

Prevention With People With HIV/AIDS

A Perspective From a Person Living With HIV/AIDS in Latin America

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Data from the United States suggest that approximately 60% of people living with HIV/AIDS (PLWHA) are aware of their HIV status. These data contrast with Brazil, where a report from 2001 estimates that 600,000 men and women are living with HIV (age range: 15–49 years), of whom 149,000 (in 2003) receive treatment.¹ The estimate for persons living with HIV (PWHIV) who are aware of their status is 215,000 (approximately 35%; D. Barreira, MD, PNSTD-AIDS, private communication). This trend toward low proportions of persons who know their serostatus has been observed in many countries in the world. So, although prevention with PLWHA who know their serostatus is certainly worthy of the attention devoted by this issue as well as by resources allocated in the United States, this strategy may not always act on the “core” of the epidemic, at least in countries where prevention efforts then miss the majority of persons who do not know they have HIV. In this commentary, I highlight some important aspects of the focus of prevention on HIV-positive persons, especially in international settings.

First, we must remember that many PLWHA were most likely aware of the threat of HIV and exposed to preventive messages before they became infected; in a sense, this means that these approaches failed for them. Moreover, it is also likely that the individual and social characteristics of their vulnerability still persist in their lives. Some people do not easily overcome the news of an HIV diagnosis, even in places where there is access to antiretroviral (ARV) therapies. Certainly, some people reshape many aspects of their lives after learning their HIV diagnosis and make positive changes such as risk reduction and being adherent to therapy. The question remains, however, as to whether HIV infection is such an important additional circumstance that it would be a logical strategy to rely on delivering the same kinds of prevention messages that had already failed for this person. It has been argued that too much focus on prevention with positive persons is blaming these individuals for new infections; I argue that this is an insufficient framework for prevention because it continues to ignore the social contexts that favor infections. Did they have easy and affordable access to preventive means such as condoms or syringes? Did they live in neighborhoods where disadvantages, discrimination, and a lack of social capital provide them with few healthy alternatives? In my opinion, criminalization of HIV transmission should also be interpreted within this frame; what kind of a barrier does this issue present for eliminating stigmatization from the prevention and treatment process?

Second, it now seems clearer than ever that it is important to listen carefully to persons who have become HIV-positive and try to see where preventive activities failed for them so as to provide new approaches tailored for others like them. I note a positive trend in that several of the studies in this issue seem to have drawn on the expertise of the consumer community for new directions. For example, in an article in this issue on an integrated behavioral intervention with HIV-positive injection drug users to address medical care,

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adherence, and risk reduction (INSPIRE), Purcell et al state that their intervention was based on the concepts of empowerment and peer leadership or advocacy. The intervention looked for a more prosocial attitude of PWHIV that can help in facing vulnerability. In another article in this issue on prevention for substance-using HIV-positive young people, Rotheram-Borus et al assert together with,² that “In order to motivate [young people living with HIV] YPLH to altruistically reduce transmission for the public good, it is necessary to address the young people’s need to improve their health and mental health, especially adherence to health regimens.” So, the challenge is to deal with the multiple needs of these people and prevention simultaneously.

Third, there needs to be careful consideration of issues related to prevention for PLWHA who are currently on ARV treatment to obstruct infection or reinfection of resistant strains. It is troubling to read in an article in this issue on lessons from the Seropositive Urban Men’s Study and the Seropositive Urban Men’s Intervention Trial that Wolitski et al report unprotected sex with other HIV-positive men was so common despite the evidence from qualitative interviews that more than one third were concerned about reinfection with a different strain of HIV and concerned about contracting other STDs. In countries that do not have universal access to health and to ARVs, how do we take this into account in developing risk-reduction strategies? As asserted by Knauth⁵: “In order to implement prevention, people must think in terms of a long future.” How do we talk with PWHIV about this future without access to health, and hence without empowerment, when people do not have access to critical treatment? Should we also address strategies to advocate for treatment, perhaps taking the place of issues like adherence in Rotheram-Borus et al’s intervention or disclosure in other “prevention with positive” interventions? What is the appropriate message about disclosure in communities without access to treatment and high levels of potential stigma and discrimination?

The fourth topic for the reader to consider for this special issue is disclosure. One of the major goals of prevention for PLWHA is to prevent HIV transmission. Does disclosure of one’s seropositivity to intimate partners actually promote safer behaviors? Some useful data are presented in this supplement. Living with HIV, we know that many people with HIV actively avoid disclosure, at least in some contexts, often with good reason. As Rotheram-Borus et al note, a reason to intervene with individuals via telephone may be to address concerns about disclosure. Purcell et al also took disclosure into account in their methods, “To eliminate the need for potential participants to disclose their HIV status in outreach venues, potential participants were told, ‘If this card does not apply to you, please give it to someone you know’.”

Disclosure of HIV status to partners as a responsibility (Centers for Disease Control and Prevention [CDC] guidelines⁶) does not seem to stem from medical or public health

reasons. On the one hand, there are the necessity and ethics of practicing safer sex and, on the other hand, the ethics of disclosing HIV status. Public health reasons clearly support the first but perhaps not the second. This is a complex issue, and some of the findings reported here highlight that research has only begun to understand how the personal responsibility of disclosure might affect risk behavior and public health. In terms of safer sex, although several studies have indicated that having problems communicating with partners was associated with unprotected sex, there is little evidence in this issue that withholding disclosure of one’s seropositive status from sex partners was associated with risky sexual behavior.³ The prevalence of safer sex among nondisclosers was similar to the prevalence of safer sex among disclosers. As Wolitski et al state, “Nondisclosers may fear negative consequences from disclosing (eg, refusal to have sex, loss of privacy, stigmatization) but still attempt to be safe with those uninformed partners. Moreover, disclosure does not ensure that safer sex will prevail, because some partners may engage in risky sexual activity even after being informed of their risk.”⁴ Wolitski et al note that most participants perceived that they had a personal responsibility to protect sex partners from HIV infection and that this belief had a strong effect on safer sexual practices.

This complicated issue of the pros and cons of disclosure as a prevention “tool” further underscores that we are not addressing a huge piece of the puzzle if we ignore the social and cultural contexts of an individual’s responsibility. Factors such as altruism, responsibility, solidarity, harm reduction, disclosure, fear of discrimination, and the need for sexual and affective relationships combine in cultural settings to provide the basis for behaviors. Also, if we raise the issue of responsibility, we can ask what is the responsibility of our society for fostering discriminating messages that may hamper disclosure? If, to increase the number of HIV-infected persons who know their serostatus, we create campaigns to diminish discrimination against HIV-infected persons and reduce stigma associated with HIV infection as stated by the CDC,⁷ these campaigns currently face environmental obstacles that have an unknown effect on HIV prevention, such as political opposition to gay civil union or religious opposition to condoms. HIV-seropositive persons have a responsibility to protect others, but that responsibility does not exist in a vacuum. What is the responsibility of the seronegative partner of a PLWHA who disclosed his/her status to the former? We all share in the responsibility to prevent the further spread of HIV, and it will take all our efforts to have a significant impact on the future course of the epidemic.

The last point I wanted to address is the need to complement the CDC guidelines for clinicians, ensuring that PLWHA do receive much more “care” than “treatment.” The first concept includes treatment but is also concerned with the individual plans and projects of patients.⁸ These personal projects

may include having steady partners (who can be seronegative) and, likely, having children. Certainly, as observed by Fontenelle and Machado,⁹ a multidisciplinary team can be an important source for PLWHA and their partners to discuss and get information about these and other subjects so that they can make informed decisions. Paraphrasing Terto,¹⁰ prevention and care should be integrated to warrant more complete assistance which aims at individual and collective well-being. In all population groups, and particularly in those socially excluded, prevention should be oriented not toward the imposition of disciplinary norms on what is correct and what is not but toward actions promoting human rights in the health field.

This supplement offers a series of articles that shed light on these subjects. Although all these efforts were undertaken in the United States, readers will agree that it is worth investing in research in other countries as well and that these experiences provide insight into which strategies will be helpful globally as well as opportunities to learn from other cultures and communities about the important understudied role that social context plays in HIV prevention and treatment.

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