PREVENTION LITERACY:

Reinventing HIV Prevention for the 21st Century
Executive Summary

Prevention Literacy: Reinventing HIV Prevention for the 21st Century

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The HIV and AIDS response has seen a rapid expansion in the past decade of the available types of prevention methods for those at risk for HIV, as well as new methods for those living with HIV to reduce transmission. These methods include a diverse array of biomedical, behavioral, and structural approaches. This expansion of prevention options comes at a critical moment in the HIV response when many HIV and AIDS organizations are passionately pushing for the "end of AIDS" by 2030. Many global organizations, however, do not seem to consider the critical role the diverse range of prevention strategies may play in achieving the end of AIDS. In spite of this, many affected populations and communities today are increasingly demanding access to the full range of prevention options, just as they have demanded access to treatment options for decades.

The effective adoption of prevention approaches, especially when used in combination, depends on individuals and communities having access to information about available methods, the ability to understand and assess what methods would be most effective in light of their specific situations, and the empowerment to demand from the government access to methods that are not being made available. Similar to the concept of ‘treatment literacy’ that was developed by HIV and AIDS activists early in the era of HIV treatment scale-up, today we need to develop ‘prevention literacy’ to facilitate response efforts as well as empower those at risk for HIV.

There is clearly no ‘one size fits all’ solution that can be prescribed to all or even specific groups of people. Therefore, it is absolutely necessary for people to make their own decisions regarding what prevention method(s) work best for themselves and their lives. There is currently an urgent need to re-conceptualize prevention, and to create true prevention literacy by and for the communities that are most vulnerable to HIV in anticipation of prevention scale-up.
In the past decade, the HIV and AIDS response has seen a rapid expansion of the available types of prevention methods for those at risk for HIV, as well as new methods for those living with HIV to reduce transmission. These methods include a diverse array of biomedical, behavioral, and structural or environmental approaches. In terms of the biomedical, both pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP) have become available in many areas affected by the epidemic. Male and female condoms continue to be available as physical-barrier devices against HIV transmission, but now exist in combination with newer approaches such as the controversial push for voluntary medical male circumcision (VMMC) and the relatively new concept of ‘treatment as prevention’ (suppressed viral loads from antiretroviral treatment leading to decreased likelihood of transmission). Behavioral and structural or environmental prevention methods, including various forms of harm reduction (needle exchanges, serosorting, negotiated safety, exclusive partners, etc.), also serve as HIV prevention options for many people at risk.

This expansion of prevention options comes at a critical moment in the HIV response in which many HIV and AIDS organizations – UNAIDS in particular – are passionately pushing for the “end of AIDS” by 2030. UNAIDS has also proposed the commitment to the ambitious 90-90-90 plan to realize this goal, which entails 90% of people living with HIV aware of their status, 90% of those aware on antiretroviral therapy (ART), and 90% of those on treatment virally suppressed by 2020. While these attempts to eradicate the AIDS epidemic by international public health bodies are admirable, they do so by almost exclusively focusing on ‘treatment as prevention’ (sometimes designated by the acronym, TasP) as the means to achieve it. This is especially true for the 90-90-90 plan. Beyond PrEP for certain key populations and the recent push for VMMC, many global organizations do not seem to consider the critical role the diverse range of prevention strategies may play in achieving the end of AIDS. Many affected populations and communities today, however, are increasingly demanding access to the full range of prevention options, just as they have demanded access to treatment options for decades.

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Conscious and effective application of diverse prevention methods must play a fundamental role if we are to have any chance of truly achieving the end of AIDS. Dynamic and tailored HIV prevention strategies that utilize all approaches and incorporate the input of those most affected by HIV, foster empowerment and the pursuit of human rights. As a first step, global organizations involved in the HIV response should promote the use of ‘combination prevention’ as a critical strategy moving forward.⁵⁻⁶ The effective adoption of multiple prevention approaches also depends on individuals and communities having access to information about available methods, being conscious of the methods that would be most effective in light of their specific situations, and being empowered to make decisions about the prevention options that make the most sense for their lives. Similar to the concept of ‘treatment literacy’ that was developed by HIV and AIDS activists early in the era of HIV treatment scale-up, which recognized the need to do more than just get ‘pills into bodies’, today we need to develop ‘prevention literacy’ to facilitate response efforts as well as empower those at risk for HIV. Treatment literacy was developed in order to help people turn the promise of treatment access into reality in their lives. Today, it is equally important to incorporate prevention literacy in the push to ‘end AIDS’ in order to allow the millions at risk of HIV to take control of the full range of prevention options available to them. The similarity between the situation of today’s array of prevention options (and the need to use them in combination) and the situation of HIV treatment access and scale-up in the late 1990s (when combination antiretroviral therapies began to become available) offers an important advantage for activists and practitioners to learn from both the mistakes and the successes made 15 years ago in trying to promote treatment literacy and empower people to take control of their health and wellbeing.

The Development of Treatment Literacy

The history of treatment literacy can provide an excellent context to situate the current need for prevention literacy. ‘Treatment literacy,’ as it is now understood, did not develop until the end of the epidemic’s second decade. In the first years of the 2000s, activists from the Treatment Action Campaign (TAC) in South Africa advocated for the provision of antiretroviral medications for pregnant women who were HIV positive in order to prevent HIV transmission to their children.⁷ Antiretrovirals had been recommended for use with seropositive pregnant women since 1994,⁸ and the use of ART as HIV treatment became available in 1996, yet the government of South Africa was not providing these life-saving drugs to its people. After a landmark suit against the government – as well as remarkable efforts from civil society that provided the movement with the backing for social reform in addition to legal reform – the Treatment Action Campaign successfully championed the provision of ARTs for seropositive pregnant women as both a human right and an obligation of the government.⁹ This treatment activism that occurred in South Africa and other low-income and high-need countries shined a spotlight on the right to treatment access on a global scale, prompting a remarkable surge of international funding that largely characterized that decade.¹⁰

With the increased provision of ARTs came the increased need for more enlightened understanding and empowered decision-making regarding treatment. As a result, AIDS activist groups promoted ‘treatment literacy.’ Treatment literacy was a tool used (without necessarily being named as such) throughout the 1990s among AIDS activist groups in the USA, such as Gay Men’s Health Crisis (GMHC) and ACT UP, to understand what the disease was doing to their bodies, how treatment would alter the course of HIV, and what research was needed.¹¹ With the

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⁹ RAY, Sunanda et al. 2012. Activism: Working to reduce maternal mortality through civil society and health professional alliances in sub-Saharan Africa.
help of GMHC and ACT UP, TAC was the first organization to bring treatment literacy to a low-income country in 1999.\(^{12}\) From its beginning, TAC set out to create resources necessary for the poor to advocate for human rights entitlements. This insistence on a movement rooted in and owned by the poor was the result of a distrust of the professionalized AIDS and human rights movement, which they believed to be ineffective. For TAC members the dignity and human rights of all people, and especially those living in resource-limited settings, was a guiding tenet of their efforts – they held firmly to the conviction that human rights are a necessity for poor people, not just an issue taken up “out of conscience” in the way that many academics, lawyers, physicians, and other professionals who take up human rights causes might.\(^{13}\) TAC’s treatment literacy is therefore presented in a way that connects medicine and health with politics, human rights, equality, and the duties of the government. It places treatment in a context in which governments, service providers, and policy makers are legally held accountable and people have the means to hold them accountable.\(^{14}\) This type of treatment literacy importantly defines empowerment as finding a way to document how social contexts, violence, and the disease itself affect people living with HIV.\(^{15}\) The point is to make people who are HIV-positive the owners of their own treatment.

The European AIDS Treatment Group (EATG),\(^{16}\) which was founded in 1992, and the International Treatment Preparedness Coalition (ITPC),\(^{17}\) founded in 2003, are two activist groups established on the premise of treatment activism and literacy. While EATG places an emphasis on HIV co-infections and other health issues, both groups describe treatment literacy as a comprehensive understanding of treatments, particularly antiretroviral therapy. This includes early identification of symptoms and basic information on how the drugs work and, specifically, what they can and cannot do.\(^{18}\) The World Health Organization also utilizes treatment literacy, which it describes as having the ‘appropriate knowledge’ about HIV and treatment medicines.\(^{19}\) According to the WHO, appropriate knowledge allows the patient to make his or her own decisions regarding treatment and care, ensures proper treatment adherence, helps combat false claims made by under-trained healthcare workers, and bolsters advocacy. The WHO also considers literacy as ‘empowerment,’ which it defines as meaningful involvement in decisions

\(^{12}\) HEYWOOD, Mark. 2009. South Africa’s treatment action campaign: Combining law and social mobilization to realize the right to health.

\(^{13}\) HEYWOOD, Mark. 2009. South Africa’s treatment action campaign: Combining law and social mobilization to realize the right to health, p. 17.

\(^{14}\) RAY, Sunanda et al. 2012. Activism: Working to reduce maternal mortality through civil society and health professional alliances in sub-Saharan Africa.

\(^{15}\) NIEHAUS, Isak. Treatment literacy, therapeutic efficacy, and antiretroviral drugs: Notes from Bushbuckridge, South Africa. Medical Anthropology: Cross-Cultural Studies in Health and Illness. Published online 27 June 2014: http://dx.doi.org/10.1080/01459740.2013.802319.

\(^{16}\) For more information: http://www.eatg.org/gallery/362094-1346846410.pdf.

\(^{17}\) For more information: http://itpcglobal.org/treatment-education-knowledge/.


regarding care. This understanding of empowerment is noticeably different from that which TAC describes because it focuses more narrowly on decision making regarding treatment and care, not providing a voice to speak out about social vulnerability as a violation of fundamental human rights. Both, however, still promote the empowerment of those accessing and advocating for care, which is critical.

Ensuring ownership and empowerment of one’s treatment regimen is essential in creating an effective HIV treatment response. Empowering people to be their own advocates allows them to have the voice to let providers and policymakers know when aspects, or the entirety, of their care is not working. This can be juxtaposed against the massive scale-up of treatment that started in the early 21st century and still continues. As important as the scale-up of treatment access was, many countries often provided patients with drugs, but not empowerment, let alone education or free-will. This systematic and mechanized provision of medications may work for certain diseases and certain contexts, but it is ineffective for HIV treatment. Treatment regimens are complex and require certain dietary and behavioral changes. It is easy for people to fall out of touch with the healthcare system and therefore his or her treatment, leading to a population of people who know they are seropositive, and that have access to treatment, but are not able to effectively use the access they have. This is not for lack of trying, but rather a lack of empowerment. Treatment activists and the concept of treatment literacy have championed the notion that access should not be viewed as something done unto populations, devoid of choice and comprehension. Treatment literacy provides a type of treatment access that those most impacted by the epidemic can take hold of and engage in relentlessly until the care they receive is exactly what they have asked for.

Treatment scale-up was the result of rapidly increased funding and the intense will to expand access to treatment globally. In the area of prevention, such systematic scale up in the past decade has probably only been seen in a comparable way with the promotion of VMMC. This campaign is currently being endorsed by the World Health Organization, UNAIDS, PEPFAR, and USAID, and is being promoted in 14 focus Eastern and Southern African countries. Despite its push by some of the largest and most influential health- and HIV-related organizations, there is a considerable absence of cultural and social considerations regarding its implementation. VMMC is a salient example for the argument against the same type of systematic implementation that treatment scale-up has undergone. Rather than being a global effort owned by the very people it directly affects, VMMC is a way of controlling the epidemic without allowing for self-reflection by either health care providers or the people accessing its services. Systematic scale-up of prevention based on this kind of approach is destined to fail. A different approach to prevention scale-up is needed – one that is supported with both funding and global advocacy, but that also guarantees the inclusion, empowerment, and ownership of the people accessing prevention services.

The Convoluted and Contested History of HIV Prevention Efforts

By the early 2000s, when an understanding of the need for treatment literacy began to be consolidated and implemented by organizations such as TAC, the long struggle for treatment access had achieved remarkable success. While there still was (as there still is even today) much to be done to guarantee effective ART access to all those who need it, an important consensus had emerged with regard to treatment access as a basic human right for people everywhere. Unfortunately, the same cannot be said about access to HIV prevention. On the contrary, as a...
result of deeply-rooted stigma and discrimination, access to prevention has frequently been denied, and the history of HIV prevention efforts has been convoluted and contested.

In the 1980s when HIV and AIDS first appeared and no effective treatment options existed, prevention was the main focus among advocacy organizations, particularly for gay men. The concept of “safe sex,” with major (but not exclusive) emphasis on condom use, was created to help prevent the spread of HIV while still maintaining the pleasure of sex. The strength of sexual liberation and the absence of governmental response shaped the eroticized “safe sex” prevention model in many of the most affected communities during the early years of the epidemic. In the USA, Callen and Berkowitz’s 1983 pamphlet “How to Have Sex in an Epidemic” provided advice regarding safer sex practices that is largely still considered correct, years before scientists and doctors officially weighed in on risk reduction. 23 Although AIDS at the time was associated with sexual behavior as a major means of transmission, gay men’s groups fought to prevent sex from being seen as a negative behavior meant to be avoided. The open expression of and discussion about sex as a positive act, as well as about desire, pleasure, and care for one’s partner, was the strength of these prevention efforts.

By 1986 it became clear to health officials that AIDS had the potential to spread to the “general population” — that is, among heterosexuals — and previously silent public health officials then began to be more engaged in sexual education efforts. Until this point in the epidemic, there was essentially no organized global response to HIV and AIDS. In the USA and a number of other high-income countries, however, prevention efforts were frequently divided into two categories: programs that targeted those most at risk and programs that advocated for behavior change throughout the population. Advocating for risk reduction among those considered most at risk, however, lacked funding and political will, because that would mean condoning the socially-stigmatized actions and behaviors of the people most at risk. Behavior change throughout the population was not readily taken up either; members of the “general population” largely believed their behaviors were not in need of modification and, for the most part, governments and public health officials wanted them to continue believing they were not at risk. 24 Both approaches clearly lacked the positivity and openness that characterized the safe sex approaches developed by gay and other communities (such as sex workers), leading to a sterile and systematic risk reduction approach that was spearheaded not by the people but by health officials and policy makers.

With the perceived increased threat of the spread of HIV that came to a head in 1986, the World Health Organization created the Global Programme on AIDS (GPA). This new program had a significant positive impact on the HIV prevention effort for several reasons. One reason is that GPA was the first organized global response to AIDS. This meant that GPA had to look at the similarities between all of those living with HIV and AIDS around the world in order to talk about and frame prevention. In the USA, for example, it may have been primarily homosexual men and IV drug users, but in Uganda it was heterosexuals and especially women, and in Thailand it was commercial sex workers and their clients. To understand AIDS in different countries and contexts, WHO/GPA


and the other agencies and programs that would follow it needed to look beyond specific epidemiological patterns found in different countries in order to understand issues such as sexual orientation, gender, and behavior as social determinants of health. The expansion across cultural, social and political norms revealed for the first time a drastic shift in the way HIV and AIDS prevention was conceptualized. Prevention could now be discussed and developed in terms of social, cultural and economic vulnerability. There was a necessary shift away from individual behavior and towards a comprehensive social vulnerability that initiated the discussion about human rights and health. This new form of prevention also sought to remove blame from the affected populations and focused instead on the responsibilities of government and society at large. Early leaders of the HIV response, such as Jonathan Mann and others like him, argued that there are universal human rights to health and that social vulnerability caused by stigma and discrimination prevents people from those rights. This helped frame HIV prevention as a collective societal effort that demanded the inclusion of those most commonly ignored and stigmatized.

Despite all of the progress made throughout the 1990s regarding society’s role in the conditions of health, by the time that effective treatment options became available and the massive global scale-up of the HIV response began to take place in the early 2000s, many of the important lessons that had been learned from the early community mobilization against AIDS were largely ignored – especially in relation to the scale-up of HIV prevention. The U.S. President’s Emergency Plan for AIDS Relief (PEPFAR), which was developed beginning in 2003, framed prevention with the simplistic and moralistic “ABC" approach: abstinence, be faithful, and if all else fails use a condom. This approach, with heavy religious over-tones, was enforced all over the globe as a condition for governments and organizations to receive necessary funding. For example, in 2003 PEPFAR did not fund HIV programs that supported sex workers, and refused to acknowledge them as a vulnerable group; because of this many organizations lost funding.26

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The limited success of narrow and moralistic prevention efforts that dominated the early 21st century tended to be overshadowed by the very real achievements taking place in expanding treatment access – achievements that allowed many to overlook the obvious failure of initiatives such as PEPFAR in relation to HIV prevention. The years between 2001 and 2008 saw an enormous push for treatment and treatment as prevention, with 2005 to 2008 being the years with the greatest global funding and greatest optimism that HIV could now begin to be treated as a chronic disease rather than a ravaging epidemic. The global market crash of 2008, however, caused money to become scarce, even for rich countries like the USA, and donors had to pull back spending. As often happens when resources become more limited, there was a re-prioritization that also went hand-in-hand with what has sometimes been described as an AIDS backlash,27 particularly with the application of cost-effectiveness arguments. These arguments pushed to reduce spending on expensive, lifelong antiretroviral treatment and increase focus on cheaper alternatives, such as preventing transmission. As a result, biomedical and public health researchers have since developed and advocated for a complex range of prevention options that are detailed below, but the discussion of these options has often taken place in a way that largely ignores the complex and contested history of HIV prevention debates (and the way in which this contrasts with the much more linear development of consensus about HIV treatment options). Despite the fact that global funding for HIV and AIDS has remained at a standstill since 2008, UNAIDS has continued to push for the “end of AIDS” by 2030. It is crucially important that prevention be utilized in working towards this goal, but there is still the need for suitable discussion, information, and access on the part of the populations and communities whose needs these prevention efforts are intended to serve.

Current Prevention Methods

Today, prevention methods are often categorized into biomedical, behavioral, and structural or environmental methods and approaches. No one prevention method is necessarily the best because each one offers its own advantages and disadvantages depending on the context of use and the needs of different people. Arguably the male condom is the least expensive and therefore the most widely available; it is also perhaps the most championed of HIV prevention methods. This should not, however, prevent activists and public health practitioners from acknowledging it for how it is used in practice. Condoms, both male and female, may not always be a viable or appropriate option for everyone at risk for HIV. For example, women in certain contexts may lack the resources or agency to effectively negotiate condom use.28 Some men, regardless of sexual preference, may also choose to not use condoms for various reasons, ranging from their own pleasure seeking to the perception that AIDS is no longer a threat. The condom has proven to be a very effective physical barrier preventing the transmission of HIV, but it is not the only prevention option.

A range of biomedical prevention methods now exist that for a variety of reasons may be more appropriate for some people. These include PrEP, PEP, and treatment as prevention to reduce viral loads. PrEP is a daily ARV (though other, longer-term modes of delivery, such as injections, are currently under development) that is taken prior to HIV exposure and has shown to drastically reduce the risk of becoming HIV positive, even from very high-risk exposures. In addition to a daily oral pill, the use of PrEP, like HIV treatment, includes routine lab work and regular primary care follow-up. People who choose PrEP should be able to understand how the medication works within their bodies in order to understand the importance of adherence to the daily regimen, to be able to understand the figures of their lab results, and to feel comfortable in discussing openly and honestly their sexual practices with their provider. PrEP has the potential to be an extremely empowering method if its application is tightly wed to informed use. PEP is very similar to PrEP but it is taken post-exposure for typically 30 days, with 90 days of medical follow-up in an ideal setting.29 An example of PrEP versus PEP in use may be an HIV negative person who

takes PrEP because his or her partner is HIV positive, while a habitual condom user who experiences a condom break may take PEP.

Another biomedical approach to prevention that is being heavily promoted currently is VMMC, especially in regions with generalized epidemics in Sub-Saharan Africa. Some studies have shown that male circumcision helps reduce the female to male transmission of HIV.\textsuperscript{30,31,32} However, as previously discussed in the Development of Treatment Literacy section above, VMMC is a culturally sensitive medical procedure, and research regarding both its efficacy and its effectiveness has demonstrated that there are issues surrounding implementation. Additionally, this method is primarily concerned with heterosexual sex, without considering other key populations.

Finally, in addition to pharmaceutical products such as PrEP and PEP, and techniques such as circumcision, it is important to highlight the role that “treatment as prevention” (or TasP) has assumed as central to biomedical prevention approaches. The strategy of TasP has become more common today in more countries around the world than either PrEP or PEP or VMMC. Effective treatment suppresses HIV viral loads and has been shown to make HIV transmission very difficult. The importance of ARV treatment for all people living with HIV therefore plays an integral role in the 90-90-90 plan, and TasP has increasingly been promoted as the single most important form of biomedical prevention in many HIV prevention programs, although the question of access continues to pose huge challenges given the fact that still only roughly half of the people in the world who are estimated to need access to HIV treatment actually have this access.

In other contexts, where neither condoms nor biomedical methods are available or considered to be appropriate, a range of different behavioral methods may be used alone or in combination. These behavioral methods include abstinence, strategic positioning, serosorting, negotiated safety, sex with exclusive partners (“being faithful”), and anal or vaginal sex without fluid exchange (colloquially, ‘pulling out’ prior to male ejaculation). Strategic positioning involves taking sexual roles that carry potentially less risk of transmission, such as only engaging in oral sex or only performing insertive anal sex. Serosorting is only having sex with those of a similar serostatus. Negotiated safety can be considered a form of serosorting between regular partners who agree on which sexual practices are allowed within and outside the main relationship. This takes into account the HIV status of both partners, but is often between partners who are both negative.\textsuperscript{33} All of these practices, including sex with exclusive partners and sex without fluid exchange, are recognized as having important limitations in terms of their effectiveness, but can be used to help reduce some level of risk.

It is important to note that the terminology used to categorize the different HIV prevention methods, such as ‘biomedical’ and ‘behavioral,’ are limited. These terms give the false impression that these prevention methods act in isolation from each other, whereas in practice this is far from the truth. In almost all contexts, some level of behavioral change is necessary for biomedical methods to be utilized. For example PrEP requires complex behavioral changes such as adherence to a daily pill, consistent engagement with a primary care provider, and a basic understanding of the physiological interaction between the medicine and one’s body.

There are also other HIV prevention methods that do not revolve around sexual activity. Prevention of mother-to-child transmission (PMTCT) includes a round of antiretroviral medication for the infant for six weeks after birth, as well as exclusive breastfeeding for the first 6 months of life if the mother’s viral load is low (and if clean water for formula is not available) or no breastfeeding if viral load is high and clean water for formula is available. Needle and syringe exchanges, which are structural interventions that help reduce the use of unsanitary needles and syringes, offer important interventions for both substance use harm reduction as well as HIV prevention. Despite the WHO’s recommendation to enact this form of prevention globally, it is considered controversial, and is not legally available, in many countries because it is assumed to condone illicit drug use. Structural barriers to prevention such as the criminalization of needle and syringe exchange only further increase risk of HIV transmission for IV drug users because they drive practices underground, making resources such as clean needles and syringes harder to access.

The complexity of prevention choices currently available mirrors the complexity of human reality, and as such, one method may be sufficient for one person but not another. It is extremely important to emphasize that these methods do not exist in isolation from each other. An approach to prevention that facilitates not only the ability to use a prevention method but also its access and the empowerment required to choose to use it, is needed. This is where the concept of literacy – in conjunction with combination prevention – becomes so significant in moving forward with HIV programming, planning and activism. The vast array of prevention options, whether sexual or non-sexual, can seem overwhelming and intimidating. People may not know how or where to access many of the different prevention options, or they may not even know they exist. Without empowerment, populations and individuals are often forced into prevention categories that neither suit them nor affirm their experiences. What is needed moving forward is prevention literacy.

**Literacy: From Treatment to Prevention**

In order to address the complexity of prevention options, it is important to acknowledge the complexity of individuals and communities. Major international governing bodies such as UNAIDS and the Global Fund, as well as national governments, have attempted to prioritize those who are most vulnerable to HIV transmission by identifying “key populations.” These populations are often defined to include displaced persons, migrants, children, pregnant women, and a particularly heavy emphasis on seven specific groups: sex workers, men who have sex with men (MSM), injecting drug users, transgender persons, prisoners, young girls, and women. While data might show that these specific groups of people are the most vulnerable to HIV transmission, policies and programs rarely confront the reality of frequent overlap among these categories or the fluidity and change in categories.

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throughout a person’s life. More often than not, each key population is discussed as separate from the other populations – i.e. an individual is a prisoner or a woman or a sex worker, instead of a cisgender female who is incarcerated for prostitution because she lives in a country where prostitution is illegal. The reality is that many people can and do represent an overlap of these various populations and do not exist in isolation from each other. In addition to this overlap, there is an intersectionality of race or ethnicity, socioeconomic status, gender identity, and sexual orientation that impacts each person’s unique sexual and daily experiences. For example, a cisgender female sex worker who is also an IV drug user is not going to have the same sexual experience as a transgender woman sex worker who is also an IV drug user. This overlap and intersection create a diversity of distinct experiences and vulnerabilities that may characterize the situations of different communities as well as different persons, suggesting the need for a more thoughtful and meaningful decision-making process for the complexity of needs among the variety of prevention methods.

With the current situation, there is clearly no ‘one size fits all’ solution that can be prescribed to all or even specific groups of people. Therefore, it is absolutely necessary for people to make their own decisions regarding what prevention method(s) work best for themselves and their lives. In order to do this, they need to have the information to assess their options, the access to prevention methods in order to best evaluate their own needs, and the right to demand these prevention methods if they are not accessible. Similar to the conditions that created the need for treatment literacy as combination ART began to become available, conditions now exist that create the need for prevention literacy.

‘Literacy’ in this context goes far beyond the simple ability to read medical information and understand directions from health care providers. An example of this simplistic ‘literacy’ is used today in many healthcare settings, especially in the USA, with the concept of health literacy, which focuses on the readability of health information for patients who have limited reading comprehension and/or language barriers when it comes to communicating with healthcare providers. In contrast to this narrow concept of health literacy, prevention literacy, as we seek to define it here, extends far beyond the ability to read. It entails the ability to process and assess health information in order to make decisions based on what might be best for each person, to negotiate and demand the right to these options, and to discuss these decisions with partners and peers. Prevention literacy is not simply the processing of information, but a process of “consciousness raising” and empowerment that allows people to put their knowledge into action; the education and political theorist, Paulo Freire, makes a clear distinction between these two concepts of pedagogy.

In his work *The Pedagogy of the Oppressed*, Freire argues against what he describes as ‘banking education’, in which the student is merely a receptacle of the teacher’s omnipotent knowledge – like an empty or deficit bank account waiting to be filled up with the right kind of knowledge that will be provided by the instructor. In this structure, students have no agency, no drive to understand what they are being taught, and simply do as they are told to do by their instructor. Freire states that this reinforces a power dynamic between oppressor and the oppressed and denies the humanity of both. As an alternative to this oppressive educational paradigm, Freire proposes a process of consciousness-raising in which the student is encouraged to both understand and engage in knowledge in a dynamic duet with the instructor. This consciousness should not be conceptualized as the simple “awareness” of information and options available, but rather as the situation of ‘self’ within one’s own social context and environment, which includes all of the structural factors that place one at risk for HIV. Consciousness also seeks to create the collective agency to demand the positive change of these social constructs that continue to oppress


[37] Pedagogy is the method and practice of education and teaching, especially in terms of theoretical concepts.

people. This could be done by creating spaces for discussion and debate – and thus engaging in community-based consciousness raising – as well as providing the social support needed for people to make their own best choices. While the construction of health literacy in many healthcare institutions, as described above, is comparable to Freire’s ‘banking education,’ prevention literacy, as we define it, can be fully realized only through the process of consciousness-raising and engagement, as described by Freire and other similar educators. We therefore advocate for a concept of prevention literacy that is fundamentally comparable to the concept of treatment literacy that was advocated for by organizations such as TAC more than a decade ago: as a necessity and a fundamental right for all of those who are vulnerable in the face of HIV infection.

It is important to connect Freire’s ‘consciousness’ to the context of HIV prevention because socially marginalized groups too often do not have access to proper medical care, including access to prevention and preventive medicine, and frequently face stigma and discrimination in health care settings. How can these people rely on medical providers to tell them what their best prevention methods are? How is a sex worker or a transgender woman expected to receive information on the best prevention methods for their specific needs where prostitution is illegal or where the medical system discriminates against transgender people? In the absence of a competent health care network to acknowledge and address these diverse needs, prevention literacy serves as a viable conduit for these marginalized persons to make appropriate choices regarding their prevention options. They must be considered experts because only they know the intricacies and needs of their own experiences. Prevention literacy calls for people to collaborate with and support one another in solidarity because it has the potential to empower marginalized groups, which would require a strong revitalization and continuation of the community-based responses that appeared in the first years of the AIDS epidemic. But it also depends upon building health systems and services that will truly respond to the needs of those who use them. Without health systems that are responsive to the communities they serve, community mobilization and empowerment would be undercut and truncated. Prevention literacy therefore has the potential to strengthen community responses in a way that is symbiotic. Through empowerment and community leadership, literacy can give a voice to those who might not otherwise have one.

Prevention literacy is intimately wed with the progressive expansion and inclusion of human rights for all. It is important to emphasize that access to prevention methods, their understanding, and the empowered choice to use them, are all rights. Similar to the way treatment access and literacy are described – and advocated for – as human rights, so too should prevention access and literacy be described and advocated for. If the right to health is a universal human right, then prevention must be considered a part of this right to health. In this sense, we argue that access to full information about the full range of available options and choices in relation to prevention must be every bit as much a human right as access to treatment is now considered – a position that would obviously be very different than that adopted by programs like PEPFAR as part of the scale-up of HIV services during the past decade. Civil society and community-based responses – of which, revitalization is needed – should advocate for the comprehensive human right to prevention and must ensure that prevention and prevention literacy are not a privilege for only a few, but rather that the two benefit all who are at risk of HIV.

Conclusion

Currently, while there are multiple, and often conflicting, discourses about different approaches to HIV prevention, prevention literacy as we define it here really does not exist. Rather, there is an urgent need to re-conceptualize prevention, and to create true prevention literacy by and for the communities that are most vulnerable to HIV, in anticipation of prevention scale-up. It is needed in order to properly address the complexity of prevention methods available as well as the right to access these methods.


There is constant discussion about the need for ‘tailored responses’ to the epidemic if we are to realistically end AIDS by 2030. In order to do this, the people most affected by the epidemic must have a voice in how to respond to it and the power to make their own tailored decisions about the prevention options that best match their needs. They must be able to evaluate health information and to make decisions about this information, to negotiate and demand access to the options that exist now and in the future, and to discuss these issues with their partners and their peers as well as their medical providers.

The question of HIV prevention today thus presents many parallels with the scale-up of treatment. If we are to learn from history’s lessons, the formation and application of ‘prevention literacy’ is just as necessary as treatment literacy is in order to extend the line of empowerment to not only those who live with HIV, but to those who are at risk as well. The instance of seroconversion should no longer be the defining moment in which we seek to legitimize those marginalized by the AIDS epidemic. Now, rather, we have the available tools to keep people HIV negative, as well as offer them a way to take command of their bodies and their health. But taking prevention literacy seriously requires us to recognize that this can only happen when people collaborate and support one another – it depends on solidarity and empowerment, and on the revitalization of meaningful community-based responses to the epidemic. It also depends on health systems and services that respect the rights and respond to the needs of those who use them. True prevention literacy can only be achieved when built upon a solid foundation of mobilized communities and health systems that are truly responsive to the populations that they serve.

The AIDS epidemic has been defined by its devastating tendency to affect those who are already excluded by society – the poor, racial and ethnic minorities, injecting drug users, gay, bisexual and other MSM, sex workers, and women. If we are truly to end AIDS by 2030, we cannot do so without dismantling these inequalities and the social constructions that seek to maintain the oppression of the vulnerable. We can only achieve this goal by confronting them deliberately and head-on. The concept of HIV prevention literacy is both a way to frame this strategy as well as a battle cry meant to give voice to those among us who are so often silenced.