

NHIVNA Best Practice

The language of HIV: a guide for nurses

Shaun Watson¹, Angelina Namiba² and Vickie Lynn³

¹Clinical Nurse Specialist HIV community, Chelsea and Westminster NHS Trust

²Associate Project Manager, Salamander Trust

³School of Social Work, University of South Florida, USA

Background

Without communication it would be difficult for us to exist and language plays a dominant role in how we communicate. As nurses, verbal and non-verbal communication including language is an essential part of our training. The ability to communicate with patients and colleagues effectively is vital to our work, allowing us to assess, plan and evaluate the care we provide. As we develop and grow into our profession, our language and communication skills expand. Listening to what patients tell and don't tell us or observing the nuances of body language communicates more than what we are verbally told. Language matters, it has power, it has the power to categorise people in descriptive terms that can be empowering or reductive [1].

Language impacts how we think about ourselves, and shapes how we see others. Over the past 30 years, people living with HIV have helped shape the language we use and their work has changed the way we discuss death, dying, sex and sexuality; ensuring that new discourse in the HIV field does not stigmatise, but rather catalyses empowerment for community members [2]. Language has shaped person-centred care and, on the whole, people living with HIV have become empowered self-managers informing the delivery of healthcare services.

Keywords

HIV, language, stigma, words

Aim

This guidance aims to inform nurses working in HIV, generic nurses and other healthcare professionals. Please pull out this section and share with others.

Evidence

In this best practice guidance we will examine HIV communication. This work builds on previous work by the CDC [3], UNESCO [4], UNAIDS [5], Kerr [6] and an article by Dilmitis *et al.* [2]. Discussing language and HIV is not new, in 1983 the Denver Principles stated:

"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."" [7]

In 1990, Kerr published the first article on the use of medically accurate terminology and HIV [6]. Yet, the use of stigmatising, and inaccurate language still exists and is often repeated by those who hear it or read it. Even today we hear the phrases 'innocent victims,' 'AIDS sufferers,' phrases many of us stopped using years ago. Yet the popular press uses misinformation and medically inaccurate terminology with alarming frequency.

This misinformation continues even in research articles. A recent (April 2019) Google Scholar search using the search terms 'full blown AIDS' revealed over 11,000 results. Limiting the search to the year 2018 revealed 180 results. There is no, and never has been, medical definition for 'full blown AIDS', yet the phrase is still in use today.

Over the past few years advocates and health professions have recognised the stigmatising nature that certain words have [8]. As more people living with HIV become involved in research design, strategic planning, and guidance people working with, writing, and presenting HIV-related topics must examine the terminology that is used. Health issues are '*not a choice, but our language and terminology in how we, as a society, describe it, and those [living with] it, is.*' [9]

Some of the terminology we hear and use is medically inaccurate, and adds to myths and stereotypes surrounding HIV. Negative terms can further add to the self-stigma for people living with HIV. One of the challenges around the use of language is found in academia. Where language focuses on managing, avoiding or eradicating HIV, rather than on enhancing health and wellness.

WHO defines health as '*a state of complete physical, mental and social well-being and not merely the absence of disease or Infirmary*' a statement that is positive and life enhancing in concept and tone [10]. People living with HIV are leading campaigns aimed at tackling stigma around language. A good example is the Positive Affirmation Day (www.positivelymindful.org/padhiv), a campaign focused on redefining the term HIV; it follows World Aids Day when HIV is in the media spotlight. However, HIV is still often associated with loss, death, and suffering. Having inspiring or

empowering statements connected with HIV helps redefine what it means, tackles perceptions and offers an alternative view. I am 'healthy, intelligent, vibrant' declares a status and so much more, it challenges understanding and supports a sense of self-worth and respect.

Guidance

Rule 1. Positive words

Focus on using positive words such as 'promoting health' (two positive words) rather than 'ending disease' (two negative words)

Let's start with the basics. There is a very good resource (Figure 1) developed through ongoing conversations with people living with HIV over a 3-year period (2012–2016) [11].

HIV or AIDS

People often use HIV and AIDS interchangeably and use HIV/AIDS as a coverall diagnosis, when they are very different diagnoses. We need to be clear when talking about HIV (a virus) or AIDS (a clinical syndrome). Although associated they are not the same thing leading to confusion and misinformation. Some people still think there is an 'AIDS test', and that people are 'dying from AIDS' rather than dying from HIV-related conditions.

Disclosure

We've used this term to describe how someone tells another about their HIV status but the definition of disclosure is 'the action of making new or secret information known' a fact, especially a secret, that is made known 'is the act of giving people new or secret information' [12]. The word secret is highlighted in many definitions and its associated words exposure, confession, revelation, divulgence, are almost biblical! Disclosure is a loaded, legal, negative word. When people living with HIV 'disclose' their status, they are reinforcing self-stigma and the belief that they have done something wrong. Using words such as 'telling', or 'sharing' carry less stigma – becoming less about hiding something.

Infection/infectious/infected

Avoid the word infection when discussing HIV, especially when referring to a person. Dilmitis *et al.* stated 'in an English thesaurus, the word "infection" is associated with "corrupt, dirty, tainted"' [2]. Referring to "catching HIV infections" rather than acquiring HIV conjures thoughts of 'contamination, impurity and even death' [13]. Alternative, more neutral words, such as 'acquire' or 'transmit' say the same thing, but carry a different feeling.

Owing to this association issues remain with using the word 'clean' and it frequently rears its head on gay

apps such as Grindr or Scruff: 'drug and disease free' 'clean as of ...'.

Lost to follow-up

This is another term commonly used within healthcare settings and, lost to follow-up refers to patients, not a lost set of keys or an object. Using 'need to find' puts the emphasis and some responsibility on healthcare providers to find ways to be accessible and accountable and to find ways to keep patients engaged in healthcare.

People living with HIV

Taking the experience of people living with HIV and turning it into an acronym such as PWLH, PWH, or PLHIV is unnecessary. Dilmitis *et al.* point out that 'spelling out people living with HIV ... is preferable to highlight that actual persons are being referred to rather than using an abbreviation', it's dehumanising, adding that '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' [2]. UNAIDS suggests that abbreviations for population groups can be used but should be limited to charts or graphs where brevity is required [5].

Rule 2. Person-first language

It is important to use language that puts people first. Using language that puts people first acknowledges people living with HIV as fellow human beings

Person first language/people-first language

Many erroneously believe people-first language started in the mental health community. However, this concept was first discussed in the Denver Principles and later advocated by other groups [7].

Mother-to-child transmission (MTCT)

Dilmitis *et al.* described the accusatory tone that this statement has, firmly placing the blame on the mother. They state that women find comprehensive prevention of 'vertical transmission' is less accusatory and more conducive to male involvement; it also has the potential to increase access to services by not stigmatising women living with HIV.

Serodiscordant

This word is often used in discussion about PrEP and Undetectable equals untransmittable (U=U). Serodiscordant simply means one partner is a person living with HIV and one is not. Discordant is something that is harsh and jarring because of a lack of harmony. Over medicalising what is a human relationship fuels stigma and discrimination. Most people in a relationship where one partner is living with HIV find it's rarely an issue. Even the word sero-different or magnetic (positive/negative) over medicalises the situation. Although, for ease, 'sero-different' focus on the fact that what is different about the couple is their HIV status.

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
Prostitute or prostitution	Sex worker; sale of sexual services; transactional sex
Promiscuous	Has or having multiple partners
Unprotected sex	Condomless sex with PrEP, Condomless sex without PrEP, sex not protected by condoms, sex not protected by antiretroviral prevention methods
Death Sentence, Fatal condition or life-threatening condition	HIV is a chronic health condition, a manageable health condition (as long as people are in care and treatment)
"Tainted" blood; "dirty" needles	Blood containing HIV; shared 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 of HIV, PrEP
End HIV, End AIDS	End HIV transmission, Be specific: are we ending HIV or AIDS?

Thanks to those who have assisted in the creation and dissemination of this information.
We continue to educate in order to reduce stigma and improve the quality of life for those living with HIV.
In honor of those who have gone before us and those who continue to advocate for human rights.
V Lynn



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Figure 1: Preferred language to describe HIV [11]

Rule 3. Avoid the language of war

Describing HIV in militaristic ways such as immune cells as soldiers fighting HIV, or ending HIV as elimination, killing or the scourge of AIDS or using these words may lead people to think those living with HIV have to 'fought' or 'eliminated' [3]

War! What is it good for?

Avoid language around living with HIV and HIV cure strategies such as elimination, shock and kill, fight, battle or war. This language is commonly used by researchers investigating the possibility of a cure. However these terms are militaristic and not helpful

or truly descriptive. The word ‘ending’ is a much softer and just as descriptive a term as elimination.

What nurses need to know

Keep it kind and simple; use easy to understand medically correct language. Be mindful of jargon, particularly in presentations where the audience maybe mixed and you aren’t aware of their HIV status, one negative phrase or word can alienate and audience or lead to further self-stigma for those living with HIV.

Use people-first language, which puts the person before the diagnosis or label It shows respect describing who they are, not what they have been diagnosed with. People-first language helps eliminate prejudice and removes value judgments, e.g. instead of saying HIV-infected women, use women living with HIV. It conveys the same meaning but with respect and compassion.

Educate. Challenge misinformation. It may be tricky but as nurses working in HIV, we have a duty to educate. It may be difficult at first but getting to know the correct language and why it important is a good start. NHIVNA is committed to ensure we use the right wording in our documents and presentations.

Challenging language that stigmatises is important and Bob Leahy challenged the use of wording such as ‘very low’ in a *Lancet* article discussing risk, stating that that kind of language is problematic: *‘it is not just semantics but rather a recognition that precise use of language is important. Suggesting that those living with HIV with undetectable viral loads pose an unproven but slight risk to others unnecessarily stigmatises millions.’* [14]

Think about your audience. Many of us have worked in HIV care for many years and old habits die hard. If you are writing an article and you have a tight word count then avoid using acronyms that may stigmatise, you usually have a few hundred words either way so get creative.

Use empathy. How would you feel if your life experience is boiled down to a few letters for the sake of a word count? 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 [3]. Using medically correct language when discussing HIV, either with a patient or colleague, is essential to building relationships. Medically inaccurate terminology communicates misinformation, adding to the barriers that lead people with HIV to disengage from services. We have a responsibility to our patients and our profession to use proper terminology when discussing HIV and AIDS.

Supportive and sensitive language is critical in our efforts to achieve goals towards an HIV-free generation and support those living with HIV [2]. I can think of no better way to end this guidance than by quoting the CDC’s *Let’s Stop HIV Together: A guide to talking about HIV* who state [3]:

‘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 openly about HIV’

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Correspondence: Shaun Watson
Shaun.watson@nhs.net