

### Metaphor and Illness: HIV and AIDS

HIV is human immunodeficiency virus. As suggested by its name, the virus gradually weakens the immune system, making the patient more susceptible to infection by other diseases. HIV replicates itself in the blood in the CD4+, or T-helper, white blood cells that fight against infections. When CD4+ cells are infected, the body keeps on producing new cells to compensate. When the body slowly stops being able to compensate, the number of CD4+ cells drops as the number of HIV multiply. As the CD4+ cells decrease, the immune system becomes weaker and more prone to illness. HIV officially becomes acquired immunodeficiency syndrome (AIDS) when the CD4+ cell count drops below a certain number. In the end, it is usually a secondary infection, such as pneumonia, which is usually not life-threatening, that can kill the AIDS-weakened patient. (WebMD)

HIV can be detected at six months past infection: there is a window period when HIV is transmissible but not detectable. It is transmitted through blood and sexual fluids. Early symptoms of HIV are similar to those of influenza or mononucleosis, and go away after two to three weeks. The person can then be symptom-free for many years, but HIV can still be spread to others. Recently, a fast oral test has been approved for use in the United States, but an official diagnosis is only made after at least two blood tests. If HIV is caught early and a steady treatment of retro-virals employed, it may never develop into AIDS. (WebMD)

Early HIV is often treated with highly active antiretroviral therapy (HAART) to retard the replication of HIV and help decrease the severity of the symptoms. Established HIV is treated with a "cocktail" of three or more medications. Every three to four months, the patient's CD4+ counts and viral load is compared to the baseline readings taken upon initial diagnoses to check the progression of the disease. When the counts and load suddenly spike, it often means that the HIV or AIDS has become drug resistant, and a new regimen

must be devised. Untreated, HIV will develop into AIDS in an average of twelve to thirteen years, and death occurs within 18-24 months after that. (WebMD)

Before and after diagnosis, patients often receive counseling. HIV and AIDS, considered interchangeable by many though they are not, have been highly stigmatized against from the first awareness of their existence. Initially, when a condition similar to HIV was found in chimps and monkeys, many thought that patients have had unusual contact (likely sexual in nature) with animals. Later, gays were stigmatized because AIDS was more prevalent in the homosexual population: AIDS was a divine punishment for their perversion. The first speculation has mostly lapsed now, but the second is still common: many AIDS-awareness campaigns emphasize that anyone can get AIDS, not just gays.

In general, the stigmas are linked to perversion and personal irresponsibility. In some parts of the world such as Africa, women who are infected are treated worse than men, often blamed for transmitting it while men are excused. Families and communities have rejected people with HIV/AIDS. Despite the fact that HIV/AIDS cannot be transmitted through casual contact, many people refuse to touch and be around those with HIV/AIDS. Governments deliberately underestimate the number of people who suffer from HIV/AIDS. There are limitations on international travel and immigration for those afflicted. Attacks on those who have spoken on being HIV+ or having AIDS and on members of groups associated with AIDS (mostly gays) have increased all around the world. In healthcare systems, there has been persistent lack of confidentiality problems: diagnoses of HIV+ status have often been revealed to others without the patient's consent. (AVERT)

HIV/AIDS is so associated with shame, deviancy, and immorality that many do not reveal their condition to even their closest friends for fear of rejection, forcing them into an emotional isolation, if not a physical one, and many patients suffer from depression. It also likely affects compliancy with treatment schedules as people are forced to hide their condition. In response, many hospital now offer counseling, and there has been increased public education on what HIV and AIDS are, which is helping to de-stigmatize the disease.

You thought *your* doctor's appointments were bad, Part III

~ Scene 1 ~

Nurse: Please come in, Ms. Waite.

*[As eighteen-year-old firefighter Katie Waite walks through the door of the reception area to the doctor's office, she wonders why her doctor had asked her to come in; Dr. Yu had told her that she may have HIV but she felt perfectly fine. I wouldn't feel this way if I had AIDS, she thinks.]*

*[Dr. Yu is attending to an energetically babbling 4-year-old. She takes the child's hand and brings her to the stickers and her mother. The child proceeds to place stickers all over her body. Dr. Yu makes a few notes in her files, and then pulls Katie's, reading through it quickly to remind herself. Katie's an active young woman whose only pre-existing condition was eczema; she is a newly diagnosed HIV patient. Dr. Yu enters the room. ]*

Katie: Hi, Dr. Yu. Did you see the girl – before she even went into the exam room, she started attacking people with stickers! I had to remove two Barney stickers from my knee! *[laughs]* That dinosaur is evil, I swear. Anyways, how are you?

*[In a well-practiced professional tone]*

Dr. Yu: I'm fine. And you?

Katie: I'm doing pretty well... I hope you agree?

*[Dr. Yu is unsure how to react. Visibly ducks the question.]*

Dr. Yu: Well, I'm glad you could make it in so quickly...

Katie: Well? *[She chuckles nervously.]*

*[Dr. Yu takes a moment to open the file. She places it down, separating the two of them with the physical barrier.]*

Dr. Yu: Are you in a relationship right now?

*[Nervous, Katie jumps to a non-medical reason for the doctor to ask a question about her personal life, rather than interpreting it as a veiled question about her sexual history as it would pertain to her medical condition]*

Katie: No, why do you ask? *[to the audience]* Is she hitting on me? *[quickly glances at the doctor]* She's pretty hot but I'm straight...

*[Both women are quiet for a moment.]*

Dr. Yu: Your blood tests came back positive.

~ Scene 2 ~

*[Katie panics, starts shaking her head; begins to babble. From time to time, she lifts her head, spittle flying in her somewhat incoherent rambling. The doctor backs away, washes her face at the sink, then returns, but stands out of range.]*

Katie: No! I feel fine! I ran six miles this morning after I volunteered at the Park Manor. It's this really wonderful retirement facility. I met this wonderful little old lady when I was at the library. She told me about how lonely they were sometimes, and how she was so grateful that she could read while her friends' eyes are so

bad that they can't read anything anymore. So I'm spending my weekends, in between the cancer research I do, reading to the elderly. This can't be happening to me! I'm a good person. I don't sleep around I don't have AIDS. I'm healthy as a horse; I had the flu months ago but that's it. Not AIDS. *[She ends with a sob]*

Dr. Yu: We've double-checked. Your bloodwork came back positive for HIV. Your flu-like symptoms are symptomatic of the first months after infection.

Katie: Am I going to die? That's what's going to happen now? I have HIV – that's another term for AIDS, right? And then I spend my life taking thousands of pills, running my life by them, lose all my friends and my job because everyone is afraid of people with AIDS. Then I die a horrible death, all wasted away, all alone? Isn't that how AIDS works? *[Katie stares out the window longingly at the young children on the playground, the young mothers who were barely older than her. She almost whispers to herself.]* I'll never get a chance to have kids, never have a family.

*[Takes a deep breath, touches Katie's clothed shoulder lightly to get her attention.]*

Dr. Yu: So let me explain how HIV and AIDS work, since they are different. First of all, HIV is transmitted through blood and sexual fluids. I'd like to track down the source of the transmission. Common means of infection are blood transfusions, contact with the bodily fluids other than sweat and saliva, of someone who is HIV+ or have AIDS, as well as needly sharing while doing intravenous drugs.

Katie: You see? I'm not HIV+!

*[Dr. Yu is beginning to look frustrated, but speaks in a modulated, professional tone.]*

Dr. Yu: You weren't HIV+ last year. Which means you acquired it sometime this year – at least six months ago. HIV – human immunodeficiency virus – can be detected at six months past infection; before there is a window period when HIV is transmissible but not detectable. It can become AIDS – acquired immunodeficiency syndrome. Sometimes, if HIV is caught early and a steady treatment of retro-virals is employed, it may never develop into AIDS.

Katie: So it's like a fire. If you catch it early enough, you can smother it and everything will be okay?

Dr. Yu: Actually, I'd rather avoid the metaphors, if you will.

*[Ignores Dr. Yu; scene cuts away to a movie clip of forest fires.]*

Katie: Or maybe I'm one of the lucky ones. It's like the forest fires that are put out by a lucky summer storm. Not all fires started in a forest actually become a huge fire. *[pause]* Oh, god, how am I going to be a firefighter anymore? That's my life!

Dr. Yu: HIV, in the body, replicates itself. It replicates itself in a type of white blood cell called CD4+, or T-helper cells. White blood cells protect your body from infections. They have mechanisms to compensate for illnesses.

Katie: What does that mean?

*[Pulls out some diagrams.]*

Dr. Yu: When CD4+ cells are infected, the body keeps on producing new cells to *[pause to find a synonym for fight]* compensate for the effects of the infection, but,

without the use of medications to prevent HIV replication, the body slowly – in an average of 12-14 years - stops being able to compensate, and the number of CD4+ cells drops as the number of HIV multiply. Because the CD4+ cells decrease, the immune system becomes weaker and more prone to infection by other things. HIV officially becomes AIDS when the CD4+ cell count drops below a certain number, and the patient develops an infection or a disease that would not be as severe or life threatening in normal, healthy people. In the end, it is actually the secondary infection that can kill the patient.

We can start you on antiretroviral medications now. It will likely help decrease the severity of the symptoms, and slow the replication rate of the HIV. It's possible to entirely stop the HIV from becoming AIDS.

*[Struggles to create a new metaphor that the doctor, apparently obsessed with science, would accept, if not a firefighting metaphor.]*

Katie: What? I don't understand. So it's a math problem? It all comes down to numbers? Once I reach a certain level, I get sick?

Dr. Yu: *[Pause]* We try to avoid metaphors here. *[Pause]* And it's really not that set in stone; there is no one single number we look for – we'll take your blood every 3-4 months to monitor your CD4+ and HIV loads. When there are dramatic changes, such as an increase in HIV load and a corresponding decrease in CD4+, then the HIV has likely gone drug-resistant and we'll have to switch to something new. If that doesn't work, the HIV could develop into AIDS.

*[Looks confused]*

Katie: It's like a forest fire – we keep putting up firewalls and clearing land in order to contain in, but there are still embers that could develop as soon as we firefighters stop being diligent and working our butts off? And not every firewall will hold up under the fire, though some will?

*[Exasperated.]*

Dr. Yu: Yes. It's like a fire in that way. *[Ironically, to the audience]* Dr. Sontag is going to kill me slowly. Like dying through smoke inhalation rather than the actual fire.

Katie: But how will I be on the drugs? I'm going to get sick, right, and have to spend my life taking hundreds of drugs, and I should quit being a firefighter.

Dr. Yu: Actually, exercise can help make your immune system stronger. You should continue your life, keeping healthy. It's your choice whom you tell, but your sexual partner, and any who may have contacted your blood or have had sexual contact with should be informed. It cannot be transmitted through tears, sweat, urine, or feces.

Katie: My friends are never going to touch me again. They'll be too afraid to get it. I'm not going to tell them.

Dr. Yu: It really is your choice, and you can choose to never tell them. On the other hand, you can tell them and explain to them exactly what type of contact is required to transmit the virus. You'd be able to have a support network to help you deal with it.

Katie: No, but if I tell them, they'll think I slept around or had some sort of weird sex.

*[Scene flashes to a slide show showing her walking through her apartment door with various men.]*

Dr. Yu: HIV can be transmitted in non-sexual ways. For many years, hemophiliacs became infected through the blood transfusions that saved their lives: that was before HIV was identified and a reliable method of screening donated blood was found.

[End of Scene]

Dear Dr. Sontag,

In the past week, I had to inform a longtime patient of mine that she was HIV-positive. She was understandably interested in the pathology of HIV and worried about the impact that her disease would have on her social life, given the stigma that exists against people infected with HIV or AIDs. I followed your instructions to eliminate the use of metaphors in illness as the method by which to remove the stigma. However, in doing so, I feel that I have failed in my other responsibilities as a doctor: to be compassionate and to develop a relationship that treats the patient as a human being rather than simply a list of symptoms.

As a physician, I am separated from the patient by my professionalism, and thus, cannot offer the emotional support that many people would otherwise give upon such diagnoses – I cannot call up her friends to rally about her, nor can I take her out to dinner to discuss the problem with her over less sterile and stressful settings. My only way to show my compassion and sympathy, which is non-stigmatizing, as any illness requires sympathy, is through my words. I fear she viewed me as cold and unfeeling, forever damaging our relationship as patient and doctor. I believe that I actually helped to perpetuate the social stigma against the disease, by treating the patient so impersonally, as if she, being ill, is now undeserving of human compassion. She expressed a common worry of those with serious illnesses – other people will withdraw from them – that I confirmed when I verbally seemed to have withdrawn from my previous position as a caregiver into the role of a dry scientist.

Regardless of the verbal metaphor, there is always the physical metaphor that all physicians employ upon donning a lab coat, gloves, and a stethoscope. Physically, I perpetuated the non-touching stigma by not touching her skin to skin. Though she was concerned about not being touched, I could not put my own health at risk; contact with the eczematous areas of her skin

that may crack and bleed may transmit HIV to me, and I may unwittingly transmit it to others. My, and the hospital's, policy has always been to minimize skin-to-skin contact. It is a required metaphor. Unfortunately, it serves to reinforce the verbal withdrawal on my part due to the removal of the metaphors from my speech, for example, not engaging in her responses by accepting the fire metaphor, and not offering my condolences.

Removing all metaphors also made comprehending the physical implications of the disease difficult. Repeatedly, as I was describing the scientific background of her disease, she was confused and attempted to create metaphors from her experience in order to grasp the concepts. I informed her of our hospital's policy of not using metaphors and continued to explain the pathology without the use of any metaphors, such as war, wherein there is an invasion of the body by the virus. She became more and more frustrated as she attempted to understand. If I had not eventually agreed to the use of a fire metaphor by the patient, I do not believe that she would ever have truly grasped the nature of her disease. Agreeing to her basic metaphor allows for a foundation upon which the scientific facts of her disease can be laid and true understanding can be established. The pathology of the disease is complex; a patient who has recently discovered that she has a critical illness is not in an emotional state to intellectually contemplate her condition. The use of a metaphor that is personally relevant to her as a firefighter helps to overcome that barrier. Further, bringing the idea of illness to her world reminds her that she does not have to relinquish her normal life because of her new condition. The metaphor provides her hope, allowing her to visualize HIV as the same as fighting a normal fire; HIV is not a menacing monster that is undefeatable.

Moreover, all words have metaphorical resonance and denotations. Words that you and I may not assign any specific emotional value to may create an emotion in the patient. It is

impossible to eliminate the nuances of each word in order to create a sterile, emotionless, and completely metaphor-free explanation of a disease without eliminating the compassion and humanity. The best attempts only serve to distance the patient from the physician, as very few patients prefer a doctor who does not appear to be compassionate.

The policy set by you and the hospital has served well through the years when public speculation ran wild on the causes of HIV and AIDS. However, I believe the metaphors of seeing AIDS as a plague and as a divine judgment are much less prevalent in this community. This is due to new awareness of what HIV and AIDS are, and a general shift in the attitudes of the religious community towards sympathy and compassion rather than rejection of those afflicted. Metaphors are now desired; the idea of a war against AIDS helps to create public support and funding of research. It helps people to realize that they can protect themselves against AIDS. For the patients themselves, the will to live is a strong and powerful one and those who have given up have a decreased immuno-response to illness. The belief that one can battle against an assailant increases the will to live.

In conclusion, I believe that the hospital should trust in the physician's judgment on which metaphors and which words to use, which will necessarily differ depending on the patient and the patient's background. Although the policy served to remind physicians to choose their words with more care because of the subtle ways in which words can impact patients, it should now be reconsidered.

Sincerely,

Hial Yu, M.D.