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# **EDITORS' NOTE**

# HIV/AIDS,1 its stigma and history

Amidst the fog of uncertainty engulfing Brazil in April 2018 – of arbitrariness, intolerance, sectarianism, prejudice, and authoritarianism – the latest issue of *História, Ciências, Saúde – Manguinhos* stands as a beacon, with a collection of articles that bear witness to the vigor of research in the history of medicine and the life sciences in recent years. We draw this comparison between *História, Ciências, Saúde – Manguinhos* and a guiding light to underscore the role that knowledge communication can and should play in the debate over the direction our society should take, with the outlook for the future shaped by choices made in the present and grounded in a conscious stewardship of the past. Sustaining the vitality of academic research is an act of resistance that fosters a clear, open, and democratic exchange of ideas.

Although Brazil has taken many steps backward of late, the country managed to move forward in its HIV prevention policy by adopting pre-exposure prophylaxis, or PrEP, since December 2017 available at 36 treatment centers in 11 states. In 2012, the World Health Organization recommended the use of PrEP for more exposed populations, like men who have sex with men, transgender women and men, and sex workers. In PrEP, uninfected people from these groups take an antiretroviral drug (in this case Truvada) alone or in combination. While this advance certainly calls for celebration, it should not lull us into complacency about looming threats to Brazil's free, universal health system, such as reported problems with the distribution of medicine. At a time of tightening funds and the promotion of conservative agendas, heightened attention must be paid to the sustainability of prevention programs and the renewal of alliances with civil society.

The reception and promotion of this new prevention strategy have, however, corroborated the persistence of stigmatizing metaphors about HIV and AIDS that have endured since the disease's early days, when it was labeled the "gay plague" (Sontag, 2007). Ignoring the numerous findings about PrEP that have been gathered in Brazil and abroad, the magazine *Época* recently published a report entitled "A outra pílula azul" (The other blue pill) that links the infection to gay men while painting this population as inclined to promiscuity (Thomaz, 2 abr. 2018). The article did a disservice both in suggesting that only gay men should concern themselves with HIV prevention and in failing to stress that PrEP is part of an integrated prevention strategy that includes other approaches. As a result, the report effectively encourages the stigmatization of those who contract the virus. Its use of the expression "risk group," abandoned in the 1990s, reveals ignorance as well as prejudice against the gay community, which has struggled to free itself from the stigma of "vector" of the virus.

The sub-title of the *Época* article – "O novo medicamento que está fazendo os gays abandonar [sic] a segurança da camisinha" (The new drug that is making gays abandon the

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safety of condoms) – itself is a display of both misinformation and disinformation, since there are no data to support any such claim. Yet based on this argument, the article asserts that gays are contributing to the rise of other sexually transmitted diseases. The report also ignores the 99% safety level obtained with PrEP and says the method accounts for the increase in the number of infections – an inference that cannot be drawn given that the method was adopted only a short time ago.

Individuals and institutions that are engaged in HIV control and the defense of LGBT rights have justly decried the sensationalist tenor and errors of the *Época* article. Criticized for presenting inaccurate information and preconceptions, the article also came under fire for its moralistic, biased portrayal of gays. The affinity between this type of discourse and the recent advance of conservatism and fundamentalism in Brazil have not gone unnoticed (Abia, 3 abr. 2018; Anaids, 2 abr. 2018; Brasil, 2 abr. 2018; CRT DST/Aids-SP, 2 abr. 2018; Foaesp, 2 abr. 2018; INI, 2 abr. 2018; Super Indetectável, 2 abr. 2018; Vasconcelos, 31 mar. 2018; Wyllys, 3 abr. 2018).

The controversy fueled by PrEP and the *Época* article tells us as much about the society we live in as about the perceptions and ideas that HIV/AIDS trigger in the social imagination. Even though the profile of HIV/AIDS has changed drastically over the course of its short history - from death sentence to chronic disease - it is still a culprit behind high mortality rates around the world, as a result of inadequate public policies, cultural factors, political instability, and poverty in areas where the infection is widespread. The Brazilian Interdisciplinary Association on AIDS (Abia, 3 abr. 2018) warned that an efficacious prevention policy demands well-designed strategies along with a favorable social and cultural environment, that is, an environment free of stigma, moralism, and disinformation. When stigmatization is reinforced, it jeopardizes the physical and mental well-being and social inclusion of diagnosed individuals and may also discourage them from seeking treatment. What remains apparent is that diseases, morbidity rates, and infections are not restricted to laboratory research, clinical trials, diagnostic protocols, innovations in treatment, and limited epidemiological studies. When a disease acquires a name and a meaning, it stirs entrenched cultural signs and perceptions, and these find expression in the private lives of individuals, who gain a new "citizenship" once diagnosed (Sontag, 2007). Behaviors and identities are framed and formulated on the basis of these acts of definition, prompting complex, entangled processes of negotiation among the various sectors directly or indirectly involved with the disease. With this in mind, the eminent historian of medicine Charles Rosenberg (1992) described diseases as "social actors," since once they are named and defined, diseases behave as factors that structure social circumstances. As this recent controversy has shown, the negotiation process is not peaceful, as the term might suggest, but rather entails disputes over meanings, conflicts, and opposing interests on the part of the various collective groups competing for a position as the voice of authority and legitimacy in discourse about the disease.

This controversy demonstrates the complex and often times challenging interplay between different types of knowledge and demands surrounding HIV. When "authorized" knowledge is "translated" for the lay public (or publics, given the heterogeneity of the audiences touched by this discourse), it is not along a linear path. To the contrary, since the virus made its dramatic appearance in the public sphere, HIV and AIDS have substantially altered how "patients" and

activists participate in definitions and enunciations. The scientific discourse has not been received passively. Groups averse to having their behavior circumscribed by medical discourse have singled out and criticized its moral components. This recent case evokes the history of traditional epidemics, like yellow fever, cholera, and the bubonic plague, when on more than one occasion the press has fueled social panic and transmitted moral discourses on health.

The design and reception of health measures reaffirm cultural attitudes and social values. In the case of HIV/AIDS and PrEP, we have witnessed the persistence of biases rooted deep in the social imagination, the eagerness of hegemonic social segments to punish groups and behaviors labeled as "abnormal," and a tendency to blame illnesses on individual behavior. So far, neither new approaches to the infection nor educational campaigns have achieved any substantive changes in this regard. This is one of the many areas where the fight against the disease must continue, strengthened by positive initiatives, like making PrEP available in Brazil.

In the pages of *História, Ciências, Saúde – Manguinhos*, readers will find articles that can help them reflect on the stigmatization of people diagnosed with certain pathologies, affording comparisons with the case of HIV/AIDS. Some articles also explore how medical discourse takes part in the framing of behaviors and identities, like those tied to sexuality and gender roles. Our journal has also published studies on the role of media discourse in the public debate on science, disease, and treatment. There is nothing new about major newspapers and magazines influencing discussions and perceptions in the realm of social issues, where diseases are often at the fore. We invite you to look back over our issues to arm yourself with critical tools to use in examining the events and processes that affect us. This is how *História, Ciências, Saúde – Manguinhos* can serve as a living vehicle of knowledge, rather than a mere receptacle for writings worth perusing solely for narrow research purposes. As naïve or outmoded as the belief in the transformative power of knowledge may seem, we reaffirm our conviction that it is a sure light that allows us to look beyond the shadows.

# NOTE

<sup>1</sup> UNAIDS (6 abr. 2018) has advised against using the expression "HIV/AIDS," an unquestionably important step toward separating out what are in fact two distinct elements, infection by the virus and a syndrome. However, we have employed it in this text because, when analyzed from a historical and sociological perspective, the infection triggers perceptions and reactions that tie in to both dimensions. In fact, it is this interweaving that enables biases and stigmas to endure even though the availability of efficient treatment options has radically altered the effects of the virus in the body. Thus, from a historical viewpoint, talking about HIV means talking at the same time about the epidemic with which it is associated, not for biological reasons but for social and cultural ones. Where we felt the two words could be separated out, we have done so.

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