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Of HIV, Kings, and Cures: Troubling the Apocryphal Apothecary

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In this commentary we respond to Jing-Bao Nie and colleagues’ (2016) discussion of the use of military metaphors in HIV cure research. We commend the authors for raising important questions about the use of violent metaphors, such as “shock and kill” to describe the process of activating viral “reservoirs.” We share their interest in critical approaches to the study of HIV treatment and prevention technologies, and the importance of interrogating the use of language in bioethical inquiry. We complement their analysis by drawing on additional research, including our own, that further theorizes the use of militaristic metaphors, but also surfaces the perspectives of those most affected—persons living with and at risk of acquiring HIV.

First, we locate the growing use of militaristic metaphors within what Elbe (2009) described as a shift in the global response to HIV from viewing it as a health issue to an issue of national and international security. HIV became framed as not just a threat to individual health, but also to collective social and economic prosperity and military preparedness (as it moved within and across borders unchecked). In the United States, these trends have culminated in the implementation of what the U.S. Centers for Disease Control and Prevention (CDC) (2011) have called “high impact prevention,” which involves “using combinations of scientifically proven, cost-effective, and scalable interventions targeted to the right populations in the right geographic areas.” This approach includes, in part, the scale-up of testing, diagnosis, and early treatment initiation to reduce viral replication in individuals and decrease HIV transmission at the population level, or—“seek, test, and treat” (Hayden 2010).

Questions have been raised about the ethical implications of asking individual patients to undertake risks associated with early treatment initiation, even as this may support the public good (Haire and Kaldor 2013). While more recent clinical research provides further support for the individual benefits of early combination antiretroviral therapy (cART) initiation, the larger ethical questions remain relevant. Additional concerns have been raised about individual viral load becoming reportable in some jurisdictions; this may provide data to map concentrations of people living with HIV to identify “viral hotspots,” target “unsuppressed” people in clinical care and through prevention messaging, and pursue HIV non-disclosure criminal cases (Guta, Murray, and Gagnon 2016). Some have argued that we are witnessing an articulation of the HIV response that seeks to find and suppress the virus in individual bodies and whole communities in ways comparable to forms of social control seen only in dictatorships (Patton 2011). But perhaps martial law serves as a better analogy.
As with all military campaigns, there is a great deal of rhetoric deployed to keep those in the trenches motivated. Similar to the way in which “drug cocktail” sounded better than antiretroviral chemotherapy in a previous phase of biomedical advancement, so too may using “cure” to describe research on HIV viral suppression and remission. Yet this has concerning ethical implications for all those involved in HIV research. Most “HIV cure” research involves strategies like intensive antiretroviral treatment, radiation, and immune activation (the body at war with itself) to reduce transmission and replication within and between systems (Purcell et al. 2013). However, this is not a “cure” as many would understand it—the virus and its evidence remain present. The language of cure has even been extended to those who are HIV seronegative, such as in the promotional video for a clinical trial testing HIV Pre-Exposure Prophylaxis (PrEP), in which participants express wanting to be part of finding the cure, and invite others to mobilise around the cause (Global iPrEx 2010). However, PrEP is a strategy that requires daily use of HIV treatment to prevent infection (another aspect of “high impact prevention”) and is clearly not a cure for HIV. In all, these approaches do not vanquish the “enemy” but require long and protracted suppression of an insurgency. A crucial concern is that the excitement of “cure” research will further eclipse the myriad social-structural factors and ethical challenges that produce vulnerability to HIV in the first place, and that lead to disparate health outcomes among people living with HIV (Purcell et al. 2013).

Nie and colleagues (2016) note as a limitation the absence of first-person narratives in their analysis. We turn to empirical results from studies about participation in HIV vaccine research, which illustrate the impact of language and metaphor in the fears and desires of potential trial volunteers and key populations more broadly (Newman et al. 2008; Newman et al. 2011). In addition to evidence of altruism and a desire to give back to one’s community, participants expressed fear and trepidation about enrolling in HIV vaccine trials. In particular, they worried about being targeted as “high risk” persons (indeed, they are often engaged in practices that may be stigmatized and criminalized in the same contexts in which cure research is being conducted) and that such interventions may be a pretext for unwelcome forms of future monitoring, control, and even exploitation. Importantly, participants from key populations have their own worldviews and knowledge, and ways of describing research—which often include the legacy of past unethical research practices and measures deemed ethical in clinical trials that may not be construed as such by
affected communities, such as placebo; this was “conspiracy” and “trickery” for some Black women in North America (Newman et al. 2011). Communities clearly articulated wanting opportunities to be engaged from the beginning to inform how HIV vaccine research is designed and explained, in part to ensure the risks and benefits are communicated transparently in accessible terms. As with the worry of maintaining peace in the militaristic sense, participants were concerned about the risk of trial-related or future HIV infection. Thus, fear was a prominent component of many community stakeholders’ relationship with HIV vaccine research—and may be expected to remain so in new approaches to “cure” research. In militaristic terms, they seemed to worry about being the collateral damage amid numerous casualties in a protracted war between scientists and the virus.

Finally, in recommending future theoretical and empirical bioethics research on this topic, we support Nie and colleagues (2016) in calling for greater consideration of language and symbolism in clinical research, and the need for better integrating the perspectives of the range of stakeholders from people living with HIV to researchers. This integration is necessary throughout pretrial, trial implementation, and posttrial phases of clinical research (Newman et al. 2011). Of particular concern to us, having followed numerous media releases over the last few years proclaiming the cure is imminent (based on a result from an in vitro lab experiment), or that someone has been completely cured (only to print later, and with much less fanfare, that they were not), is the broader issue of the ethics of knowledge exchange and dissemination in HIV research. While the HIV sector has a long and celebrated history of community stakeholders proactively demanding to know the state of the science and to be engaged in defining best practices, it is important that we engage in more careful thinking and empirical evaluation of how research agendas, policy statements, and early results are framed and shared to limit false expectations and misinformation. Rather than unintentionally substantiating misconstruals perhaps more apropos of the “royal touch”—an apocryphal laying on of hands, once the provenance of the divine right of kings, reputed to cure numerous ailments, and not incidentally instrumental in the persistence of monarchic rule—rather than modern science, an HIV research agenda that more thoughtfully promotes metaphors consistent with a rational and democratic process may ultimately gain more traction in supporting our shared goal of ending the epidemic.
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