The social life of PrEP in Kenya

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By

I have perhaps an unpopular position to declare: Although pre-exposure prophylaxis (PrEP) is an enormous biomedical breakthrough in the prevention of HIV, it also symbolizes much of what is wrong in current global health practice.

Since 2013, I have been working on HIV prevention research in Kenya, which, as pointed out in this series introduction, has the second highest number of enrollees on PrEP globally. Kenya was one of the first African countries to approve PrEP for HIV prevention and currently 43,000-44,000 individuals are reportedly enrolled on PrEP (AVAC 2019). While I never intended for my work to focus on PrEP, I couldn't help but to learn about it as part of my ongoing research among "key populations" at high risk of HIV infection, including people who inject drugs, sex workers, and men who have sex with men (MSM). As PrEP was scaled up, my research team leveraged the social moment to collect systematic data on attitudes, preferences, and experiences with PrEP as part of our broader concern with engagement in HIV prevention and care. In fact, we have argued in the global health literature for a need to better listen to the voices of "key populations" who could benefit from PrEP (Bazzi et al. 2018, Syvertsen et al. 2014, Bazzi et al. 2019). Throughout my fieldwork, I have also engaged in ongoing conversations with multiple researchers and local research assistants about new projects, challenges in implementation, and shifting policies and infrastructures that have become part of my fieldnotes documenting an evolving social life of PrEP in Kenya.

To be clear, PrEP holds promise in reducing HIV incidence in regions hard hit by the epidemic like Kenya, and applied anthropological PrEP research giving voice to socially marginalized populations is an important contribution toward addressing health equities. But based on my ongoing research and observations in Kisumu, western Kenya, I increasingly see the need to more deeply question PrEP's commonsense biomedical exceptionalism. PrEP is the latest technology to become part of a broader "re-medicalization" of the HIV epidemic that casts HIV as a purely medical condition in which biomedical scientists should be in charge (Nguyen et al. 2011). As a point of contrast, this commentary takes up what Nancy Scheper-Hughes calls a "critically applied medical anthropology," including her suggestion for a radicalization of medicine to produce social

critique and subversive action towards greater health equity (Scheper-Hughes 1990). Specifically, I examine how the "projectification" (Prince 2013) of PrEP privileges certain forms of evidence-making and suggest that we need to rethink our focus to better address the HIV epidemic.

The projectification of PrEP

Kenya is a major global site of PrEP evidence-making. As of 2018, there were 17 active PrEP trials, demonstrations, and implementation projects across Kenya sponsored by 12 different funding agencies (AVAC 2019). Multiple projects are active in Kisumu, not to mention other investigator-initiated grants that may be active or under peer review at any given time (my own work included). This concentration of research and services in Kisumu is not baseless, as the general HIV prevalence in Kisumu County (16.3%) is the third highest in Kenya (NASCOP 2018).

Medical anthropologists who spend years observing the social context in which global health interventions unfold have the advantage of navigating between clinical and social worlds to see a bigger picture across time and space. During my fieldwork, I have seen immense changes in Kisumu. Its population of 400,000 represents one of the fastest growing cities in East Africa, but much of this growth is unchecked slum development around the city margins. Despite new shopping malls, restaurants, coffee shops, road construction, and luxury hotels, Kisumu remains marked by tremendous socioeconomic inequalities and health disparities, including its ongoing HIV epidemic. Much of its development is interrelated with the constant influx of government and non-governmental workers, aid workers, researchers, students, and other well-meaning people (myself included) that continually flood into Kisumu to "help" with health projects. The implementation of PrEP is very much part of a shifting social landscape in which despite the concentration of funding and research, HIV remains frustratingly entrenched.

PrEP has become part of what Ruth Prince has called the "projectification" of public health in many African contexts (Prince 2013). In Kisumu, this means much of the healthcare, especially HIV-related services, is funded by donors and provided by non-governmental organizations and implementing partners. These services are often characterized by a lack of coordination, fragmentation, and inequalities in priorities, quality, and access. Furthermore, many programs are short-term projects that target specific "risk groups" or health conditions rather than build an integrative "public" health. These projects are often devised in "corridors of power" where global HIV priorities are crafted far from the fields of their implementation (Dionne 2017). Donor-driven audit cultures set "targets" and organizations need to show that they are enrolling

individuals into programs and quantify the services they provide (e.g., numbers enrolled, pills dispensed) in order to merit funding. Researchers also compete for funding and carve out their turf to devise increasingly innovative “interventions” to enhance results. But what many see on the ground and few publically admit is how this system creates competition between organizations and a duplication of services that ultimately wastes resources.

I have sat in on organization meetings that have become subsumed by donor-demanded metrics: cases screened for HIV, cases HIV negative, cases HIV positive, cases initiated on PrEP, cases retained on PrEP, and new cases of other sexually transmitted infections that reflect a worrisome “risk compensation,” or the practice of individuals discarding condom use once on PrEP. Some of the numbers are disappointing. Others are downright grim. I saw a recent presentation by an organization conducting a demonstration project of PrEP that showed high uptake among women, but tremendous drop-off: the 100% enrollment at baseline dropped to 0.4% retention 11 months later (Digolo et al. 2018). I have heard multiple stories of similarly discouraging drop-out rates from other organizations providing PrEP. Further, increasingly invasive forms of surveillance over those who enroll on PrEP, including self-reports, pill counts, and biological measures of drug levels in bodies are revealing poor adherence, which renders PrEP much less effective, and has been documented elsewhere (cf. Marrazzo et al. 2015). In short, people are enrolling into PrEP programs to generate massive numbers, but then many do not actually take the pill. *Why is that?*

PrEP: What counts as evidence?

Within projectified landscapes of PrEP, the concerns of actual people often get glossed in the numbers. In her critique of the global health push towards evidence-based medicine, Vincanne Adams has observed that “studies that foreground the individual speaking subject as the primary source of truth have virtually no purchase, nor do those additional truths garnered from the families, communities, or relationships that help form that speech” (Adams 2013:56). Even when we enable participants to speak, PrEP studies are primarily framed around notions of “risk” (my own included).

HIV risk is real and important, but it is not the whole story. What gets erased is the lived experience of PrEP beyond “risk” frameworks that impose boundaries on individuals. One of Scheper-Hughes’s key suggestions for a critically applied medical anthropology is to untether ourselves from biomedical agendas to reclaim medicine as “a tool for human liberation” (1990:194). The current focus on enumerative evidence and “risk compensation” could be part of the problem underlying steep

drop-offs in PrEP use because this is not meaningful to people. What if, for example, we turned our attention away from risk and towards the potential of PrEP in generating new forms of sexual subjectivity and pleasure in African contexts?

Elsewhere in western contexts there is a growing body of literature, particularly in regard to MSM experiences, that push beyond biomedical discourses of PrEP. To many of these men, PrEP symbolizes new forms of sexual citizenship, lessened stigma, pleasure, and agency in intimate relationships (Hughes et al. 2018, Malone et al. 2017, Mabire et al. 2019). This re-focusing is a reaction to histories of risk-based interventions that promote medicalized discourses of sex as a "risk" requiring "intervention" or the consequences could be infection and death (Whitacre 2018).

However, the subjective experiences of "risk groups" are rarely considered in donor-driven initiatives in sub-Saharan Africa. If metrics, adherence, and "risk compensation" dominate PrEP discourses across African contexts, critically applied anthropologists should ask ourselves: *Why is that?* Could it be that PrEP represents just the latest example of colonialist, racist foundations of knowledge systems where "pleasure" seems to be a luxury only certain communities can afford?

Toward a critically applied PrEP agenda

Instead of enslaving ourselves to the re-medicalization of an epidemic that is inherently social and political (Nguyen et al. 2011), a critically applied medical anthropology calls for careful evaluation of the global push for PrEP. It should take up unpopular positions that poke holes in biomedical hegemony and critique projectified landscapes of PrEP that prioritize meeting targets over the concerns of the supposed beneficiaries of PrEP. It should question if we have misplaced our priorities, not to mention resources, in promoting PrEP as a tool to offset risk, rather than to increase sexual pleasure and empowerment. In short, it should advocate for a more radical rethinking of PrEP moving forward.

To this end, I wonder: how do we reimagine the donor-driven audit culture to create a system of collective accountability in reducing HIV incidence? And how do we reclaim a global health research agenda that grants everyone the choices, respect, and voice they deserve? It seems to me that steering the discourse on PrEP away from risk and toward pleasure to generate greater health equity is "exercising to the core what our discipline has always been about" (Scheper-Hughes, 1990:195).

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