



## **AIDS: Is It Time to Change the Terminology?**

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### **Introduction**

Mary, a recent addition to my patient roster, was unfortunately diagnosed with AIDS. Her CD4 count registered significantly below 200, indicating a compromised immune system. To ensure her comfort during the initial appointment, Mary was accompanied by her supportive sister. As we began, I introduced myself and provided them with an opportunity to express their concerns and share any pertinent information. Once they had spoken, I proceeded to carefully review the comprehensive lab results. It was with sensitivity that I relayed the diagnosis of AIDS, taking the time to clarify the distinction between HIV and AIDS, ensuring that Mary and her sister had a clear understanding of her condition.

Upon learning about the intricacies of HIV/AIDS and comprehending Mary's specific diagnosis of AIDS, both Mary and her concerned sister posed questions that weighed heavily on their minds. Mary's inquiry was straightforward: "Am I going to die?" Meanwhile, her sister sought reassurance, asking, "Is my sister going to die?" In response, I empathetically inquired about the origins of their concerns, prompting them to explain their reasoning behind anticipating such an outcome due to the AIDS diagnosis. Subsequently, I embarked on clarifying the comprehensive management plan that would be implemented, highlighting the use of antiretroviral (ARV) treatment to effectively manage her condition. Moreover, I outlined the potential for significant improvement in Mary's CD4 count and the achievement of viral suppression, providing a ray of hope for a more positive prognosis.

During subsequent visits, Mary approached me with a new query, expressing her desire for a potential change in her diagnosis from AIDS to HIV. Curious about the motivation behind her request, I asked Mary to elaborate on the reasons behind her inquiry. It became apparent that her recent emergency room visit had left her feeling stigmatized as a result of her AIDS diagnosis, leading her to seek a different label. In response, I engaged in an extensive conversation with Mary, emphasizing the significant advancements made in reducing stigma and improving the quality of care for individuals living with HIV. Despite my thorough explanation, I couldn't discern with certainty whether Mary had been fully reassured and convinced by our conversation.

Thanks to the effective administration of the appropriate ARV therapy, we witnessed a remarkable improvement in Mary's CD4 count, surpassing the 500 mark, and achieved viral suppression within a span of just three months. These favorable outcomes left Mary feeling incredibly satisfied with her progress. However, despite her

overall contentment, she continues to harbor a deep-seated concern about being diagnosed with AIDS rather than HIV.

During our most recent interaction, I took the opportunity to inquire about the persisting significance of her diagnosis. Mary candidly expressed her ongoing desire for a future day when she would be identified as having HIV instead of AIDS. It is precisely this heartfelt sentiment shared by Mary that has prompted me to write this personal perspective.

Recently, I had the opportunity of attending the American Conference for the Treatment of HIV (ACTHIV) virtually, where I had the chance to engage in a captivating session led by the esteemed Dr. William Short. Dr. Short, a prominent figure in the field of HIV medicine and an exceptionally compassionate physician, welcomed questions from participants at the conclusion of the session. Given the time constraints, only a select few questions could be addressed.

Among the numerous queries, my question caught Dr. Short's attention. I expressed my belief that there is a heightened stigma associated with an AIDS diagnosis compared to an HIV diagnosis, and I questioned whether it was time to reassess and potentially alter the terminology. In response, Dr. Short illustrated his viewpoint with a poignant real-life example. He shared a touching story about a man who had been diagnosed with AIDS, highlighting how the weight of that label consumed his thoughts throughout his hospital stay. Dr. Short, displaying thoughtfulness and consideration, responded to my question, expressing his agreement that it may indeed be beneficial to reevaluate the terminology used in diagnosis [1].

This encounter with Dr. Short served as the second catalyst for my motivation to write this viewpoint, as his insights reinforced the importance of examining and potentially re-examining the language and labels we employ in HIV diagnoses.

Once again, I found myself compelled to delve into this topic, as a third motivation emerged from a conversation with a friend residing in Italy. It transpired that a dispute had arisen between my friend and another acquaintance regarding the relationship between HIV and AIDS. While my friend challenged that HIV and AIDS were connected, he struggled to articulate the precise distinction between them. On the opposing side, the other individual vehemently argued that HIV and AIDS were entirely separate medical conditions.

Caught in the midst of this debate, my friend decided to reach out to me, aware of my involvement in the field of HIV medicine. With the speakerphone on, I engaged in a

conversation with both parties, endeavoring to clarify the distinction. The conversation extended longer than anticipated, as I expounded on the concept that AIDS represents an advanced stage of HIV infection. This crucial point enabled the individual who had maintained the belief in their complete separation to grasp the interconnectedness. Simultaneously, my friend, who had already recognized the connection, absorbed a clearer understanding of the rationale behind it. This encounter served as the third and final impetus for me to write about this topic, as it illuminated the ongoing need to elucidate the intricate relationship between HIV and AIDS, even among those within the same conversation.

After each of these three encounters, I was motivated to write this piece, but I wanted one final assurance that it was necessary. I needed one more push. I decided to talk to Mary and a few others with the diagnosis of AIDS. Almost everyone felt there was increased stigma associated with saying “I have AIDS” vs “I have HIV”. That was the final push I needed to write this post.

Before making my final point, let me share a few examples of some medical diagnoses that were changed due to various reasons including stigma. There was a time when we used the term “mental retardation” instead of “intellectual disability”. Recently, I published an article on substance use disorders and infectious diseases. During the process, many referred to the topic as “substance abuse” instead of “substance use”. This terminology was a recent change. Just to provide you an idea, terminology keeps changing when there is an appropriate reason. Allow me to share a few examples [2,3]:

Previous name	Current Name
Black dog	Depression
Falling sickness	Epilepsy
French pox	Syphilis
Change of life	Puberty or menopause
The shakes	Parkinson's disease

If you have not heard some or all of the previous names, please don't be surprised. I assure that you are not alone. I came to know some of these previous names as I was preparing to write this article. So, the point here is that names keep changing when there is a compelling reason. Stigma plays a significant role during that movement.

I foresee a range of opinions regarding the potential change in terminology from AIDS to a more appropriate terminology. It is expected that some individuals will support this change, while others may express disagreement. To illustrate the possibility of evolving terminologies, let's consider the example of intellectual disability, which replaced the previously used term "mental retardation." Initially, there were individuals who resisted the change, but over time, "intellectual disability" has become widely accepted due to its more positive connotation. I encourage you to read the article titled "Change in Terminology: 'Mental Retardation' to 'Intellectual Disability,'" [4], which highlights both supportive and unsupportive perspectives on this terminology shift.

Implementing changes in terminology is not always easy; some changes are straightforward, while others pose greater challenges. In the case of AIDS, I firmly believe that a change in terminology is necessary, though it may encounter obstacles. It's important to note that 'acquired immunodeficiency syndrome' (AIDS) is clinically and medically appropriate terminology, which holds scientific significance unlike some of the examples I've shared in this article. The concern isn't about the medical or scientific accuracy of the term AIDS; it's about the negative connotations and stigma associated with it. I want to clarify that I'm not disputing the medical and scientific appropriateness of the AIDS terminology. Rather, I'm suggesting that its use can perpetuate negative associations and connotations. Presently, I remain open to various ideas and proposals for a new term. One suggestion I propose is "Advanced HIV" (AHIV), as it maintains a clear connection to HIV while emphasizing the advanced stage of the infection. This terminology has the potential to reduce confusion and carry more significant meaning for the general public, fostering a better understanding of the relatedness between HIV and advanced HIV. Additionally, such a change could help mitigate the stigma associated with the current term, as mentioned in the aforementioned article. I am also aware that The Centers for Disease Control and Prevention (CDC) has been considering a stage classification - HIV Stage 3 in lieu of AIDS. I think that's another terminology to consider and remain receptive to alternative ideas accompanied by a thoughtful rationale. I believe that an open-minded approach, considering different perspectives, will contribute to a constructive and meaningful discussion surrounding the change in terminology from AIDS to a more appropriate diagnosis, such as "Advanced HIV."

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