

Language and HIV communication

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Dear editor

I am writing to comment on Kontomanolis et al's recent article entitled "The social stigma of HIV-AIDS: society's role".¹ Although I applaud the authors for writing about this important topic and I wholeheartedly agree that HIV-related stigma is devastating to women living with HIV, I want to point out that using stigmatizing language when writing an article about HIV-related stigma is counterproductive.

The first sentence of the Abstract is medically incorrect and fuels the myths associated with HIV and AIDS. AIDS is not a "devastating and deadly disease". It is a diagnosis, a syndrome, a collection of diseases. One must be careful when referring in speech or writing to HIV and AIDS to ensure that terminology is medically correct, debarring social stigma. Research articles need to reflect the differences between HIV and AIDS rather than confuse the terms.

There are also added stigmatizing phrases and terminology in the article. For example, the authors pointed out that "Stigma is a multifaceted social structure that has its own pathway; it starts with labeling, separation, status loss, and ends up in discrimination" (p. 112), yet labels are used throughout the article. Tagging women as "AIDS patients" or "HIV positive women" further stigmatizes, dehumanizes, and reduces them to a diagnosis, which adds to the stigmatization of this population.

To reduce stigma and discrimination, it is vital that researchers use medically appropriate and preferred language, that is, the language preferred by the population of people that the researchers are describing. The use of "people-first language", as suggested by the Denver Principles and Dilmitis et al, puts the person before the diagnosis.^{2,3} Using "women living with HIV" or "women diagnosed with HIV" is preferred and less stigmatizing. People-first language emphasizes the person not their illness, diagnosis, or label.

Over 35 years into the HIV epidemic, researchers and health professionals are still using stigmatizing language regarding this population. As a scientist and as a woman living with HIV for 32 years, I urge the scientific community to rethink the use of language and how it affects HIV-related stigma.

Disclosure

The author reports no conflicts of interest in this communication.

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Author's reply

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Dear editor

In our civilized world, all human beings are entitled to their own opinion. I agree that AIDS is a collection of diseases, a syndrome. A good number of people though have passed away because of AIDS. I do admire the courage of our colleague and congratulate her on declaring in written form that she is an AIDS patient since very few people have the strength to do that in our established society today.

The purpose of our article was to point out the existence of stigma and labeling on these patients, to sensitize society that social isolation is improper and demoralizing. Our intention to express our opinion has been misunderstood.

As a trainee years ago in a European country, during our daily visit in the ward, we walked by a room with its drapes closed. We were not allowed to enter the room and were told by the leading clinician that within the room there was an AIDS patient. This is what I call stigma.

I strongly believe that a good number of people worldwide would hesitate to disclose their aforementioned health problem, despite the good efforts throughout the years to eliminate their fear of being left aside.

Scientific language must be strict, straightforward, evidence-based and devoid of emotions. This is actually the real meaning of science, the opportunity to speak, write, and express different viewpoints. It is not always necessary for scientific opinions to coincide.

Even nowadays, I believe that regardless of how many articles will be written, traces of stigma will always be there present in societies. It is the severity and seriousness of the disease that makes things different. Unfortunately, it is the origin of the human nature that cancels any effort made towards the annihilation of labeling; it is the weakness of human nature that feeds ethical derailing.^{1,2} To conclude, there was no intention of either insulting or excluding social groups.

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