



“These African stories”: Life, labor, and dying in northern Zambia

Joshua Garoon

Department of Community & Environmental Sociology, University of Wisconsin-Madison, United States



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ABSTRACT

This paper analyzes the effects of antiretroviral therapy (ART) on the social worlds of people living with HIV and ART (PLHA) in rural northern Zambia. Studies have demonstrated high rates of ART adherence over a range of sites in southern Africa. Drawing on a year of ethnographic research conducted in Zambia's Mukungule chiefdom between 2006 and 2008, this study investigates expectations of this exemplary adherence, and experiences of treatment failure. Motivated by the life and AIDS-related death of a Mukungule resident, Grace, it moves beyond asking “what made initial cohorts of African PLHA exceptionally adherent?” to raise the pressing question of “what happens next?” Previous scholarship addressing this question has analyzed how PLHA navigate the competing moral and political economies of local kinship and social networks and global HIV/AIDS initiatives. Scholars have emphasized the afterlives of access and adherence, looking beyond survival to what “the good life” means for PLHA, and placing PLHA at the center of action and analysis. This paper flips that script, by focusing on the stories that Grace's death spurred Mukungule residents to share. It shows how attention to and analysis of stories told not just about, but by members of PLHA's kinship and social networks, are critical to developing a more robust understanding of exemplary adherence and treatment failure. Such understanding critically depends on paying more attention to how those living with and caring for PLHA (and especially their families) facilitate PLHA's pursuit of good and “normal” lives – not just while, but also through, pursuing their own.

Along with the lazy man, and more than he, the dying man is the immoral man: the former, a subject that does not work; the latter, an object that no longer even makes itself available to be worked on by others.

Michel de Certeau, *The Practice of Everyday Life* (1984, p. 190)

It is very true: if you become lazy before you die, you can expect more problems to come. Some die strong, others weak: they spend maybe three years doing nothing, just sleeping. It is better to die strongly; it is bad to be in bed for three years. It is better to struggle while we still have life – better to die with an axe in your hand (*cawama ukufwa na isembe muminwe*).

Gideon Kasakula, interview in Mukungule, Zambia, 2007

1. Prologue: Grace (The funeral and after)

Grace Musolo died of AIDS on Monday, November 21, 2006. After her death, Grace's maternal uncle, Philemon Bwalya, found a month's worth of her antiretroviral therapy (ART) among her possessions. As people gathered to mourn Grace's passing, a rumor began circulating: members of Grace's church, Pentecostal Holiness, had advised her to stop taking her medications, persuading Grace that her adherence to ART interfered with her faith in God's plans to heal her. On the walk to

the graveyard for Grace's burial, however, people discussed another story: Philemon's family, particularly his wife and mother-in-law, had hectored a beleaguered Grace about her flagging contributions to the family's farm, driving Grace to stop taking her ART in despair.

A preacher from the New Jerusalem congregation (to which the rest of the Bwalyas belonged) delivered the funeral's first sermon, decrying false churches and their deceitful promises of health and wealth, with a clear subtext. Isaac Matete, the officer in-charge at the Mukungule Rural Health Clinic (RHC), spoke next. Just before the funeral, he'd told me he believed the stories of Pentecostal Holiness' role in Grace's death. Now he was more circumspect, eulogizing Grace and her involvement with the local HIV/AIDS support group, and stressing the need to protect oneself from HIV, get tested, and take all prescribed medicines. Next, Joseph Chungulo, elder of Pentecostal Holiness, addressed the crowd. He vehemently denied that he or any other congregants had advised Grace to stop taking her ART, and said he'd always preached that faith in medicine was faith in a gift of the Lord. Philemon Bwalya followed Joseph, emphatically repeating the denials that Pentecostal Holiness was responsible for Grace's death. Philemon acknowledged that his niece had stopped taking her ART, and commented that she'd always “worked very hard” (*ukubombeshya*, which can also mean “work too much”) on the family farm. The last speaker was Jeremiah Mumbi, Chief Mukungule's representative. He delivered a scathing philippic on

E-mail address: garoon@wisc.edu.

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moral decay in Mukungule, invoking Sodom and Gomorrah and condemning young women who left Mukungule “to compete to attract men as the most beautiful,” before returning home, “where we can all see the consequences.”

When Mr. Mumbi finished, the men began to shovel dirt onto Grace's coffin, and a solemn procession of friends and family laid flowers on top of the burial mound. The crowd left the graveyard debating Grace's death. They pondered the contradictory accounts from the funeral. Why had Grace really stopped taking her ART? Had it been advice from church members, pressure from the Bwalya family, depression over the difficult conditions of her life in Mukungule, or something else altogether? Had she been fully aware of the consequences of her decision; was this a case of suicide by non-adherence? What did her death suggest about ART in Mukungule, barely a year after it became available?

2. Therapeutic trajectories: citizenship, clientship, kinship, and “the good life”

The roll-out of ART throughout sub-Saharan Africa sparked contentious debate, as researchers, citing the challenges facing ART adherence in resource-poor (and particularly rural) settings, warned of “antiretroviral anarchy” (Harries et al., 2001). Subsequent analyses, however, demonstrated high rates of ART adherence over a range of African sites (Mills et al., 2006), such that by the time of Grace's death, Nguyen et al. (2007) could assert, “the relevant research question is not why a small minority of [African] patients are non-adherent, but rather, why are patients so exceptionally adherent to treatment” (p. S32).

Nguyen answered this question with the concept of therapeutic citizenship. Therapeutic citizenship entails a person's ability to utilize serostatus to “claim resources from public sector or non-governmental organization (NGO) programmes” (Nguyen et al., 2007, p. S33), and thus secure “position in the kinship networks that, in the absence of a viable state, are the only available forms of social solidarity” (Nguyen et al., 2007). Therapeutic citizenship is enabled by global HIV/AIDS programs, which have created a novel moral economy among people living with HIV and ART (PLHA) – one that encourages individualistic approaches to adherence, with emphasis on self-reliance and personal responsibility – a “responsibilisation” which, Beckmann (2013) argues, threatens to elide PLHA negotiations over other forms of responsibility (e.g., to their families) (pp. 161, 171). These programs urge PLHA to work together in coping with their social and biological vulnerability, by supporting and being responsible to one another as individuals. This creates a novel form of social solidarity rooted in serostatus: a “biosociality.” The demands of this globalized moral economy of HIV/AIDS programs co-exist but contrast with demands of extant moral economies rooted in kinship and local social networks. Nguyen employed the concept of therapeutic citizenship to analyze the ways in which PLHA navigate these different moral economies, striving to maintain adherence to ART and advance their life goals. “Exemplary adherence,” Nguyen et al. (2007) asserted, “should be viewed through the lens of therapeutic citizenship” (p. S31).

As a case study, Nguyen et al. (2007) and Nguyen (2010) narrated the story of Abdoulaye, a Burkinabé who tested positive for HIV in the late 1990s. Abdoulaye garnered early access to ART through his leadership of a small HIV/AIDS NGO, which helped him tap into global HIV/AIDS resources. He also helped his HIV-positive aunt access ART. The aunt died soon after, however, and Abdoulaye moved out of his family's compound, upset by accusations of witchcraft sparked by her death, and his daughter's frequent illnesses. As he departed, “Abdoulaye told [Nguyen] he was ‘tired’ of these ‘African stories’” (p. 131). Nguyen ended Abdoulaye's narrative there, preserving focus on how Abdoulaye advanced “a political claim to belonging to a global community that offers access to treatment” (Nguyen et al., 2007; S34). Details of everyday life in Abdoulaye's family – and the ramifications of his choice to distance himself from his kinship network, in favor of alternative moral

economies and social solidarity – remained peripheral.

Abdoulaye's “African stories” raise questions about how the “therapeutic revolution” (Nguyen, 2010, p. 89) actually plays out in the lives of PLHA – and the lives of those in their kinship and social networks. If, as a therapeutic citizen, Abdoulaye reveals key dimensions of “exemplary adherence,” what might this suggest about the burdens and costs of such adherence – and who bears them? Whyte (2014) suggest a different lens for examining these “African stories”: therapeutic clientship. Whereas therapeutic citizenship deals with PLHA's claims on the state and international actors via NGOs and other intermediaries, therapeutic clientship emphasizes the ways in which PLHA pursue HIV/AIDS resources within their more local networks (p. 58). “Clientship,” they argue, “corresponds more closely to what Nguyen refers to as ‘local moral economies,’ in which individuals call on networks of obligation and reciprocity to negotiate access to therapeutic resources” – adding that therapeutic clients were much thicker on the ground in their work (in Uganda) than therapeutic citizens (Whyte, 2014). While Whyte and colleagues position therapeutic clientship as complementary to therapeutic citizenship, they observe that, pace Nguyen, the PLHA with whom they worked “did not seem to feel caught between conflicting moral economies ... [C]lients joined groups not only for “self-care” and bio-fellowship, but also to (re)gain the ability to participate in family sociality. In the end, that was the most important concern for most of the people most of the time ... Those relations [of therapeutic clientship] were the condition for continuing life in their families” (Whyte, 2014, p. 277).

Whyte's work reflects a broader body of scholarship that moves beyond asking, “what makes African PLHA exceptionally adherent?” to raise the pressing question of, “what happens next?” A key strand of this literature emphasizes the afterlives of access and adherence: looking beyond survival to what “the good life” – thriving, not just surviving – means for PLHA (Marsland, 2012; Meinert, 2014; Whyte, 2014). These studies, like Nguyen's, place PLHA at the center of action and analysis: featuring them, primarily as protagonists, in the life-and-death dramas they present. Family members often occupy key supporting roles, but analyses rarely focus on them (or their stories) in their own rights.

In this paper, I flip this script. Drawing on ethnographic research on health, development, and environment I conducted in Mukungule in 2006–7 and 2008, I analyze the stories Grace's death spurred family, friends, neighbors, and caregivers to share. Attention to and analysis of these “African stories” – told not just about, but by members of the networks and relations (kinship, social, therapeutic) of PLHA – are, I show, critical to developing a more robust understanding of the ways in which PLHA navigate moral economies, social solidarity, and efforts to secure “the good life” in a world of triage and precarity. This is a world in which PLHA – whether therapeutic citizens or clients; entrepreneurs or patrons; or all or none of the above – are, for better and worse, not solely responsible for decisions about who's made to live, who makes a living, and what makes a good life and a good death (Foucault, 1997; Marsland and Prince, 2012; Whyte, 2014).

3. Methods

I first heard about Grace's death on the day of her funeral. John Musakanya, the fieldworker on my study, arrived at my home that morning and informed me that we would need to adjust our survey schedule. He reported that the Bwalya family had suffered a loss, and encouraged me to attend the funeral as a show of respect.

The Bwalyas were one of 20 households in my study. I identified those households with the help of Mukungule's RHC and Area Development Committee (ADC), a group formed in order to coordinate local development projects. The RHC and ADC convened a public meeting during my first trip to Mukungule in 2006. Meeting participants generated a list of more than 50 potential households, and guided me in narrowing the roster to 20. All household members above the age of 12 initially agreed to participate; one two-person household

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