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“They are looking just the same”: Antiretroviral treatment as social danger in rural Malawi

Amy Kaler [a], [*], Nicole Angotti [b], Astha Ramaiya [c]

[a] University of Alberta, Canada
[b] American University, United States
[c] Drexel University, United States

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A B S T R A C T

Research on the social impact of ART pivots on questions of individual adherence and community acceptability of treatment programmes. In this paper we examine unexpected and unintended consequences of the scale-up of treatment in rural Malawi, using a unique dataset of more than 150 observational journals from three sites, spanning 2010 to 2013, focusing on men's everyday conversations. Through thematic content analysis, we explore the emerging perception that the widespread availability of ART constitutes a form of social danger, as treatment makes it difficult to tell who does or does not have AIDS. This ambiguity introduced through ART is interpreted as putting individuals at risk, because it is no longer possible to tell who might be infected - indeed, the sick now look healthier and “plumper” than the well. This ambivalence over the social impact of ART co-exists with individual demand for and appreciation of the benefits of treatment.

1. Introduction

The treatment of HIV infection with anti-retroviral therapies (ART) is lauded as a modern miracle (Mukherji et al., 2003, Gazzard, 2005; Robins, 2005; Panos, 2011; Vella et al., 2012). The ongoing rollout of ART to countries in sub-Saharan Africa with high HIV burdens reflects a commitment by donors and governments to saving lives. In 2013, the World Health Organization (WHO) estimated that over 9 million people were on treatment in Africa (WHO, 2013). This shift from an era of AIDS in Africa to an era of treatment is a remarkable achievement.

ART extended the lives of those who were once condemned to death. The widespread availability of the drugs, however, has had an effect unexpected by those who develop, fund and deliver the medicines: the fear that treatment poses a risk to the communities in which they circulate. This fear is gendered, and takes the form of shared anxieties about the possibility that women on treatment, who appear healthy, may actually be dangerous to men seeking a wife, a steady girlfriend or a casual partner, because treatment restores the body to a healthy appearance, thus concealing evidence of infection. This “social danger” is the subject of this paper.

By “social danger” we mean the appearance of a new form of risk – people living with HIV who are on treatment may look sexually appealing, but are able to spread their HIV infection, and are thus perceived as dangerous. While the actual probability of infection from sex with someone on treatment is vanishingly small (Cohen et al., 2011), the perception of risk is much greater. The risk is experienced at the individual level by people seeking sexual partners, but the danger itself is collective, since many people are exposed to that risk. This collective risk attaches not to the experience of taking ART drugs oneself, but to the experience of living in a community in which many are believed to be taking them.

In this paper we focus on the ways young men in rural villages in Malawi, a country with high HIV prevalence, talk about ART in everyday life. Our data come from a set of ethnographic journals that capture conversations occurring in public spaces throughout these communities, such as when men are playing board games outside local bottle shops or chatting while waiting for a minibus.

We argue that anxiety about ART shapes young men's “life micro projects”, foremost among which is identifying potential sexual or romantic partners (see Smith and Mbakwem, 2007 for a discussion of “life projects”, which we adapt in this paper). Our findings point to the unintended ways in which ART — for all its restorative

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[*] Corresponding author. Department of Sociology, University of Alberta, Tory 5-21, Edmonton, Alberta, T6G 2H4, Canada.

E-mail addresses: akaler@ualberta.ca (A. Kaler), angotti@american.edu (N. Angotti), akramaiya@gmail.com (A. Ramaiya).

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capabilities for health and longevity– is being integrated into the social lives of those experiencing the AIDS epidemic from day to day. We focus on the conduct of mundane, everyday life — the small interactions and speculations through which men share gossip, bond with each other, and pass the time.

Our findings are consistent with other research on how the availability of treatment has affected community attitudes about AIDS. Yeatman et al. (2013) investigated changes in attitudes about the transmissibility and severity of HIV disease as a result of the availability of ART in some of the same Malawian communities covered by our work. They found that, contrary to expectations, increased access to or knowledge of ART did not produce a disinhibiting effect — that is, people did not appear likely to increase their risky sexual behavior or discount the seriousness of contracting the virus because they knew treatment was available. Our qualitative work supports this view that the availability of treatment does not result in perceptions of a safer sexual environment.

2. Conceptual framework

2.1. ART skepticism and gendered risk

Before the widespread availability of ART in these communities, visual cues and local biographic knowledge exchanged in social networks helped people believe that they could distinguish “safe” women from those who were considered “risky”. Rural Malawians have long known that “you can't tell by looking” whether someone is HIV positive: in a survey conducted in 1993, when asked whether one “can get AIDS from sex with healthy looking people” about 70%, of women and about 80% of men said “yes” (Tavrow, 1994). Yet in practice, researchers have found that they continued to use personal perceptions as evidence in deciding whether someone was HIV-positive or not (Kaler, 2004; Watkins, 2004; Santow, Bracher and Watkins, 2008).

These strategies, however, are confounded by ART. Ambivalence about ART is based on one feature of the treatment regime: its capacity to restore an appearance of good health, replacing the wasting and weakness associated with AIDS. Zuch and Lurie (2012) observe that:

> as ART reconstitutes the immune systems of PLWHA [people living with HIV/AIDS], HIV/AIDS is transformed from what was once a “disfiguring and consumptive disease” into a manageable condition, largely invisible to the outside. (p. 565, see also Castro and Farmer, 2005)

Where once people with AIDS were “dead before dying” (Niehaus, 2007:845), with ART they continue their lives.

Rural Malawians know from observation that ART saves lives, but its transformative power is thought to conceal valuable, possibly life-saving, information. The focus of this paper is how ART disrupts strategies for identifying potential sexual partners for young, presumably sexually active, men.

2.2. Community perceptions of ART and unintended consequences

In a public health enterprise as massive and far-reaching as the expansion of ART, unintended consequences are perhaps inevitable. Leclerc-Madlala (2006), for example, found a perverse relationship between ART programmes and the South African government disability grant: successful treatment reduces viral load, which may disqualify people with HIV from accessing the grant once their health is restored. Similarly, in urban Tanzania, Mattes (2011) investigates the friction between the “ideal patient” implicitly figured in ART programmes and the other imperatives, desires and norms shaping actual ART patients' lives, such as the counseling imperative to restrain from sex even while in a stable relationship.

Nguyen's pioneering work on “therapeutic citizenship” (Nguyen et al., 2007; Nguyen, 2010) also draws attention to the unintended consequences when a biomedical practice such as treatment meets co-existing social formations and subjectivities, particularly those generated by neocolonial political relations. Along these lines, several ethnographic studies have explored the ways in which the availability of ART intersects with everyday life and suffering, such as hunger (Kalofonos, 2010), political marginalization (Biehl and Eskerod, 2006), and other social maladies (for additional examples, see Ashforth and Nattrass, 2005; Zhou, 2016). The conversations in our paper are shaped mainly by the sexual and gender politics of the village, so the association of ART with other manifestations of politics is not foregrounded here, as it sometimes is with other researchers. However, we are similarly interested in what happens in the social moments following the arrival of treatment, when knowledge, often imperfect, about new medical technologies is embroidered into the fabric of daily life, including individual concerns about survival and happiness.

2.3. ART and men

Since early in the epidemic, a common slogan of international organizations working to prevent AIDS has been “AIDS has the face of a woman” (Annan, 2003). Only recently has attention been given to the higher mortality of men with AIDS, who are less likely to be tested and thus less likely to access treatment. This stimulated concerns that HIV testing and treatment programmes are not working well for many men, either because these interventions target women, or because health facilities focus on conditions of women (pre-natal care, childbirth) and their children (illnesses, vaccinations), or because men are less compliant than women (Bila and Egrot, 2009; Kipp et al., 2010; Lesia et al., 2013, Dovel et al., 2015; see also Nyamhanga et al., 2013; Skovdal et al., 2011a,b; Mburu et al., 2014).

Although we too focus on men, our focus is not on men who are being tested or treated for HIV. In the communities in our study, ART is well-accepted by both men and women. Although some are doubtful about side effects and efficacy, in general, willingness to be tested among men and women is high (see Angotti et al., 2009), as is the uptake of treatment, estimated at 51% coverage for all HIV positive adults in Malawi, for a total of 533 027 people on treatment in 2015 (Government of Malawi, 2014:37).

Our focus instead is on the ways in which the growing presence of ART within communities interacts with what we call the “life micro-projects” of men in general, whether or not they are directly involved with HIV testing and treatment. Our treatment of gender is not as a variable (male or female), nor as a set of abstract norms and values to which people are said to adhere. Rather, we examine *gender in action*, in the form of everyday conversations, in order to understand how men's strategies (in particular, their “life micro projects”, defined below) are affected by the pervasiveness of ART in their communities.

2.4. ART and life micro projects

In their work on Nigeria, Smith and Mbakwem (2007, 2010) argue that people on ART want to live a “normal life”, and therefore integrate ART into the pursuit of “life projects” — the culturally and personally meaningful goals of adult life, particularly marrying and having children (see also Smith, 2014). As such, ART is not simply an end in itself; it is also a means to the end of achieving and sustaining a successful adulthood, marked by marital and reproductive success. In rural Malawi, adulthood as a stage of life is not