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The Language of HIV: a NHIVNA Best practice guide for nurses

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Declaration of interests relating to this presentation

- None

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Background

Aim

Some stigmatizing terms

Good Practice – The rules

What nurses need to know

Acknowledgements

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Background

- **Communication**: an important part of existence
- **Language**: plays a key role in how we communicate
- **Verbal & non verbal communication**: Essential in nursing training
- **Communicating well with patients & colleagues**: vital to nursing helps assess, plan and evaluate care
- **Listening & observing body language** complements verbal communication

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Background

Language matters:

- Power to categorise people
- Impacts on how we think about ourselves & see others
- Has shaped person centred care

People living with HIV have shaped the language we use & the way we discuss death, dying, sex & sexuality.

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Background

Discussing HIV & Language is not new

- Guidance builds on work done by the CDC; UNESCO; UNAIDS; Kerr DL & Dilmitis et al...

*“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”**

*The Denver principles. 1983

Dilmitis S, et al. *Journal of the International AIDS Society* 2012, 15(Suppl 2):17990
<http://www.jiasociety.org/index.php/jias/article/view/17990> | <http://dx.doi.org/10.7448/JIAS.15.4.17990>



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,

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Watson S, Namiba A, Lynn V. **The language of HIV: a guide for nurses**. HIV Nursing 2019; 19(2)

This guidance is aimed at nurses working in HIV, generic nurses and other healthcare professionals.

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full blown aids



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Rule 1. Positive Words

Focus on using positive words such as ‘Promoting Health’ rather than ‘ending disease’

Instead of	Use
HIV/AIDS	To refer to Virus or Syndrome
Disclosure	Talking/Telling/Sharing
Infection/infectious/infect/ed	Acquire/Transmit/Pass On
Lost to follow-up	Need to find

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Rule 2. Person first language

Focus on using language that ‘Puts people first’ and acknowledges people living with HIV as fellow human beings

Instead of	Use
Mother to Child transmission	Vertical Transmission
Sero-discordant	Sero-different

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Rule 3. Avoid using the language of war

Commonly used by researchers investigation the Possibility of a cure or others to describe how immune cells work...

Instead of	Use
Elimination/Eliminating/shock / kill	Ending

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Good Practice – What Nurses need to know

- **Keep it kind and simple:** Easy to understand medically correct language
- **Use people-first language:** Person before disease
- **Educate:** Challenge misinformation
- **Think about your audience:** Avoid acronyms that may stigmatise

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Good Practice – What Nurses need to know

- **Use empathy:** Supportive & sensitive language is critical in our goal to achieve an HIV-free generation and support those living with HIV.
Eg when communicating about U=U (=U)

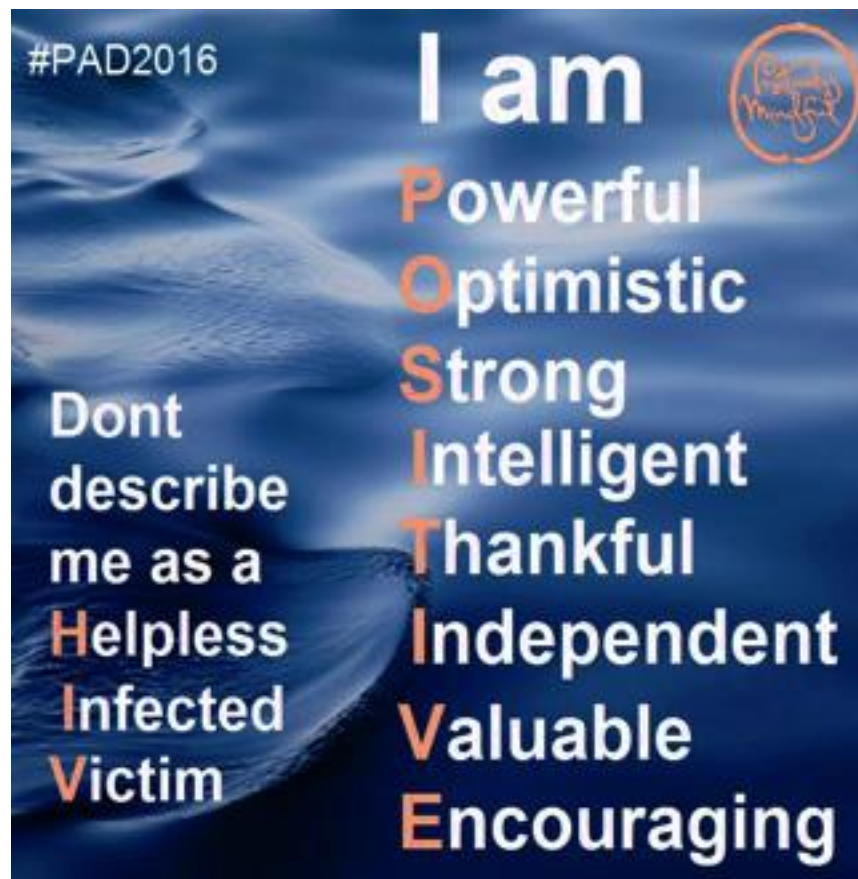
*“Using such words or language may result in real or perceived stigma, discrimination, fear and anxiety. Which may prevent some people from getting tested or treated for HIV. We can do our part by being thoughtful when choosing our words and choosing to use supportive rather than stigmatizing – language when talking about HIV.”**

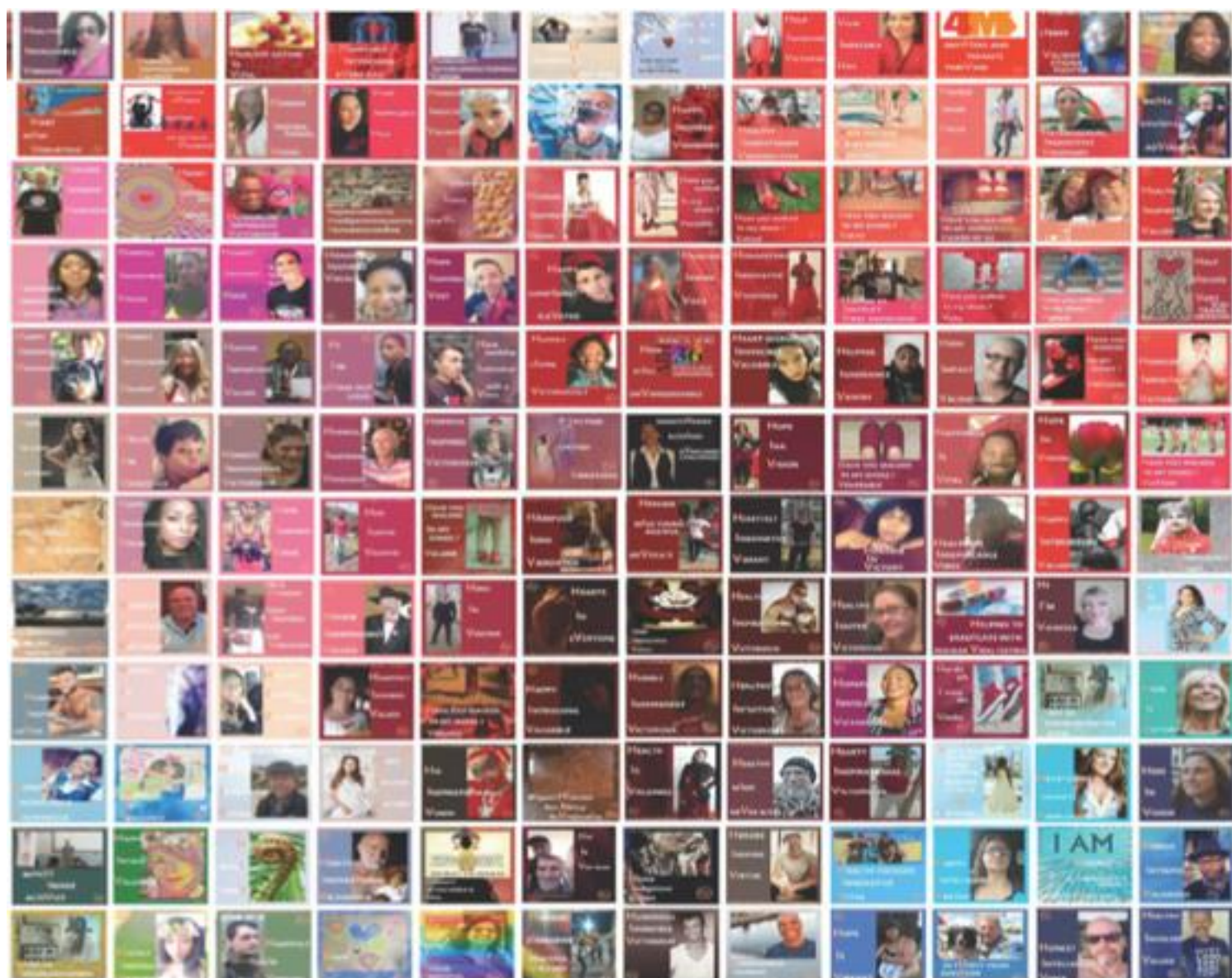
*CDC. Let's stop HIV together: a guide to talking about HIV. (Accessed April 2019)

HIV #LanguageMatters: Using Preferred Language to Reduce Stigma

Created for and by People Living with HIV

Stigmatizing	Preferred
HIV infected person	Person living with HIV, PLHIV. Do not use "infected" when referring to a person.
HIV or AIDS patient, AIDS or HIV carrier	Use People First Language , which puts the person before the diagnosis or label. For example, instead of "HIV positive women", use "women living with HIV".
Positives or HIVers	
Died of AIDS, to die of AIDS	Died of AIDS-related illness, AIDS-related complications, or end stage HIV
AIDS virus	HIV (AIDS is a diagnosis not a virus and 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 HIV
Zero new infections	Zero new HIV acquisitions/transmissions
HIV infections	HIV transmissions, diagnosed with HIV, people living with HIV
HIV infected	Person living with/diagnosed with HIV or acquired HIV
Number of infections	Number diagnosed with HIV or /number of HIV acquisitions
Became infected	Contracted, acquired, diagnosed with
HIV-exposed infant	Infant exposed to HIV
Serodiscordant couple	Serodifferent, magnetic, or mixed status couple
Mother to child transmission	Vertical transmission/perinatal transmission
Victim, Innocent Victim, Sufferer, contaminated, infected	Person living with HIV; survivor, thriver; warrior (Do not use "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 such thing as an AIDS test)
To catch AIDS, Transmit AIDS, To catch HIV, to spread HIV	An AIDS diagnosis; developed AIDS; to contract HIV; the transmission of HIV
Compliant	Adherent; taking medication as prescribed





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Thank you

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People Living with HIV in all your diversity

Watson S, Namiba A, Lynn V. **The language of HIV: a guide for nurses.** HIV Nursing 2019; 19(2)

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