ages 35–39 years (10.3%) and lowest (2%) in ages 15–19 years. The central region had the highest prevalence rate (10.7%); the lowest

rate (3.7%) was in the Mid-East region. Kampala had a prevalence rate of 6.9% in 2011. The prevalence rate in the Southwest Region, which includes the city of Mbarara, was 7.9% in 2011.

In the late 1990s, treatment became available in Kampala on a paid basis or through participation in research. Today, although ARTs are available free or at low cost at facilities countrywide, demand still exceeds availability: only 23% of children, 42% of men, and 55% of women needing ART currently receive it (Uganda AIDS Commission 2012). Under new guidelines to initiate ARTs at higher CD4 counts more people will need medications; but only 34% are expected to receive them (Joint United Nations Programme on HIV/AIDS 2010; UNITAIDS 2010).

The study on which we draw examined what it means for HIV-infected participants to get into and stay in HIV care and treatment (see also Winchester et al. 2013.) In this article, we present qualitative data on daily experiences of HIV care and treatment. During the study, it became apparent that these findings are salient to considering the chronic disease paradigm as applied to HIV/AIDS.

Participants were recruited at two clinics: the Joint Clinical Research Centre (JCRC) in Kampala and the Immune Suppression Syndrome (ISS) clinic of Mbarara Hospital, which is affiliated with the Mbarara University of Science and Technology (MUST). Participants had to be 18 years or older and to have been receiving ART for a minimum of six months. A counselor associated with the project asked every third client who appeared eligible for the study if they were interested in learning about the study. If they agreed, they were introduced to a study interviewer (FN, GS, AN, EK, SK, NA) who described the study, confirmed eligibility, and obtained informed consent. At each site, equal numbers of men and women were recruited.

Participants (N = 949) agreed to be interviewed at baseline, 6, 12, and 24 months, providing written informed consent in Luganda, Runyankole-Rukiga, or English. At 12 months, a subsample of ten men and ten women at each site (N = 40 total) was recruited purposively to achieve equal gender representation and to capture a range of experiences, and gave additional consent to participate in an ethnographic substudy.

Semistructured interviews were conducted with all participants at each visit; ethnographic substudy participants also participated in in-depth open-ended interviews and home visits. The baseline study instrument was designed to collect data on demographics, illness history, treatment experience, and adherence to medication. Several variables were used to assess daily experience of HIV. These included variables related to subjective experience (e.g., how people with HIV perceive others to treat them, hopes for the future) and structural factors (e.g., costs of accessing care). Subsequently, questions about medication adherence, distance to clinic, and social network support were added, as were questions regarding changes in life situation.

Participants were interviewed at the clinic where they received care. Interviews took place in a private location, either a separate room or at a distance from other patients. Study interviews were administered in Luganda, Runyankole-Rukiga, or English, according to the

participant's preference. For the ethnographic substudy, interviewers visited participants' homes, workplaces, or the clinic over three or more visits to gather more in-depth data on domains identified in previous studies or in the initial year of this study. Ethnographic data, collected through open-ended interviews and observation to allow for triangulation of the data, focused on six aspects of the experience of being on ARTs: disclosure experiences; treatment and care seeking; social network influences on treatment seeking; daily routines, including drug taking and buying; life events time line; and perceptions of and plans for the future. These interviews were tape recorded with permission; ethnographers kept field notes.

Interviews consisted of both closed and open-ended questions. Interviewers translated and transcribed responses during the interview. Interviews were checked for completeness and entered on the computer. For the ethnographic substudy, interviews were recorded and transcribed verbatim by the interviewer. Handwritten field notes were typed and maintained in the participant files for reference. All data entry occurred onsite in Kampala. Electronic files were transmitted to Case Western Reserve University, Cleveland for cleaning and backup and a copy returned to Kampala.

Descriptive statistics and bivariate analyses were generated using SPSS. Two independent researchers generated initial codes for open-ended questions at baseline, based on both a priori and emergent themes. Codes were subsequently compared and streamlined. A 10% sample of responses was double coded to enhance inter-observer reliability. Frequencies were generated for key variables and bivariate analyses using chi-square statistics examined for associations by site and gender. Ethnographic data were coded using codes developed in analysis of the semistructured interviews; new or divergent themes were identified and coded. Descriptive statistics of the ethnographic component were generated to characterize the subsample.

RESULTS

Location of Care

Here we briefly describe the two care settings so as situate the experiences for HIV-infected persons receiving care at the two clinics.

Participants from Kampala receive care at the JCRC. The JCRC was one of the first HIV treatment facilities in Uganda, and because of its early prominence in providing HIV care, it is commonly viewed exclusively as an HIV/AIDS facility. Now a regional Centre of Excellence, the JCRC is the premier treatment center in Uganda. When this study began, JCRC was located in Mengo, an area of Kampala close to the headquarters of the former king of Buganda, but set apart from both residential housing and commercial enterprises. The campus is verdant and quiet, away from the usual noise of the city, and even on busy clinic days, JCRC offers a quiet respite. Its location and preeminence draw clients from across the social and economic spectrum, with a bias toward more elite patients.

Mbarara is a growing district capital in Southwest Uganda, located along primary transportation routes to both Rwanda and the Democratic Republic of Congo. Participants from Mbarara received care at the ISS Clinic, which opened in 1998. The clinic is situated

within the busy campus of the main hospital in the center of town. Therefore, although the ISS itself is separate within the complex, travel to and from the hospital is common and travel to the hospital does not de facto suggest a visit to an AIDS facility. Because it is the regional referral center, the clinic handles cases from the surrounding region of small villages, trading centers, and farms. The hospital grounds and clinic space are typically noisy and crowded with patients.

In Table 1, we present the demographic data by site. Participants in Mbarara were more likely to report being married and JCRC participants were more likely to report being widowed or single. Participants in Kampala were more likely to report employment and to have completed secondary school or more. Reported household size in Kampala was larger. Eleven participants (1%) died during the study, 77.4% (n = 735) participants completed all four visits. JCRC participants were more likely to have completed follow up than MUST participants and women were more likely than men to have completed four visits.

Experiences of HIV

Three points emerge as relevant to a chronic disease model of HIV. First, participants describe the burden of HIV infection in terms of economic costs, time for care taking and seeking, and, often, of keeping their diagnosis secret. Second, we describe how experiences, including privacy concerns, reflect need for a ‘social space’ in which HIV-infected persons can undertake the ‘identity work’ needed to adopt the role of a chronically ill person. This social space is situated between the ‘sick role’ that permits sick individuals to be relieved of social obligations while seeking care, and the ‘normalization’ promised by the chronic disease paradigm. Finally, we describe the synergy between social and economic realities of participants’ daily lives and explore opportunities to address the social transformations needed to mitigate the long-term impact of HIV.

All study participants were taking ARTs at the time of their recruitment into the study. The daily burden of managing HIV occurs across two domains: costs of care and privacy and stigma management. HIV care incurs a range of direct and indirect costs, including monetary costs related to treatment and the cost of maintaining health in general, and numerous nonmonetary costs related to treatment, such as time required to seek and acquire care. Although drugs are free for clinic patients, other costs of HIV care and treatment and maintenance of good health can be substantial. The majority of participants reported nondrug treatment-related costs, particularly food and transport to the clinic, with 79% reporting such costs at baseline increasing to 83% at 24-month follow up ($p = 0.006$). The median cost of the trip to clinic was the equivalent of US \$2, increasing to US \$2.50 at study close, with no significant differences between sites (see also Namutiibwa et al. 2012). This cost was prohibitive for some participants, and directly impacted HIV health care when people were unable to obtain needed medication: “I walk half of the distance due to lack of transport money. The cost of the journey is 5000 shillings [approx. US \$2] but this is too much for me to afford” (53-year-old female, Kampala). Clearly the ability to walk partway to clinic depends on one’s health; the healthiest are able to reach clinic. Those who are weak or sick have a difficult time getting to clinic to obtain drugs, as one man in Mbarara

explained: “I missed taking my drugs for two days because I did not have enough transport. I need 10,000 shillings [approx. US \$4] for transport” (36-year-old male, Mbarara).

Both clinics in this study addressed this difficulty by providing patients with enough drugs to last for one to three months, so decreasing the number of trips to acquire drugs. However, time between clinic visits fluctuated according to the clinic’s ability to sustain funding and procure drug supplies. This contributed to uncertainty for HIV-infected persons, making frequent clinic visits still necessary.

The cost of obtaining enough healthy food was also a frequent point of concern. Countrywide in 2011, the annual food crop inflation was 29.1% and the Food Prices Index increased by 32.2% (Uganda Bureau of Statistics 2012). Participants report that doctors urge them to eat healthy food to maintain good health and maximize the benefit they get from the medications. ‘Food is medicine’ was a recurring theme that expresses how people understood food in health maintenance and successful treatment. The following two participants express the importance of ‘food as medicine’ that ‘play(s) a very crucial role’ in maintaining health:

To me food is medicine. I have to take the drugs until I die however it’s difficult to get dietary supplements and food on a daily basis. (52-year-old male, Kampala)

And before I reach home I make sure I have eaten something. I usually have to have something to eat because if I don’t I feel very bad and the drugs taste awful and in turn this makes me even more hungrier. And that component of eating plays a very crucial role to my health. (46-year-old male, Kampala)

For those on ARTs, rising food prices directly threatens the ability to manage disease.

Although time spent on disease management or care seeking is rarely quantified, it is an important component of long-term chronic disease. HIV-infected persons invested significant time traveling to and waiting at clinics, creating opportunity costs in the form of lost wages. The time needed to get to the clinic to obtain medicine is one example of this. Participants employed a range of modes of transport to attend clinic, including walking, taking *matatus* (public taxis) or *boda boda* (motorcycle taxis). Travel time was extensive. As noted, the Mbarara clinic serves a wide geographic area. Many clinic attendees live in rural areas, often far from paved roads. For those participants, a trip to the clinic could take several hours using several modes of transport. In Kampala, most participants live within the city. Nonetheless, extreme traffic congestion can mean a lengthy journey. Over a two-year period, reported average distance traveled rose from 6 to 12 kilometers at the JCRC and 7 to 16 kilometers at MUST.¹ In Kampala the median time spent one way to clinic was one hour at 6, 12, and 24 months; in Mbarara the median declined from two hours at 6 and 12 months to one hour at 24 months. The range, however, was vast: time to clinic for a patient ranged from less than an hour to 11 hours in Kampala; in Mbarara the range was from 1 to 7 hours.

¹During this time period, the JCRC clinic changed locations, so some patients had to travel further to get there. In Mbarara, two things resulted in longer distances at the 24-month interview. First, persons lost to follow up between 6, 12, and 24 months had reported distances below the median and secondly, 33 persons reported that they had moved and now lived further from the clinic. Together these factors result in a greater median distance to the clinic for the MUST sample.

At 6 months, 41.4% of the participants spent one to two hours each direction to attend clinic; by 24 months, 31.2% of participants spent one to two hours one way to attend clinic.

Another important feature of the experience of HIV for study participants was the ongoing daily vigilance needed to protect privacy, with stigma management at the core of privacy concerns. Privacy management occurred both at the family and household level where HIV-infected persons sought to protect their privacy in crowded homes, and at a public level where HIV-infected persons sought to avoid anticipated or experienced stigma. Efforts to preserve privacy, although difficult to quantify, affected people's ability to remain adherent to medications, and some invested extensively in time and effort to maintain the appearance of health.

As we have already noted, in Kampala, going to JCRC is associated with going to an HIV clinic, whereas for those in Mbarara the trip to Mbarara Hospital is less overtly linked to HIV. Yet despite differences between clinics, participants at both sites described privacy and stigma issues in similar terms. For example, even after inviting the study ethnographer to visit his house, one Kampala participant requested secrecy. As expressed in ethnographic field notes:

Participant is 28-year-old male (JCRC): He suggested that I pose as someone who was looking for land to buy. He also requested that I do not spend much time at his place because it would lead to some suspicions from his wife. He also told me that his wife is not aware he is HIV positive. The participant introduced me to his wife and told her I was looking for the local council leader of the area. He further said that no one in the neighborhood knows his status and (he) would prefer to keep it a secret.

The average household size in Kampala was significantly larger than that in Mbarara (Table 1). Crowding exacerbated privacy concerns, making daily routines of taking medicine and managing illness more difficult. Smaller household sizes in Mbarara provide some degree of privacy, but since rural households conduct many of their day-to-day activities out of doors, maintaining privacy concerning illness requires effort. For participants at both sites, therefore, privacy and stigma control were frequent points of reference as factors that impact on daily life with HIV.

Identity Work: Being Sick While Being Normal

One aspect of the shift from an acute to a chronic disease is the 'identity work' required for HIV-infected persons to take on the identity of a chronically sick person. This requires recognition of the long-term nature of the condition and commitment to its ongoing management within the realm of everyday life. Although the study was not designed specifically to study the 'identity work' of our participants, ethnography participants were asked about their expectations regarding long-term treatment and their concerns for the future. Responses to these questions shed light on their identity as a person with a chronic disease.

The theme of 'getting on with life' emerged. One male participant in Mbarara, who was also an 'expert client,'² spoke of his decisions in this regard:

My first choice was to make a family and I have made it. We now have a one year and five months daughter born to HIV parents and she's HIV free. Again my wife is expecting a baby next week.... I have also chose to go back to school after knowing that HIV doesn't kill and again being with HIV is not the end of one's life one can still be productive with HIV. Now I am looking at developing myself so that I improve the quality of my life. (35-year-old male, Mbarara)

Along with childbearing, the resumption of 'normal' life includes a turn inwards, with a focus on self and family, and 'moving on' from blame or accusations to rebuilding one's life. As one man expressed it:

I condemned my former wife. Of course, I told her that 'I have always told you, if I die of AIDS it will be you this and that [*accusing*]' but then, that was not the end of life and life kept on going. When I got drugs it was ok because now I had started becoming somebody. (52-year-old male, Kampala)

The resumption of health also means being able to selectively engage with the outside world as a sick person. One participant, when asked about possible accidental disclosure, responded: "Really I do not care about them [other people]; I only care about my life and family. That's all." (51-year-old male, Mbarara)

Another dimension of identity was work and productive life. With the resumption of health, many participants spoke of future plans and career ambitions. In Kampala, one man spoke of having switched livelihoods due to his ill health, but now continued to work in his new career because his children had grown, not because of his illness: "I have concentrated more on poultry and not so much on the brick laying business due to my health. But now that the kids are all grown up, I might only settle for poultry in future" (56-year-old male Kampala).

Identity work is an ongoing quest to build a self and have hope for the future. In Uganda, many turn to religion for assistance in their quest. One participant spoke of utilizing his social network to speak about religion and assuage fears for the future:

The most important help is spiritual help. He preaches to me the word of God, as he gives me hope that I can live a happy life since I am not the only one in such a situation and shouldn't worry about that much but have hope that I can live. And when I feel I am scared we sit and discuss about it, but nowadays I am okay. (41-year-old male Kampala)

Long-term treatment can overwhelm, however, as described by one woman in Mbarara, who reported having been on medication for eight years. She expressed concern about and fatigue with the lifelong regimen: "Are there not some side effects of these medicine? Because we have been swallowing this medicine since long ago and I keep wondering when it will all end" (32-year-old female, Mbarara). Another participant, when asked about any worries he had about treatment, said: "Nothing. But my worry is [if] in any case this drug gets finished, I don't know what to do because it's my life" (48-year-old male, Kampala). These perspectives show the two sides of long-term life with HIV: the resumption of a

²'Expert clients' are HIV-infected persons who disclose their status publically and then work with HIV outreach at various venues. They are used widely in Uganda to encourage testing and treatment.

normal life—“HIV is not the end of one’s life”—versus the long-term uncertainty—“I keep wondering when it will all end.”

CHALLENGING THE PARADIGM: EVERYDAY EXPERIENCES OF ART

Daily struggles threaten individual efforts to remain on ART. Economic challenges occur in the context of complex and sometimes strained social relations. Whyte (2012) argued for a model of chronic disease that emphasizes the fundamental role of social relations in accessing HIV care generally and ART specifically. We argue, further, that HIV requires merging social and economic considerations, which are clearly synergistic. Currently, for the poor, the ability to focus on ‘disease management’ is threatened by the hardship of drug stock outs, lengthy and frequent trips to the clinic, and food insecurity, challenges that constitute ongoing hardships experienced by the poor and sick. At this intersection of disease with ongoing poverty and hardship, HIV attains a degree of ‘normality’ within a landscape of disease and suffering in vulnerable populations. As is poignantly described by Russell and colleagues (2010), even if HIV-infected persons achieve a state of normality, it is one characterized by ongoing social and economic suffering and hardship.

Scandlyn (2000) noted that AIDS is only truly chronic in developed countries where biomedical resources are available. Kendall and Hill (2010:177) remarked that lack of access to medication “makes a mockery of” the notion of HIV as a chronic disease in the poorest populations that are ravaged by HIV. For these people, the promise of ‘manageable’ HIV disease is buried under the weight of these daily struggles, most of which cannot be ‘managed’ through the health care system. McGrath and colleagues (2012) reported that even when infected persons engage with medical care, they can ‘slip through the cracks’ of the medical care system, failing to receive HIV-specific care until late in the disease process. Indeed, the very factors that increase vulnerability to HIV risk, such as poverty and lack of education, make it difficult to receive the care needed to achieve the promise of a manageable disease.

In rural Uganda “a new life on ART had, in effect, returned participants to the *normal worries and struggles of poverty* and making a living in this resource-poor setting” (Russell et al. 2010:381, emphasis in original). Kendall and Hill (2010) recited a litany of events in daily life that threaten the fragile gains to be had by taking medications. Similarly, Kalofonos (2010) reported that in Mozambique the consumption of ARTs can actually create hunger and with it, a greater demand for resources. Mattes (2012) also described the daily hardships of life on ART, employing a case study from Tanzania. He highlighted the multiple, competing considerations that influence adherence, pointing out that suffering from HIV is not just physical but also social. ARTs, however, only treat physical suffering, and provide no relief from other forms of suffering. In resource poor settings, the costs in money, time, and risk of disclosure associated with lifelong medication adherence, clinic visits, opportunistic infection treatment, and increased nutritional demands exacerbate already existing poverty, making HIV something that is still dealt with through a crisis mentality, albeit over a long period of time.

Colvin noted that “the economic vulnerabilisation of people ... may also worsen as a result of the transformation of HIV into a chronic disease” (2011:2) because the need for adherence, ongoing episodic care, and continued personal and societal investment in care will strain local systems. However, by focusing on long-term need for resources to achieve care, a chronic disease approach may capture the emerging social realities of long-term survival with HIV in terms of resources and re-structured social realities needed to fully benefit from life-saving medicines.

Rethinking Sick Roles: Social Space, Economic Need, and the New Chronic Disease Paradigm

The concept of a sick role has been used to explain and understand the temporary shift in social roles and relations that takes place in the face of illness (Parsons 1951). A person who has taken on a sick role is relieved of some of his or her usual social responsibilities and expectations while sick. The sick role is predicated, however, on the expectation that the sick person will act to alleviate the sickness. In essence, the sick person takes on a socially sanctioned role until the sickness passes and the patient is able to return to normal social responsibilities. For chronic diseases, the sick role may be episodic, but if managed well, the disease can be pushed to the background, allowing the patient to resume normal social roles and responsibilities.

For HIV-infected persons on ARTs, their apparent health, as evidenced by lack of disabling symptoms, suggests a return to normality and end of the sick role. However, disease management is ongoing, and as we have illustrated, difficult, expensive, and demanding. Fears around privacy and stigma shackle efforts to expand the sick role to accommodate daily HIV management. Consequently, an HIV-infected person may secretly engage in many of the same health-seeking behaviors as during acute illness. Unable to claim either the sick role or their ‘normal’ role, HIV-infected persons occupy a state of ‘social in-between,’ compounding their social and economic vulnerability. This paradox of expanded treatment access does not negate the value of treatment but reframes the impact of treatment as one that shifts the space of vulnerability not by eliminating stigma but by allowing some semblance of control over it.

How then can HIV-infected persons negotiate this terrain of economic and social vulnerabilities? We argue that what is needed is a new ‘social space’ situated between a sick role and ‘normal life.’ Current models of sick roles fail to account for the far-reaching implications of living with HIV. A reconceptualization of these models is needed to fully address the complexities of living with HIV. Programs to expand access to HIV medication should recognize that in this new social space, characterized by lifelong daily drug taking, HIV-infected persons seek to reclaim their ‘humanity’ (see Sankar and Luborsky 2003), even as they struggle to maintain health, privacy, and productive lives.

The economic reality limiting the ability to manage and control disease also creates a social reality that prevents HIV-infected persons from achieving a ‘normal life’ with chronic disease. Social hardship intertwined with economic hardship means that chronic disease models fail to capture the reality of ‘living with’ HIV in low resource settings. What is needed ultimately are drugs, clinics, *and* a social space in which HIV-infected persons can

construct daily life with HIV, a social space framed by the uncertainty of daily life that constitutes the social reality of long term survival for those with HIV.

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TABLE 1

Demographic Characteristics of Study Participants by Study Site (N = 949)

	JCRC (N = 481)		MUST (N = 468)		X ² ; p-value
	n	(%)	n	(%)	
Sex					
Male	242	(50.3)	233	(49.8)	
Female	239	(49.7)	235	(50.2)	0.026;0.87
Marital Status					
Married	238	(49.5)	273	(58.3)	
Divorce/Separate	67	(13.9)	61	(13.0)	
Widowed	115	(23.9)	99	(21.2)	
Single	61	(12.7)	35	(7.5)	10.74;0.01*
Employed					
Yes	337	(70.1)	277	(59.2)	
No	144	(29.9)	191	(40.8)	12.80;0.00†
Education Level					
Primary or Less	222	(46.2)	289	(61.8)	
Secondary Level	194	(40.3)	123	(26.3)	
Above Secondary	65	(13.5)	56	(12.0)	25.18;0.00†
Number of Children					
None	40	(8.3)	46	(9.8)	
1-3	228	(47.4)	241	(51.5)	
4-6	153	(31.8)	137	(29.3)	
More than 6	60	(12.5)	44	(9.4)	3.95;0.27
People in Household					
1-3	123	(25.6)	160	(34.2)	
4-6	197	(41.0)	195	(41.7)	
More than 6	161	(33.5)	113	(24.1)	13.08;0.00†

* Significant at the 0.01 level.

† Significant at the 0.001 level.