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Chronicity, crisis, and the ‘end of AIDS’

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Abstract

In biomedical, public health, and popular discourses, the ‘end of AIDS’ has emerged as a predominant way to understand the future of HIV research and prevention. This approach is predicated on structuring and responding to HIV in ways that underscores its presumed lifelong nature. In this article, I examine the phenomenon of HIV chronicity that undergirds the ‘end of AIDS’ discourse. In particular, I explore how the logic of HIV chronicity, induced by technological advances in treatment and global financial and political investments, intensifies long-term uncertainty and prolonged crisis. Focusing on over 10 years of anthropological and public health research in the United States, I argue that HIV chronicity, and subsequently, the ‘end of AIDS’ discourse, obscure the on-going HIV crisis in particular global communities, especially among marginalised and ageing populations who live in under-resourced areas. By tracing the ‘end of AIDS’ discourse in my field sites and in other global locations, I describe how HIV chronicity signals a continuing global crisis and persistent social precarity rather than a ‘break’ with a hopeless past or a promising future free from AIDS.

Keywords

United States; chronicity; ageing; health inequity; HIV/AIDS

Introduction

Hailed as a resounding success, advances in antiretroviral treatment (ART) and clinical care have improved the health of those who are living with HIV by prolonging their life and significantly reducing the overall risk of HIV transmission. As a result of these clinical and treatment advances, many are living longer with HIV. Recent Joint United Nations Programme on HIV/AIDS (UNAIDS) estimates indicate that at the end of 2015, 36.7 million people were living with HIV worldwide, with new infections declining or remaining stable, the number of people on treatment rising, and AIDS-related deaths decreasing sharply (UNAIDS, 2016). As life expectancies of those who have access to HIV treatment and care extend past a decade or more, at times approaching near-normal levels in low,

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middle, and high-income countries, HIV has become increasingly regarded as a chronic condition (Nakagawa, May, & Phillips, 2013).

Such transformations in treatment and care—and subsequently a marked shift in the conceptualisation of HIV as an illness to be managed over a lifetime as opposed to a highly acute disease with severe mortality rates—have led some to speculate if the ‘end of AIDS’ is within reach (Fauci & Folkers, 2012). Beginning around 2010, this narrative signalling the ‘end of AIDS’ began to emerge as both an accessible goal in the global HIV epidemic control efforts and a future within reach (Kentworthy, Thomann, & Parker, 2017). In the wake of the global economic crisis and scale-up efforts led by the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) in partnership with governments, academic, non-governmental, and faith-based organisations, and U.S. government agencies to expand treatment access, the discourse surrounding the ‘end of AIDS’ represented longstanding conflicts about how to curb the HIV epidemic globally (The Lancet HIV, 2015). Donors, policymakers, researchers, and government bureaucrats pointed to growing evidence of AIDS as a declining problem in much of the world with worldwide AIDS mortality rates falling rapidly due to biomedical advances in treatment and care, and UNAIDS made firm commitments to achieving its 90-90-90 targets by 2020 (90% of people living with HIV knowing their status, 90% of people diagnosed with HIV on treatment, and 90% of people on treatment with suppressed viral load) based on these very same arguments about the effectiveness of biomedical technologies. This focus on biomedical advances also underpinned a post-2008 global fiscal environment in which governments and donors were withdrawing support for long-term financial and political investments in HIV prevention and treatment (Kates, Wexler, & Lief, 2016).

However, such strategies for ensuring the ‘end of AIDS’ have been highly contested and politicised. Many contend that biomedical advances do not necessarily signal an end to HIV, arguing that although current treatment and care strategies may be sufficient to prevent HIV, further innovations in prevention and treatment along with sustained financial political and financial investment are needed to ultimately eliminate HIV (El-Sadr, Harripersaud, & Bayer, 2014; Vella, 2015; Wilson, Stoové, & Hellard, 2015). These discourses and debates over the ‘end of AIDS’ suggest that the landscape of HIV prevention and treatment continues to be highly contested. It also lays bare unquestioned assumptions at the heart of the ‘end of AIDS’ discourse about ‘where, how, and for whom AIDS may be ending’ (Benton, Sangaramoorthy, & Kalofonos, 2017, p. 474).

To illustrate, I argue that there is an emergent model of chronicity underpinning the ‘end of AIDS’ discourse which associates HIV with a lifelong condition. Research has shown that so long as treatment is continuous, it can be highly effective in extending life and reducing HIV transmission (Colvin, 2011; Deeks, Lewin, & Havlir, 2013). Some have championed the chronicity model, arguing that it tempers HIV-related stigma and discrimination rooted in long-held assumptions that those living with HIV are immoral and deviant (Mahajan et al., 2008). They have argued that the widespread scale-up of treatment access and the subsequent shift of HIV into a treatable and chronic disease will increase the uptake of testing, and thereby, ultimately diminish HIV-related stigma. Chronicity, in fact, has become an integral part of the global push towards changing the language around HIV to mitigate

HIV-related stigma. Globally, advocates are re-scripting HIV as a ‘chronic’ and ‘manageable’ disease, moving away from language that refers to HIV as a ‘death sentence’ or a ‘life-threatening and fatal condition’ (Dimitis et al., 2012; UNAIDS, 2011).

Less attention has been paid to understanding the contested debates around chronicity and chronic conditions among researchers and practitioners. The model of HIV chronicity, like many others pertaining to disease, is embedded in biomedical notions of time (Manderson & Smith-Morris, 2010). ‘Chronic’ is understood as the persistence of symptoms over the temporal course of a disease for which there is no curative element. Chronic conditions are also almost always understood as the flipside of acute illness. However, even within the biomedical and public health literature, definitions for chronic conditions vary widely in terms of duration, effects on individual function, and treatment (Perrin et al., 1993; van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007). This heterogeneity has led to a great deal of uncertainty in terms of determining occurrence and associated social and economic burdens, making chronic conditions more difficult to surveil and manage (Goodman, Posner, Huang, Parekh, & Koh, 2013). While longstanding methods for identifying and classifying chronic disease have relied on the presence of an individual health condition of lengthy duration, some experts have argued against such condition-specific approaches, calling instead for a more standardised method focused on shared elements such as individuals’ functional status, the prolonged use of health care over a specified time period, and individual illness experiences (Perrin et al., 1993). Yet despite these efforts, a common definition of chronic conditions remains elusive and the application of selected conditions to multiple health data systems continues to be inconsistent.

Medical anthropologists have countered such biomedically hegemonic discourses of chronicity, calling for a shift from conceptions of illness as temporally bound toward an understanding of the fluidity and flexibility of disease conditions over the life course (Manderson & Smith-Morris, 2010). Sue Estroff, in her work on those suffering from schizophrenia over the life course, defined chronicity as ‘... the persistence in time of limitations and suffering and to the resulting disabilities as they are socially and culturally defined and lived’ (1993, p. 250). In so doing, Estroff argued that conditions of time, biology, social relations, and broader contextual factors driving health structure give meaning to the lived experience of chronicity. Through long-term ethnographic work, anthropologists and other social scientists have explored these notions of chronicity by demonstrating that conditions often considered chronic are interposed with moments of ‘acute’ intensity—eruption and abatement of symptoms, spread and remission of malignancies—and subsequently, how acute conditions such as malaria often affect individuals in chronic ways (Becker, 1998; Chandler & Beisel, 2017; Manderson & Smith-Morris, 2010; Whyte, 2012). They have also highlighted the various processes of disruption, transition, and transformation which constitute chronic illness experiences such as HIV and how continuous disease management poses significant medical, economic, and social challenges for those in resource-limited settings (Berger, 2004; McGrath et al., 2014; Russell & Seely, 2010; Watkins-Hayes, Pittman-Gay, & Beaman 2012). Furthermore, they have troubled longstanding dichotomous relations between ‘chronic’ and ‘acute’ by exploring how a variety of everyday conditions continue to become medicalised (addiction, trauma, sleep, etc.), highlighting the many facets of life which are ‘now based on conceptualizing self and society through the lens of chronic, constant medical intervention' (Wolf-Meyer, 2011).

This work in medical anthropology is particularly helpful in understanding how the 'end of AIDS' rhetoric has underscored the shift of HIV from 'acute' to 'chronic' as naturally evolving and as an inevitable medical reality, while obscuring HIV chronicity as induced by biotechnological advances and as on-going crises in particular communities. Using her work on diabetes among the Pima Indians in Arizona, Smith-Morris argues, 'if…chronicity is no longer defined by the natural course of disease (e.g., the 'slow killers') but by the availability of biotechnical strategies to address them, then the chronicity of an illness experience is not a medical fact but a technological, political, and economic one' (2010, p. 21). If we are to understand the 'end of AIDS' discourse as a critical moment that indexes a shift in our understandings of HIV and the lives of those it impacts, then it is imperative that we trace the ways in which the logic of HIV chronicity, as a sign of progression towards a disease-free future, masks the continued disadvantaging of those who are poor and socially marginalised.

Below, using a summative analysis that draws on more than 10 years of research studies on HIV in the U.S. South, I attend to this emergent model of chronicity that undergirds the 'end of AIDS' discourse, and the ways it obscures the on-going HIV crisis in the southern United States and other global locales. The word 'chronicity' stems from Latin 'chronicus' relating to time and from the Greek 'khronikos' or 'khronos,' meaning of time. It designates the 'condition of being chronic,' and refers to a disease condition that is 'prolonged or slow to heal' or a problem that 'continues over an extended period of time' (English Wiktionary, n.d.). By focusing on the everyday experiences of HIV chronicity in the United States in areas and communities which continue to be hardest hit by the epidemic, especially among ageing populations who largely reside in areas that lack robust primary care health care systems, I argue that HIV chronicity signifies both a condition that is now often marked by extended duration by way of treatment availability and an on-going, endemic HIV transmission that continues to be a crisis in many communities despite biotechnological advances that currently make AIDS preventable. In doing so, I propose a reorientation of this logic of chronicity to one that regards HIV as a continual crisis as it is lived and experienced for many around the world.

ART does not fully reinstate individuals to a state of health. For reasons that we still do not know well, ART—specifically long-term ART use—has been associated with both accelerated ageing and non-AIDS morbidity (Deeks & Phillips, 2009; Smith, de Boer, Brul, Budovskaya, & van Spek, 2012). Current health care systems in many regions where most people with HIV reside such as the U.S. South are fragmented and under-resourced, and do not have the capacity to provide adequate and timely care for continuous chronic care for the management of HIV, especially for an increasingly ageing population (Deeks, Lewin, & Havlir, 2013). Furthermore, despite the decreases in the number of new HIV infections in the United States overall, the burden of disease and death continues to mount in the U.S. South among poor African Americans concentrated in non-urban locales (Sangaramoorthy & Richardson, 2017). I contend that HIV is a chronic crisis in the U.S. South as in many other regions of the world, signalling disparate HIV infection and treatment rates among the poor and socially marginalised. HIV chronicity, then, does very little to substantiate the logic of the ‘end of AIDS’; rather, it reinforces the unending possibility of suffering, poverty, and illness.

Methods

I have been conducting ethnographic research on HIV in the United States since 2004, almost entirely in the U.S. South on projects exploring the ways in which social, economic, and political structures influence disparities in risk, experience, and management of HIV. Data for this summative analysis draws on several hundreds of hours of participant-observation and over 150 semi-structured interviews spread over the years of my involvement with medical and social service providers, those living with HIV, and community members across various sites in the U.S. South including Florida (2004-2006), North Carolina (2010), Louisiana (2011), and Maryland (2014-present). Longitudinal engagement through ethnographic fieldwork has allowed me to witness changes over the course of more than a decade and to develop long-term relationships with those living with HIV, health and social service providers, public officials and administrators, and community-based organisations. All participant observation and interview field notes and transcripts were analysed using narrative and thematic analyses. Results and findings were shared and discussed with key informants and collaborators to enhance accuracy. Participant observation in various settings along with content from conversations, interviews, and field notes was used to triangulate data to confirm findings and conclusions.

Although I use findings based on rapid ethnographic assessments from Louisiana and North Carolina (Sangaramoorthy & Kroeger 2013a; 2013b), in this paper, I focus primarily on previous work in Florida (Sangaramoorthy, 2012; 2014) and current work in Maryland (Sangaramoorthy, Jamison, & Dyer, 2017a; 2017b). The former, based on 15 months of ethnographic research in South Florida, documents an on-the-ground view of HIV/AIDS prevention programmes and their effect on the health and well-being of Haitians, a transnational immigrant community long plagued by the stigma of being AIDS carriers. From 2004-2006, 53 HIV experts, public officials, and Haitians were interviewed multiple times about HIV prevention, treatment, and care. Extensive fieldwork was also conducted at county and state health departments, hospitals, community-based clinics, service organisations, homes, and other private spaces to understand how information and knowledge about HIV prevention circulates and travels from sites of surveillance and regulation to various clinics and hospitals to the social worlds of Haitian immigrants.

I also draw upon current collaborative work in Prince George’s County (PGC), Maryland which centres on intersectional stigma and ageing among older Black women living with HIV. From 2014-2015, 35 Black women over the age of 40 living with HIV were interviewed using a semi-structured interview guide developed from discussions with community partners, HIV experts, and my own previous research. Interviews lasted between 45 and 90 minutes, with an average duration of 60 minutes, while questions explored domains related to experiences of living with HIV, relationships with providers, facilitators and barriers to care, social relationships and support, and everyday experiences of gender, racial, and age discrimination. The study employed both purposive and snowball sampling techniques to recruit participants from local HIV service organisations, county public health clinics, federally qualified health centres, and participant referral.

‘HIV ain’t got me like this. It’s other sickness’: Chronicity, uncertainty, and ageing with HIV

In the United States, increased funding, targeted prevention efforts, and treatment advances have been credited with slowing down the HIV epidemic, with the number of new HIV-positive cases decreasing by 19% from 2005 to 2014 (Centers for Disease Control and Prevention [CDC], 2017a). These achievements have also resulted in the rapid growth of those ageing with HIV. At the end of 2014, there were 1.1 million adolescents and adults living with HIV in the United States, with the majority (72%) being 40 years of age and older (CDC, 2015). From 2010 through 2014, the U.S. HIV prevalence rate—measured by the number and rate of persons living with diagnosed HIV—increased significantly with the largest percentage increase (59%, from 84.3 in 2010 to 133.8 in 2014) among those in the oldest age group, aged 65 years and older (CDC, 2015). Many have argued that such numbers are an indication of people living longer with HIV, at life expectancies almost reaching near-normal levels (Samji et al., 2013).

My most recent work in PGC is beginning to explore how scientific and research communities are unprepared for a largely ageing population living with HIV as well as the on-going issues related to HIV chronicity such as accelerated ageing, co-morbidity, and the uncertainties around long-term ART use (Sangaramoorthy, Jamison, & Dyer 2017a; 2017b). For midlife and older adults, living with HIV can be particularly challenging due to issues related to the loss of social support, management of comorbidities, and ageism (Sangaramoorthy, Jamison, & Dyer 2017b; Emlet, 2006a; Emlet 2006b). The cumulative effect of years of ART on bodies and everyday lives is relatively unknown, and combined with the general physical and social effects of ageing itself, the context of ageing with HIV is complicated but understudied.

As I have written elsewhere, older Black women living with HIV reported multiple transformations in their experiences with HIV including HIV care and ART adherence as they aged with HIV (Sangaramoorthy, Jamison, & Dyer, 2017a; 2017b). Similar to research on chronic illness narratives (Garro 1992; Kralik, 2002), women described undergoing a period of disbelief, denial, uncertainty, fear, and ambivalence following a positive HIV diagnosis, ‘I didn’t want to believe it. I couldn’t understand. Where? Why? I wasn’t a dirty person. I didn’t sleep with dirty men’. This initial period, sometimes lasting years, also negatively affected their experiences and perspectives towards HIV care and ART, ‘I was not taking my medication when I was first diagnosed with HIV. I had to keep it in the refrigerator and I had to take it on time everyday. It was rough for me. I didn’t want to do it. So I rejected it’. For many women, HIV represented a critical disruption to their daily life, social relationships, and sense of identity, ‘My mother doesn’t want to talk about it. She won’t face it. She doesn’t want to believe that her child has this disease that could possibly kill her’.

Despite persistent experiences and feelings of stigmatisation, many women expressed that they were better able to cope with negative public attitudes and more accepting of their condition as they aged. Women described such positive transitions as related to conceptions of successful, productive, or active ageing in various ways (Emlet, Harris, Furlotte, Brennan, & Pierpaoli, 2016; Emlet, Tozay, & Raveis, 2010; Vance & Robinson, 2008). Through narratives in which the past, present, and future are continually made and reconstructed by each other, some women depicted positive change as occurring through lived time, 'Back in the day, it was first and foremost–you're going to die. You wanted to die…Not now. I've got to live my life'. Others associated increasing resilience and maturity, often resulting from overcoming major challenges and experiencing critical life events such as the onset of serious illness or the birth of a child or grandchild, with ageing, 'At first, I don't want to know the results because I was already scared…I didn't tell nobody. I was just disappointed in me, for keep doing, you know... But then I realised later there's nothing you can do. What is God's will is God's will. I mean, I'm good. I know now that I can take care of me. I don't have to wait for people to hear I got sick to get better. I want to live to see my grandchildren get older. It's getting better'. Still others described how ART was critical to helping them feel a sense of order and control over HIV as they aged, 'Because I was getting that medicine into my system, [HIV] wasn't going to be hanging around. I was getting older and [HIV] was going bye bye'.

However, women's narratives, marked by experiences and feelings of insecurity, suffering, and endlessness, also signalled the tenuous nature of such positive transformations of ageing with HIV. For some, incorporating HIV into daily life remained unfeasible because of a loss of social support, social and economic difficulties, or psychological struggles, 'Well, you know, the HIV is controlled with medications, but I am still so uncomfortable. I'm terribly ashamed. It's like a reproach of my family. It's the worst thing that could ever, ever happen to me. I'm not comfortable with it at all. Things have changed I think with some people, but not with me'. Others described new challenges related to ageing with HIV such as the worry of death or disability and the subsequent impact on family, struggles with comorbidities, and experiences with ageism that often upset the sense of stability and progress that women felt that they had achieved, 'I'm the backbone for this family and if something were to happen to me, I don't know what would happen… I don't know what they'll do without me, when something happens. I talk to them pretty openly, my older children. We've tried to make a plan, but I don't know how well it will work out. That is my biggest fear, is not being here for my kids and grandkids'.

Women struggled with various conditions including those considered infectious (i.e., hepatitis, gonorrhoea), chronic (i.e., diabetes, hypertension, asthma, cancer, etc.) as well as mental health issues (i.e., depression, anxiety, etc.), and health concerns typically associated with ageing (i.e., menopause, osteoporosis, arthritis, etc.). They continuously experienced physical pain and were worried about their state of health, 'I developed congestive heart failure since I've got HIV. I got genital herpes. I have sinus, ulcers. I have so many things. I take about 12 pills a day and only five of them are for HIV. I take fluids. I take anti-depressants. I go to therapy. I'm really emotional when I get to talking [about my health]'. Many expressed persist concerns about accessing health and social services and navigating interactions with various providers. In particular, they had difficulties managing multiple conditions due to the challenges of affording numerous co-pays, coordinating travel for various medical appointments, synchronising complicated treatment plans, communicating with different providers, and staying vigilant about potential drug interactions. Many women felt frustrated about having all their health concerns linked to HIV by providers, ‘I tell [the doctor] my medical problem, but the way he behave. I threw the medicine out and I won’t go back again. You know how you tell a person a problem…I needed some attention for this little bump on my hand, and he said “Because of the HIV” and I said “No, not because of HIV”‘.

Finally, women expressed deep conflicts with ART. They explained even though ART had become an inherent part of their life ‘like eating and sleeping’, they suffered from debilitating and sometimes persistent short and long-term side effects as a result of on-going treatment. Many women attributed ART to their declining health, describing the very substance that kept them alive as also the source of their deep suffering, ‘My memory isn’t as good as it used to be. I think it has something to do with the medication because the medication is very toxic. It’s doing something to my brain. Sometimes it catches me off guard. I can’t think. I just can’t think’. Women also expressed serious concerns about taking ART indefinitely and a strong desire to stop, ‘It does a lot of damage to your body and if it isn’t there, why keep taking it? Because my level has been the same for a while. I don’t know how many years. I started in 1987 and we’re now in 2014. I’m thinking about asking [my doctor] next time I see him, “Hey look, I’ve had enough of this”‘.

‘I’m always at the doctor’: ART as pathology

In the United States and other high-income countries, studies have shown that those living with HIV and on ART have a greater chance of developing non-AIDS related chronic conditions which are often considered chronic or associated with advancing age (Deeks, Lewin, & Havlir, 2014). For instance, the Modena HIV Metabolic Clinic cohort study, a large case-control study that compared HIV-positive individuals on ART with HIV-negative adults from the Italian national registry, demonstrated that non-AIDS related conditions such as diabetes, cardiovascular disease, renal disease, bone fractures, and hypertension were more common among those living with HIV than those in the general population for the same age cohorts (Guaraldi et al., 2011). They also found that those with longer duration of HIV and therefore, taking ART for a longer period of time, had higher rates of hypertension and multiple chronic conditions than those who seroconverted at older ages (Guaraldi et al., 2015). Likewise, researchers using the U.S.-based Veterans Affairs medical system illustrated that although most veterans suffered from co-morbidity—the presence of one or more chronic conditions present among individuals—older veterans living with HIV had a greater than expected risk of multiple chronic conditions than older veterans who did not have HIV (Goulet et al., 2007). Furthermore, their study results highlighted that chronic conditions associated with HIV and ageing such as diabetes and vascular and renal disease were linked to ART toxicity. Findings also indicated that certain chronic conditions such as renal, vascular, and pulmonary diseases were associated with higher HIV severity, concluding that HIV may have intensified or triggered such conditions.

Some have reasoned that the impact of ART on comorbidity is expected to be similar in low as in high-income countries even though such associations have not been as extensively documented (Hirschhorn, Kaaya, Garrity, Chopyak, & Fawzi, 2012). A recent systematic review found that chronic cardiovascular and pulmonary diseases are increasing among those living with HIV in low-income and middle-income countries (Bloomfield et al., 2015). Studies in sub-Saharan Africa have suggested that those living with HIV have higher prevalence of hypertension than those without HIV, while others have found positive correlations between hypertension and CD4 counts (Dillon et al., 2013). In Brazil, researchers have observed higher prevalence of non-AIDS related comorbidities among older individuals with HIV, particularly cardiovascular and renal disease, depression, and non-AIDS related cancers (Torres et al., 2013). Researchers studying the relationship between older age and treatment outcomes in people living with HIV in the Asia Pacific region determined that older individuals living with HIV had two-fold higher risk of all-cause mortality (Han et al., 2015). They interestingly did not find significant differences in the ageing associations of HIV-related outcomes between the resource-rich population in Australia and a predominately resource-limited cohort among 14 countries in Asia, indicating that the overall burden of comorbidities among those ageing with HIV may be similar in low and high-income regions. In fact, experts have expressed deep concerns over the rise of ageing-related chronic conditions in low-resourced settings where a high number of those with HIV live and the lack of effective and feasible approaches to prevention, screening, and treatment of these conditions (Geng et al., 2010; Mills, Barnighausen, & Negin 2012; Rabkin, Kruk, & El-Sadr, 2012).

Concerns over the rise in comorbid conditions have prompted increased research on the relations between ageing, chronicity, and HIV. Specifically, researchers are asking why those on ART have increased risk of non-AIDS related conditions and if ART-treated individuals are experiencing accelerated or premature ageing (Deeks, Lewin, & Havlir, 2014). Many have argued that traditional risk factors such as smoking and drinking, co-infection with other acute conditions, and possible adverse drug interactions for comorbid conditions do not fully explain all of the excess risk for non-AIDS morbidity and accelerated ageing (Martin & Volberding, 2010). A growing body of work has shown that persistent inflammation of the immune system elevates the risk of comorbid conditions, frailty (i.e., weight loss, exhaustion, muscle weakness), and disability among those on ART (Deeks, Lewin, & Havlir, 2014). Others have suggested that ART induces mitochondrial toxicity, leading to premature and accelerated ageing (Smith, de Boer, Brul, Budovskaya, & van Spek, 2012). Much of the discourse on accelerated ageing remains highly debated because the effects of ART, especially long-term ART use, remains unclear, not well understood, and under-researched.

These debates over whether characteristics of HIV or ART transform the biology of ageing highlight the limited significance of chronological and medical time for understanding the temporal dimensions of diseases and epidemics. HIV, as both disease and epidemic, is embedded in a set of narratives about its origin, its linear progression in individual bodies and among populations in time and space, and its biotechnological management and treatment over time. Yet the convergence of HIV and ART experienced as bodily impairments and old age signal the contraction of this implied temporality, where the future is diminished and the chronic and the acute are no longer separate and distinct. It also suggests synergetic and coextensive relationship between the processes of HIV and ageing—a chronicity induced by the merger of viruses, bodies, and biomedical technologies—that underscores the radical uncertainty and unpredictability brought forth by altered (and welcomed) temporalities of HIV, where an expanded sense of time generates feelings of new anxieties, recurrent instability, and prolonged decline.

‘Seems like everybody got it’: HIV’s enduring legacy in the United States and beyond

Despite the increasing recognition and momentum of the ‘end of AIDS’ discourse, HIV continues to be a critical issue in places like PGC and globally, with 2.1 million new infections worldwide in 2015 (UNAIDS, 2016). UNAIDS estimates that only 60% of people with HIV currently know their status, arguing that the remaining 40% (over 14 million people) still need to access HIV testing services (UNAIDS, 2014). There have been no global declines in new HIV infections among adults since 2010 and the vast majority of people living with HIV, including those who are newly infected, are in low and middle-income countries (UNAIDS, 2016). For instance, new HIV infections are again on the rise in Eastern Europe, Central Asia, the Middle East, North Africa, and Asia Pacific regions as well as in certain regions and populations of North America and Western Europe. Sub-Saharan Africa, home to an estimated 25.6 million people living with HIV in 2015 and a majority (66%) of new HIV infections in 2015, continues to suffer a disproportionate global burden of HIV (UNAIDS, 2016).

Even though UNAIDS estimates indicate that 18.2 million people living with HIV had access to ART as of mid-2016, a significant increase from 2000 estimates (less than 1 million individuals), most individuals living with HIV do not have access to prevention, care, and treatment (UNAIDS, 2016). Twenty-two million people living with HIV are not accessing ART and later diagnosis remains a significant barrier to HIV treatment scale up (UNAIDS, 2016). Many individuals, particularly women, sex workers, men who have sex with men (MSM), transgender persons, those who engage in injection and non-injection drug use, migrants, and refugees continue to face discrimination, stigma, and lack of access to HIV information, testing, and treatment due to various policies and practices that uphold structural and social barriers (Arreola et al., 2015; Baral, Sifakis, Cleghorn, & Beyrer, 2007; Baral et al., 2012; Baral et al., 2013; Beyrer & Karim, 2013; Beyrer et al., 2014; Dellar, Dlamini, & Karim, 2015; El-Bassel, Shaw, Dasgupta, & Strathdee, 2014; Galeucia & Hirsch, 2016; Harrison, Colvin, Kuo, Swartz, & Lurie, 2015; Karim et al., 2010; Mayer, Grinsztejn, & El-Sadr, 2016; Tanser, Bärnighausen, Vandormael, & Dobra, 2015; Weine & Kashuba, 2012).

The United States has been long known for being one of the biggest financial contributors to global HIV prevention efforts. Yet, as I discussed in the previous section, it also continues to face an on-going HIV epidemic at home that disproportionately impacts racial and ethnic minority populations and specific geographical regions where a majority of these populations live (CDC, 2017a). Although the number of HIV diagnoses has been on the decline over the past decade, over 40,000 people were newly diagnosed in 2015, increasing in certain populations such as MSM in recent years (CDC, 2017a).

Racial and ethnic minorities, particularly African Americans, have been hard hit by HIV since the beginning of the epidemic and continue to make up the majority of new HIV diagnoses, those living with HIV, and deaths among people with HIV (CDC, 2017a). HIV diagnoses among all African American MSM increased by 22% in 2015, but among men aged 13 to 24, the increase (87%) has been staggering (CDC, 2015). African American women are also heavily impacted by HIV, accounting for 60% of new HIV diagnoses among women in 2015 (CDC, 2015). Additionally, half of all transgender persons who are diagnosed with HIV are African American (CDC, 2017b). Furthermore, African Americans have lower levels of care and viral suppression than do persons of other racial groups (Dailey, Johnson, & Wu, 2017). Longstanding issues related to poverty, stigma, discrimination, residential segregation, and lack of access to care continue to drive these acute racial disparities in HIV (Buot et al., 2014).

Racial disparities in HIV also highlight geographical inequalities. In the United States, the disproportionate burden of HIV is increasingly found in the southern states such as Mississippi and Louisiana, where larger proportions of those diagnosed with HIV are living in smaller metropolitan, suburban, and rural areas (CDC, 2016). Southern states have the highest rates of new HIV-positive diagnoses, the highest percentage of people living with HIV, and the lowest rates of survival for those who are HIV-positive (CDC, 2016). The vast majority of African Americans live in the South, and they are the hardest hit by the HIV epidemic in the region, accounting for 54% of new HIV diagnoses in 2014 (CDC, 2016).

The South suffers from disproportionate rates of concentrated poverty—the spatial concentration of poverty —which research has shown to negatively impact access to adequate and quality health care and poor health outcomes (Kneebone & Holmes, 2016). Likewise, funding and healthcare disparities have long plagued the South, likely contributing to the rising rates of HIV in the region. Federal funding is uneven for Southern states—33% of federal funding was distributed to the South, despite the region having 52% of all new HIV diagnoses in the country (Reif, Safley, McAllaster, Wilson, & Whetten, 2017). Additionally, Southern states also have some of the strictest eligibility requirements and least expansive Medicaid programmes (Reif et al., 2017). Many Southern states rejected Medicaid expansion under the Affordable Care Act, which extended healthcare to millions of uninsured Americans (Stephens, Artiga, Lyons, Jankiewicz, & Rousseau, 2014). Such healthcare policies, along with poor healthcare infrastructure, lack of qualified health professionals, and geographic isolation, have resulted in substandard or non-existent health services and treatment for those most in need (Reif et al., 2017).

Much of my work in the U.S. South has underscored that minority and immigrant populations, especially those who are living with HIV or and other sexually transmitted infections (STIs), are particularly vulnerable to disparities in health and healthcare access due to economic and political marginalisation. In South Florida, my research has indicated that Haitians, who are heavily impacted by the HIV epidemic,[1] were blamed for the continued transmission of HIV as transnational Black migrants despite facing difficult challenges receiving continuous treatment and care through public health and social welfare programmes because of their high mobility, tenuous legal status, and lack of economic resources (Sangaramoorthy, 2012; 2014).

There were critical disconnects between official discourses of unified global HIV response, community "needs," and everyday practices in funding, research, and services in South Florida. Federal, state, and local-level public health institutions and policymakers upheld spending a significant portion of a continually decreasing budget for HIV funding on populations with the most severe disease burden. They argued that such funding allocations reflected the shift toward high-impact prevention approaches—evidence-based programmes which have demonstrated highest measurable success in reducing new HIV infections in high-risk populations and geographic regions—aligned with the 2010 National HIV/AIDS Strategy, the nation's first comprehensive coordinated HIV efforts with measurable targets such as reducing HIV infections and increasing access to care for those living with HIV.

However, frontline providers, administrators, and advocates maintained that despite increases in HIV rates and growing health disparities in access, treatment, and health outcomes among Haitians, local and federal funding and resources were at critically low levels for this population. Haitians were left to engage in actively managing their own risk and care in the face of extreme political, economic, and social marginalisation. By transferring the responsibility of care away from social welfare and public health institutions onto Haitians themselves, these institutions were able attribute the continued rise in HIV health disparities to social and individual pathologies rather than to the broader structural constraints in which they were complicit.

In North Carolina, like many other states in the U.S. South, Latinos represent a growing proportion of the population as well as HIV and STI cases over the past decade.[2] HIV rates are four times higher for Latinos than for whites in North Carolina, yet very little is known about the risk factors that affect HIV and STI transmission within this population. The vast majority of new immigrants in North Carolina are young, unaccompanied Latino migrant men who experience a high degree of geographic mobility in search of economic opportunity. Like many migrants and refugees globally, these men encounter poor living and working conditions as well as laws that create severe barriers in accessing medical care and social support services.

My collaborative work with public health professionals demonstrated that Latino men in North Carolina face severe social marginalisation and experience critical challenges in accessing health care due to low-wage jobs without benefits, dangerous and debilitating

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[1] Haitians made up 4.4% of Miami's population (Bureau of Census, 2010) in 2012 but represented 11% of the total reported cases of those living with HIV through 2012. Many have stressed that even these numbers are gross undercounts due to unstable patterns of housing, family networks, high mobility, distrust of government and health officials, immigration status, and other factors (Stepick & Stepick, 1990; Marcelin & Marcelin, 2001).

[2] North Carolina, for example, experienced a rapid increase in its Latino population, from 1.7 percent in 1990 to 7 percent of the total population in 2008, a growth of more than 400 percent (Bureau of the Census, 2009). Much of the migration of Latinos to the U.S. Southeast—considered 'new immigrant gateways,' regions previously not regarded as major destinations for immigrants—has been driven by employment opportunities in construction and agriculture. As a result, the demographic makeup in these areas of the South differs from that of more established Latino communities across the country, with Latinos more likely to be young, male, unmarried, foreign-born, and recent arrivals. Public health experts have argued that these young male migrants lack the social and sexual networks found in established communities and may be at high risk for HIV and STIs (Painter, 2008).

working conditions, lack of health insurance, social isolation, fear of deportation, and immigration policies which restrict access to health services (Sangaramoorthy & Kroeger, 2013a). In addition, this work highlights how despite the diversity of migrant experiences within the U.S. South, conceptualisations of “migrant” and “mobility” are insufficiently examined and undeveloped theoretically in public health, with service delivery largely based on anachronistic models of relatively stable and settled populations of the past. My findings illustrate several implications for the future of public health practice including incorporating the concept of mobility as an organising principle for the delivery of services to large segments of the population including migrant Latino men so that the dynamics surrounding movement patterns and their impact on health outcomes could be further examined.

HIV and STIs also heavily impact those in Louisiana. The state is ranked second nationally in terms of HIV case rates (24.2 per 100,000 population), with Baton Rouge and New Orleans ranked second and third respectively for HIV case rates among large metropolitan areas in the nation (CDC, 2015). Louisiana also leads the nation in primary and secondary syphilis (14.9 per 100,000) and gonorrhoea rates (220.0 per 100,000), and is ranked second in chlamydia rates (691.1 per 100,000) (Louisiana Department of Health, 2015). Furthermore, Louisiana ranked first in the nation in congenital syphilis rates (83.9 per 100,000 live births), which was over six times the national rate of 12.6 per 100,000 live births in 2015.

African Americans are disproportionately impacted, comprising only 32% of the state’s population, but 72% of newly diagnosed HIV cases, 73% of chlamydia diagnoses, 81% of gonorrhoea diagnoses, and 78% of syphilis diagnoses in 2015. Acute stigma, lack of social support, poverty, racial segregation, discrimination in health care, and disparities in incarceration rates have been found to contribute severe disparities among African Americans in Louisiana (Louisiana Department of Health, 2015). My work with public health officials on congenital syphilis in Louisiana has suggested that individuals, particularly young African American women, and health care providers are often constrained by programme, health systems, and policy factors that hamper prevention efforts and facilitate a risk environment for HIV and STIs (Sangaramoorthy & Kroeger, 2013b). In addition to dealing with the daily challenges of living in poverty, young African American women often lack the time, financial resources, and insurance necessary to establish a continuous relationship with the health care system or with an individual provider. A dearth of referral points, discontinuities, and gaps in insurance coverage, overburdened public safety net health care facilities, and lack of providers who accept Medicaid—the national public health insurance—constitute severe challenges for poor African American women in accessing quality and timely care and increased their vulnerability to negative birth outcomes associated with HIV and STIs.

The social, political, and economic issues that plague the U.S. South reflect particular urgencies related to HIV on a global scale, especially in resource-limited areas. They also bring into focus HIV as a persistent crisis among communities which long have been targets of biomedical intervention, research, programming, and community engagement efforts. Yet, the ‘end of AIDS’ discourse centres on envisioning a present in which HIV is controlled and chronic and a post-HIV future. The retrospective dimensionality brought about by the ‘end of AIDS' discourse positions HIV as a break from 'normal'—as a disease induced by exposure to a virus and an epidemic indexed by a sudden increase in the number of disease cases beyond what is expected. Such narratives obscure the recurrent and on-going nature of HIV and the uncertainties that surround its continued impact. For many in the United States and globally, HIV is part of the broader context of inequity and suffering—an enduring crisis rather than a phenomenon to move beyond.

Chronicity as crisis

This paper explores how systems and people—researchers, clinicians, service providers, policymakers, activists, and HIV sufferers themselves—are understanding and living with HIV, not as it ends, but as it continues to develop and change. Time and temporality are deeply embedded within the 'end of AIDS' discourse and the logic of HIV chronicity (Benton, Sangaramoorthy, & Kalofonos 2017). HIV is now seen as a condition of being chronic—something to 'live with' rather than to 'die from'. Prior temporalities of finitude are postponed, not eliminated, by the extended sense of time made available by medicine. Such narratives underscore HIV as a crisis of the past and a chronic condition in the present induced by biotechnological advances and political and economic investment. They also signal future endings, which are imagined in relation to a break with the past and the creation of new moral economies where stigma towards sufferers is reduced and access to lifesaving treatment is standard.

The hope signalled by 'end of AIDS' discourse and its logic of chronicity obscures the sense of protracted uncertainty and precarious life conditions experienced by those who have lived and continue to live in the shadows of the epidemic—including poor women, people of colour, and transgender individuals. The experience of HIV for many does not necessarily offer a similar form of hopeful reinvention of time—a future free of AIDS—that this logic of chronicity entails. Ageing, toxicity from long-term ART, non-existent or crumbling health systems, and rising social, economic, and political inequities give way to a pervasive sense of uncertainty that makes HIV less a 'break' from temporally 'normal' lives than an unexceptional and a common experience in many contexts. These multiple temporal experiences of HIV make for an uncertain and unpredictable future not necessarily bound to the present or past.

Reorienting the logic of chronicity away from the realm of biomedicine to one that is anthropological directs our attention to understanding HIV chronicity as 'the experience of crisis as a constant' (Estroff, 1993; Vigh, 2008, p. 10). Chronicity as crisis shifts our understandings of HIV from an interruption to a state of constant precarity. It brings into view what the 'end of AIDS' obscures—the embodiment and perceived pathologies of crisis and the stagnant futures, deteriorating presents, and collapsed pasts of people and places left behind. But it also allows us to witness how individuals and communities situate themselves, strive for control and balance, and navigate in and through difficult circumstances, constantly anticipating and adjusting toward social worlds which are perpetually in motion but somehow experienced as without progression (Scheper-Hughes, 2008; Vigh, 2008). HIV chronicity as crisis signals not an ending, but the continual unfolding and reconfiguration of social and biological lives amidst risk, precarity, and fragmentation.

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