

Letter to the Editor

Language, identity and HIV: why do we keep talking about the responsible and responsive use of language? Language matters

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Abstract

Language matters. It impacts on how we think about ourselves, as individuals within our families and within society. As advocates and activists, we constantly use language as a tool to effect change. People living with HIV have been critical in shaping this language over the last 30 years and still play a central role in ensuring that new discourse in the HIV field does not stigmatize, but rather that it catalyzes empowerment for our community members. In this annotation, we seek to shift the language used in relation to ourselves, our medical condition, our bodies, our identities and the events we face, towards something more life-enhancing, self-affirming and positive in outlook.

Keywords: people living with HIV; women living with HIV; vertical transmission; MTCT; identity; terminology; language.

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Discussions

Language matters. It impacts on how we think about ourselves, as individuals within our families and within society. Our words are the tools we use to share our experiences and to create shared visions of the future. A simple shift in language can speak volumes not only about where we are but where we would like to be. When we make our language inclusive, we break down barriers and build new bridges for greater mutual respect and understanding.

As advocates and activists, we constantly use language as a tool to effect change. We think about how our words affect others, and we reflect on the words others use to learn what language is damaging and what language is constructive and enabling. We listen, and we act and we lobby others to do the same. Language can make all the difference towards achieving our goals.

People living with HIV have been crucial in shaping this language over the last 30 years and still play a central role in ensuring that new discourse in the HIV field does not stigmatize, but rather that it catalyzes empowerment for our community members. As a community of people living with HIV around the world, we represent diverse groups in constant change. Language is not static, and what is appropriate today, may not be in future years. As our under-

standing of HIV grows and the reality of living with HIV changes in response to improvements in treatment care and support, the language used to describe these realities must also change.

One big challenge, which we face with language as found in medical textbooks, is that it focuses on managing, avoiding or eradicating disease, rather than enhancing health. Therefore, whilst the WHO definition of health ("Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York; 1946 June 19–22) is essentially positive and life-enhancing in concept and tone, we are immediately and unfortunately faced with the language of medical textbooks, which is focused on "ending disease" (two negative words) rather than on "promoting health" (two positive words).

In this annotation therefore, we seek to advocate to shift the language used in relation to ourselves, our medical condition, our bodies, our identities and the events we face, towards something more life-enhancing, self-affirming and positive in outlook. Much of the wording we offer may still be perceived as negative in tone, so we still have a long way to go. Nonetheless, we offer these initial suggestions as some first steps to promote research,

discussion, reflection and action to harness the wealth of academic research of linguists, philosophers, psychiatrists and others to all of our own work in the arena of HIV. Below are some of the terms that we, as women and mothers living with HIV, would like to see challenged and changed as we continue a dialogue with key decision-makers, enabling us to have safe, planned pregnancies, healthy babies, and to stay alive and healthy ourselves.

Language that puts people first

People living with HIV *instead of* HIV-infected or HIV-positive person

When we use language that puts people first, we acknowledge ourselves and others as fellow human beings. For example, “people living with HIV” puts the individual first rather than “infected people”, which puts the virus first. Similarly, when we say people who are, or have been in prison, or people who engage in sex work, or people who use drugs, we are making a distinction between “being” and “doing”. It is important to acknowledge that those of us who have been, or are, in prison, or use drugs cannot be defined and reduced only to those experiences. By defining us as people first, we affirm and emphasize our shared humanity, and we acknowledge that our identities, just as the identities of all human beings, are nuanced, evolving, and layered. The Convention on the Rights of Persons with Disabilities takes this one step further, by specifically talking about “persons” as individual humans, rather than about “people” as a mass (<http://www.un.org/disabilities/convention/conventionfull.shtml>). The active use of verbs is also critical, as this further emphasizes the central role of the individual and avoids making a person passive in a situation, for example, people *living* with HIV as against people infected with HIV.

People living with HIV *instead of* PLHIV

Spelling out people living with HIV or women living with HIV is preferable to highlight that actual *persons* are being referred to rather than using an abbreviation. Using acronyms when referring to people can dull awareness of the person or people and adds to a sense of being labelled and the loss of our identity as human beings. Using the whole phrase puts people at the centre of the issue being outlined.

HIV or AIDS *instead of* HIV/AIDS

In our efforts to raise awareness of HIV and to change public perceptions, we encourage the use of the term that is most specific and appropriate in the context to avoid confusion between HIV (a virus) and AIDS (a clinical syndrome). Examples include “people living with HIV”, “HIV prevalence”, “HIV prevention”, “HIV testing and counselling”, “HIV-related disease”, “children orphaned by AIDS”, “AIDS response”, “national AIDS programme” and “AIDS service organization”. We appreciate that UNAIDS has already recognized the need for this kind of accuracy and specificity in its

Terminology Guidelines (http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2118_terminology-guidelines_en.pdf).

Avoiding the use of the word “infection” and its derivatives

Unless “infection” is an essential word to use for understanding, people living with HIV prefer more neutral words, for example, “One in seven people who acquire HIV globally do so perinatally, accounting for approximately 400,000 new children living with HIV annually”. This is because, in an English thesaurus, the word “infection” is associated with “corrupt, dirty, tainted”. Alternative, more neutral words, such as “acquire” and “transmit” can usually be substituted without any change in meaning.

Comprehensive prevention of vertical transmission *instead of* MTCT

“Mother-to-child transmission” (MTCT) is perceived to have an accusatory tone, blaming the mother for “transmitting” the virus to her child, which can have negative ramifications on the mother (e.g. criminalization, forced sterilization, physical and emotional abuse by family members). Focusing on the event, rather than the persons involved removes the onus, blame and guilt for transmission of HIV to the baby solely from the mother. This simple change in term from MTCT turns the focus away from women being “vectors of transmission”. Women find comprehensive prevention of vertical transmission less accusatory and more conducive to male involvement; it also has the potential to increase access to services.

Stopping or ending vertical transmission *instead of* elimination

The term “elimination”, in the context of vertical transmission, fails to recognize how HIV affects many aspects of people’s lives and how it can form a part of their identity. Therefore, the term “elimination” can be perceived as threatening to one’s existence and, if taken out of context and without qualifying terms, can evoke fear and be disempowering for people living with HIV. For example, it may be misunderstood to mean eliminating women living with HIV or infants living with HIV in order to eliminate “mother-to child” transmission. For those who do not support the sexual, reproductive, and human rights of women living with HIV, the term may justify the use of any means to achieve “elimination,” including the criminalization of all HIV exposure or transmission (see, for example, The Global Criminalisation Scan and the website of The Global Commission on HIV and the Law, and also those individual cases where women living with HIV have been prosecuted for not preventing vertical transmission, or have been penalised by the criminal justice system for being pregnant), mandatory HIV testing, and coerced or forced sterilizations. Even if HIV transmission is averted in a child, that child will still have to grow up in a world with HIV and will still be impacted by the virus. Whilst HIV

may no longer be in the child's growing body, he or she will still have to deal with HIV, including threats to their identity.

Supportive and sensitive language is critical in our efforts to achieve our goals towards an HIV-free generation and support those who continue to care for an HIV-free generation but who continue to live with HIV. It can empower us and motivate us to take the step to access necessary services to stay alive, stay healthy and to ensure healthy lives for our children.

We invite all stakeholders in their daily work and life to further reflect on their choice of language in research, policy making and programming to ensure that terms are clear, not clouded by ambiguity, that they do not perpetuate or play into stereotypes, and do not hurt or marginalize the very people they seek to support.

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Authors' contributions

All authors contributed equally to the writing, revisions, and approved the final version of the annotation.