Why Language Matters: Facing HIV Stigma in Our Own Words

The language we use to talk about HIV affects the well-being of people with HIV. Learn about the power of words, and less stigmatizing language for discussing HIV.

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If we spoke a different language, we would perceive a somewhat different world. - Ludwig Wittgenstein

- Have you ever heard a person living with HIV describe themselves as "I am HIV"?
- Do the words "infection" or "infected" feel negative to you?
- Are you offended when you are referred to by your health condition first, instead of as a person

first?

The words people use to talk about HIV affect the way people living with HIV feel about themselves. These words also have an impact on how others view people living with HIV.

Words, Language and Perception

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Words help shape our understanding of the world we live in. They define our experiences and are the foundation of our stories. Words and language describe who we are and how we connect with the world around us, and with ourselves.

Most of us have had one of those days when everything is going well, and someone says a single word that changes everything. That one word does something to us, deep inside; we feel it in our gut, in our heart, and in our soul. In a heartbeat, that one word builds us up or tears us down. Words can inspire, empower, and bring us hope. But they can also bully and scare and destroy our sense of self.

Why Language Matters

Throughout their lives, women may experience multiple forms of oppression and discrimination based on gender, race, sexual identity, socioeconomic status, or other factors. The oppression and discrimination are often reinforced through language. For instance, an aggressive, powerful woman is called a “bitch,” while a man with the same qualities is viewed with respect and called “ambitious.” Adding an HIV diagnosis can magnify this oppression and affect self-worth, confidence, and self-identity.

Over the years, repeatedly hearing language that reinforces stigma, oppression, and discrimination ultimately affects the health and well-being of women diagnosed with HIV. Stigma and stress have a negative effect on a woman’s overall quality of life, which can affect her family, her children, her job, and even her pregnancies. It is rare to find a woman living with HIV who has not felt stigmatized in some way.

A 2005 study from the International Center for Research on Women found that consequences of HIV-related stigma include:

- Loss of income
- Loss of hope
- Increased feelings of worthlessness

- Increased internalized stigma
- Poor care in the healthcare system, especially from professionals not delivering HIV care
- Loss of reputation in the family and in the community

HIV-related stigma affects prevention, keeps people from getting tested for HIV, and makes disclosure more difficult. The stress that stigma causes can affect the immune system, increasing susceptibility to illness and disease.

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Using inappropriate language to describe HIV and women increases the amount of stigma and stress women experience daily. Putting the label before the person, as in the phrase “HIV-infected woman” or “HIV-infected mother,” dehumanizes women and turns them into a disease or illness. Instead, preferred phrases are “woman/person living with HIV” or “woman/person with HIV” -- referring to the person first, before mentioning their health condition

What is HIV Stigma Communication?

The narrative (public story of connected events) about HIV includes myths and false stereotypes that stigmatize the disease and isolate people living with HIV. These include the stereotype that people living with HIV are more sexually active than others and the myth that having sex with a person living with HIV automatically means that they will acquire HIV (the truth is that there is no risk at all of HIV transmission through sex when the person living with HIV is taking HIV drugs and has an undetectable viral load. For more information on this exciting development, please see our fact sheet on Undetectable Equals Untransmittable).

HIV stigma communication is found in the history of the HIV epidemic, in the media, in social marketing prevention campaigns, in policies, in the research literature, in movies, and in our own heads.

But stigmatizing stereotypes make for good rumors and gossip; and the news media often uses them to attract attention to their stories. Research has shown that the emotions most often shared in rumors are fear, anger, or disgust. These rumors then become part of our social environment, regardless of whether they are true.

Certain medical conditions are stigmatized more often than others; some conditions are seen as moral issues or character flaws, instead of the biological diseases they are. Examples include leprosy, mental health, substance use, and HIV. People with leprosy are called lepers; people with mental health conditions are called "crazy"; people who use mind-altering substances are called addicts or junkies. Reducing people to a label dismisses their humanity and sets them apart from others.

Stigma communication is in the language, labels, and messages used to educate and talk about a disease, condition, or group of people. HIV stigma communication is found in the history of the HIV epidemic, in the media, in social marketing prevention campaigns, in policies, in the research literature, in movies, and in our own heads. The language we hear, whether it comes from family or friends, news headlines, or research articles, becomes the language we use to describe ourselves and the language we use to describe others.

"People-First Language" and the Denver Principles

One way to address stigma is to use people-first language. The Denver Principles were written by HIV advocates in 1983, in the very early days of the epidemic. In its opening words, the Denver Principles called for the use of respectful person-first language:

"We condemn attempts to label us as 'victims,' a term which implies defeat, and we are only occasionally 'patients,' a term which implies passivity, helplessness, and dependence upon the care of others. We are 'People With AIDS.'"

This narrative describes people living with HIV as human and valuable. It shows respect and compassion. People-first language puts the person before the illness or label and describes who they are, not what they have been diagnosed with. People-first language helps eliminate prejudice and removes value judgments. When we describe people by labels or medical diagnoses, we devalue and disrespect them as individuals. People-first language respects people for who they are.

Think about when you hear that someone "has a cold" or "has epilepsy"; this clearly describes a person who has an illness. Saying, "we saw an epileptic today" or "we saw an HIV-positive person today" describes the person as the illness, rather than a person who happens to have the illness. We never hear "cancerous people" or "I am cancer positive"; but we often hear people say "HIV-positive women" or "HIV-positive pregnant women."

It is important to note that terms and phrases like "living with AIDS" and "I am HIV positive" have been extremely empowering to many people living with HIV, while for others, these terms may not describe their experience, or may feel stigmatizing. That is okay; words and language mean

different things to different people and at different times in their lives. It is important to allow others to define themselves as they wish, but to always start from a place of respect.

Preferred Language About HIV

Over the years, as we have learned more about HIV treatment, care, and prevention, advocates have pushed HIV service organizations, media outlets, and other institutions to use language describing HIV that reflects those changes. Included in the left-hand column of the table below are some of the first terms ever used to talk about HIV. Little by little, the language we use is shifting toward the preferred terminology.

Stigmatizing Language ("Try not to use")	Preferred Language ("Use this instead")
HIV-infected person	
HIV or AIDS patient, AIDS or HIV carrier Positives or HIVers	Person living with HIV; person with HIV; PLHIV Never use "infected" when referring to a person
Died of AIDS, to die of AIDS	Died of AIDS-related illness, AIDS-related complications, end-stage HIV
AIDS virus	HIV (AIDS is a diagnosis, not a virus; it cannot be transmitted)
Full-blown AIDS	There is no medical definition for this phrase; simply use the term AIDS, or Stage 3 HIV
HIV virus	This is redundant; simply use the term HIV
Zero new infections	Zero new HIV transmissions; zero new HIV cases
HIV infection	HIV case; HIV acquisition; diagnosed with HIV
HIV infected	Living with HIV or diagnosed with HIV
Number of infections	Number diagnosed with HIV; number of HIV acquisitions
Became infected with HIV	Contracted or acquired HIV; diagnosed with HIV
HIV-exposed infant	Infant exposed to HIV; infant born to a person living with HIV
Serodiscordant couple	Serodifferent, magnetic, or mixed-status couple
Mother-to-child HIV transmission	Vertical HIV transmission or perinatal HIV transmission
Victim, innocent victim, sufferer, contaminated, infected	Person living with HIV; survivor; warrior Never use the term "infected" when referring to a person
AIDS orphans	Children orphaned by loss of parents/guardians who died of AIDS-related complications
AIDS test	HIV test (AIDS is a diagnosis; there is no AIDS test)
Catch AIDS, contract AIDS, transmit AIDS, catch HIV	AIDS diagnosis; developed AIDS; acquire HIV (AIDS is a diagnosis and cannot be passed from one person to the next)
Compliant	Adherent
HIV risk, at risk for HIV	HIV relevance; reasons for HIV prevention; vulnerable to HIV; chance of acquiring HIV; likelihood of acquiring HIV (Common "risk" framing focuses on people's individual actions; individual behavior is rarely the driver of a woman's likelihood of acquiring HIV, but rather the forces outside women's control – including systemic racism, poverty, geography, partner behavior and vulnerability, etc.)
Prostitute or prostitution	Sex worker; sale of sexual services; transactional sex

Promiscuous	Having multiple sex partners (“Promiscuous” is a value judgment and should be avoided)
Down-low man; on the down-low	Man who has sex with women and men; bisexual or pansexual man; same-gender-loving man (depends on individual identity) (“The down-low” is a term sometimes used to describe men who may not disclose that they have sex with men as well as women due to stigma against diverse sexualities and sexual practices. This term increases stigma and should be avoided)
Unprotected sex	Sex without barriers or treatment-as-prevention methods Condomless sex with PrEP Condomless sex without PrEP Condomless sex
Death sentence, fatal condition, or life-threatening condition	HIV is a chronic and manageable health condition when people are able to access care and treatment
“Tainted” blood; “dirty” needles	Blood containing HIV; used needles
Clean, as in “I am clean, are you”	Referring to yourself or others as being “clean” suggests that those living with HIV are dirty. Avoid this term.
A drug that prevents HIV infection	A drug that prevents the transmission or acquisition of HIV
End HIV, End AIDS	End HIV transmission, end HIV-related deaths Be specific: are we ending AIDS diagnoses or are we ending the transmission of HIV?

Empowering Women through Language

One way to address internalized stigma is to change the messages we say to ourselves.

The more awareness we bring to the importance of language, the more change we see. One of the first places to start is the language we hear in our own heads -- the things we tell ourselves daily that define who we are within ourselves. Sometimes, it is the story we tell ourselves that we are not good enough, strong enough, smart enough, or beautiful enough. That we deserve everything challenging that has happened to us because, somehow, we are damaged goods. This is often called negative self-talk.

There are two types of stigma: internal and external. External stigma comes from what we hear from our family, friends, healthcare providers, and others, and from what we read in the media. Internal stigma comes from self-judgment and the negative self-talk we hear in our heads. We hear these messages in our voice and the voices of our loved ones. The language used in these messages is developed by our experiences in life, with stigma and discrimination, with shame and guilt.

One way to address internalized stigma is to change the messages we say to ourselves. This helps

to change how we see ourselves, and we begin to treat ourselves with more compassion. One way to do this is through mirror work and self-affirmations, and being careful about choosing the words we use to describe ourselves.

Mirror Work and Positive Affirmations

Affirmations are messages we tell ourselves. Negative self-talk is a kind of affirmation, but not a helpful one. Mirror work involves looking in the mirror and saying positive affirmations to ourselves -- messages like:

- “Thank you! That’s wonderful!” when something good happens in your life
- “This thing will pass, but I love you, and that is forever” when something bad happens
- “Looking good!” as you look at your beautiful face staring back

Positive affirmations can fill our minds with thoughts that heal our negative self-image and build confidence and self-esteem.

Researchers have found that using positive affirmations and mirror work has helped many women improve their self-image, confidence, outlook on life, and ultimately their health and well-being.

Examining and Changing Our Self-Talk

A good way to start examining our own self-talk is to write down the thoughts and messages we tell ourselves. Write down the “internal script,” the narrative you repeat in your head, and then review these messages by yourself or with friends or with a therapist. Take the time to examine the specific language and words you choose to describe yourself and your current situation.

Examples of Negative Self-Talk

- I am infected with a horrible disease, and no one will love me
- I deserve HIV and it’s my fault
- I can’t do anything right; I am not good enough
- I am an HIV-infected mother, daughter, woman

Once you’ve done that, then ask yourself:

- Are these thoughts true?
- Are these thoughts helpful?
- Do the words and phrases tear me down, or do these internal messages empower and lift me up?

Then try replacing the old image with a new, more accurate image of yourself.

Examples of Positive Self-Talk

- I am living with HIV, and I am lovable
- I can follow my goals and dreams and live an amazing life
- I am a woman living with HIV and I can empower myself and others

Positive self-talk involves finding words and phrases that inspire us. It also involves using words that are less stigmatizing to describe ourselves and our experiences.

Changing Language, Making Change

"In order to make big changes in society we must first take the little steps ourselves. When we, as people living with HIV, begin to change the language we use, others will take notice. It will take time, change always does, but it is the right time to change how we talk and write about people living with HIV." -- Lovinglife101, "Language and HIV: 'People First'"

An empowering experience for many women living with HIV has been their ability to think about and make changes to the language they use to talk and think about HIV. For some, this process has led to pointing out the stigmatizing language used by others in their community: family, friends, and healthcare providers. Others may take the step of reaching out to members of the media, by writing letters to the editor of a publication or using social media, when a newspaper or website uses inappropriate language. Some people join campaigns that make changing stigmatizing language a part of their strategy. HIV advocates have even won changes to the stigmatizing language used by large institutions such as the U.S. Centers for Disease Control and Prevention.

These are all powerful ways to be an advocate -- and they don't all involve being the loudest voice in a big crowd. Every time you question the use of a phrase that fuels stigma and ignorance -- even to yourself -- you contribute to building hope, and to changing our culture from one that disrespects women living with HIV to one that uses language to support the power and dignity of all women.

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The Well Project is a non-profit organization whose mission is to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls across the gender spectrum. Visit their website, https://www.thewellproject.org/, to access fact sheets (English and Spanish), blogs, and advocacy tools, and to join a global community of women living with HIV.

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