

# Cultural Competence: The Impact of Stigma on Patients with HIV/AIDS

Josepha Campinha-Bacote, PhD, MAR, PMHCNS-BC, CTN-A, FAAN  
President, Transcultural C.A.R.E. Associates



# Objectives

By the end of this training, participants will be able to:

- Define stigma and its impact on people living with HIV/AIDS as they attempt to access quality medical care
- Discuss factors contributing to HIV/AIDS-related stigma
- Identify consequences of HIV/AIDS-related stigma
- Discuss at least 4 culturally responsive clinical strategies to reduce HIV/AIDS-related stigma and discrimination

# HIV Stigma

The retiree was sitting in a bed at South Shore Hospital last December, chatting with two visiting friends, when her physician walked into the room and declared, "I understand you have HIV." It was supposed to be a secret, and the patient insisted to the friends from her retirement community that she didn't carry the virus. But they left quickly and one no longer speaks to her.

"We used to eat together all the time. Now we never do. She just avoids me as much as she can," said the 65-year-old woman, who wanted to remain anonymous. "My closest girlfriend doesn't even know I have HIV. I don't want people to shun me. I'd be alone." The woman whose HIV status was disclosed at South Shore Hospital said a fellow resident in her retirement community who is open about being HIV-positive is referred to as "the girl with HIV" by other residents and shunned.

# Stigma - Definition

- Stigma (στίγμα) is a Greek noun meaning "a mark, dot, puncture" or generally "a sign", from the verb στίζω ("to puncture"). Also noted to be a cut or burn mark on the body indicating that a person's morality was abnormal or corrupt.
- Stigma refers to a "mark" (visible and invisible) that allows people within a group to identify "outsiders."

# Types of Stigma

- Internal or Self-Stigma
- Perceptions or feelings towards a group, such as people living with HIV, who are different in some respect.
- Feelings of self-hatred, self-blame, shame, dejection, self-doubt, guilt, loss of self-esteem and confidence, and inferiority.
- Feel they are being judged by others, so they isolate and withdraw.

# Types of Stigma

- Perceived or Felt Stigma - Fear that individuals have that if they disclose their HIV positive status, they may be stigmatized
- Secondary or "Courtesy" HIV/AIDS-Related Stigma - Stigmatization of people connected to the issue of HIV/AIDS or HIV positive people.

# HIV/AIDS-Stigma & Discrimination

- While stigma is covert and at times difficult to uncover, discrimination is about overt behavior. Discrimination results in that person being treated unfairly and unjustly on the sole basis of belonging or being perceived to belong, to a particular group. For example, treating a person less favorably simply because he or she has HIV.
- Depending on the situation in which discrimination occurs, it may be against the law. It is important to know that all people with diagnosed HIV are protected by the law, in the same way as people who are discriminated against because of their race, sex, age, sexual orientation or religion.
- For the purposes of these laws, people with diagnosed HIV are defined as having a 'disability'.

# HIV Discrimination Settlements - Clinician Focused

- Woodlawn Family Dentistry  
Settlement regarding dentist office's unequal treatment of people with HIV in the scheduling of future dental appointments (February 12, 2013)
- Castlewood Treatment Center  
Settlement regarding eating disorder clinic's refusal to treat a woman for a serious eating disorder because she has HIV (February 6, 2013)
- CHW Medical Foundation and Mercy Medical Group, Inc.  
Settlement regarding podiatrist's denial of treatment solely because an individual has HIV (May 10, 2012)



# HIV Discrimination Settlements - Clinician Focused

- American Laser Settlement Agreement  
Resolving laser hair removal company's denial based on HIV status of the full array of services provides to those who seek hair removal treatment (June 28, 2011)
- Occupational Training and State Licensing Press Release  
Justice Department Issues Letter Regarding Illegal Exclusion of Individuals with HIV/AIDS from Occupational Training and State Licensing (March, 21, 2011). Settlement agreement of Modern Hairstyling Institute Inc

# Rationale for Eliminating HIV/AIDS Related Stigma

## Its Profound Effect on the Epidemic's Course:

*“Fear of stigma and discrimination is the main reason why people are reluctant to be tested, to disclose their HIV status or to take antiretroviral drugs.”*

# Provider Stigmatization

- Naughton study on provider stigmatization
- Provides evidence that a subset of healthcare providers harbor stigmatizing beliefs about HIV/AIDS patients.
- Data reveals the following behaviors that are detrimental to the patient's medical care:
  - Nonverbal behaviors related to proximity, eye contact, and extra precautions
  - Expression of discomfort or negative affect
  - Patient avoidance or delayed treatment
  - Lack of touch during treatment
  - Inadequate or differential treatment
  - Avoided, delayed or refused treatment
  - Judgmental communication

# Impact of HIV/AIDS-Related Stigma

- HIV stigma relates to failure to disclose HIV status
- Interferes with psychological functioning
- HIV stigma is closely linked with resistance to HIV testing
- Is a source of depression, which is linked to poor treatment adherence

# Negative Consequences of Stigma on Health Care & Interventions

- Individuals often wait too long to access care
- Poorer treatment prognosis
- Linked to self medication
- Once in care HIV stigma impacts care retention – it drives people away from care
- HIV stigma negatively impacts safe behavior
- Has been used to justify behavior such as *Intimate Partner Violence*

# Role of Clinicians

- Clinicians can be a first line defense in combating HIV-related stigma.
- Providers must PROBE for stigma – you will not know it if you fail to ask

# HIV Stigma -- Case Study

## (Part 1)

Sara, a 29 year old married woman of Chinese descent decided to accompany her best friend, Mary, to get an HIV test at the community health center after they both attended a health and wellness program at their church. Sara believes that accompanying Mary will help dispel her fear that she is ill because Sammy, her husband of six years, has possibly given her one of "*those nasty diseases*" again. Sara knows that her husband, Tom, is a one-woman man and is confident that neither she nor Tom is positive. She has never had a medical exam outside of her pregnancy and believes she can also get a glucose test since her mother suspects she is diabetic because the urine she left in the cup outside last week was full of ants.

After 1 ½ hours of waiting for the test, Sara went to inquire why individuals who had come in later than she and Mary had already left and they were still sitting there. The nurse told her to, "...just wait her turn". Almost 2 hours after their arrival, Sara and Mary were still waiting for their names to be called. Mary was about to inquire for the second time when the receptionist announced that, "the Lab Tech is here to do your HIV test now, you can just follow him through that door." Sara quickly glanced around and was mostly relieved that only about two persons had remained to hear what was said; the majority of the people having already left the waiting area.

# HIV Stigma -- Case Study

## (Part 1)

After donning two pairs of gloves, Scott, the lab tech, directed Sara first to remove her jacket then proceeded with conducting the test. Mary also took the test and inquired of Scott when she could return to get the results. Without looking up to answer Scott replied, "Why are you so concerned now? Who did you sleep with or was it drugs? I guess you will have to sweat it out for a while uh? We'll call you and let you know. Good afternoon ladies."

I should not worry, Mary announced as she left the clinic. "Sammy is not a bad person. He is not a sex worker, drug user, or homosexual; only they get that disease."



# HIV Stigma -- Case Study

## (Part 1)

Identify **cases** of HIV stigma that are present in this case.  
How could these be:

1. Prevented?
2. Corrected?

Identify **causes** of HIV stigma that are present in this case.  
How could these be:

1. Prevented?
2. Corrected?

# Cultural Assessment

## Conduct a Cultural Assessment of HIV/AIDS-Related Stigma

1. What do you think is the cause of HIV/AIDS-related stigma?
2. How does HIV/AIDS-related stigma effect you?
3. What kind of strategies do you think would reduce HIV/AIDS- related stigma?
4. What are the most important results you want to see in reducing HIV/AIDS-related stigma?
5. What are the chief problems HIV/AIDS-related stigma has caused for you?
6. What do you fear the most about HIV/AIDS-related stigma?

# Forms of Stigma in Health Care Facilities

- Keeping patients who are HIV positive waiting a long time and serving them last, or unnecessarily referring them to other health workers or departments.
- Refusing to provide treatment e.g. doctors refusing to do surgery for patients whose HIV status is unknown, nurses refusing to inject, or give baths or bed pans to patients suspected to be HIV positive.
- Judgmental and moralizing attitudes among health workers towards patients living with HIV (e.g., “not being faithful to their partners”).
- Talking in front of patients who are HIV positive about their condition during rounds.

# Forms of Stigma in Health Care Facilities

- Forcing patients to be tested for HIV without their consent, without adequate pre- and post- test counseling, and without providing the results of the HIV test to the patient.
- Disclosing the HIV status of clients to other health staff; or to family members or other people without the consent of the clients.
- Revealing the status of patients who are HIV positive by loudly calling out their names.
- Excessive use of gloves and masks for routine tasks which doesn't involve the handling of bodily fluids; or wearing gloves only for patients who are suspected to be HIV positive.

# Organizational Strategies to Reduce Stigma

- Attitude changing education
- Increased involvement of health licensing agencies
- Create a workplace environment that discourages health disparity through stigma and discrimination.
- Use language and behavior that does not communicate stigma

# Organizational Strategies for Addressing Stigma in the HIV/AIDS Epidemic

- Implement stigma reduction interventions at the workplace
- Encourage the use of valid and reliable stigma measures
- Assess impact of stigma on programs

# Your Role as Clinicians

*Address Stigma  
Wherever it Exits*



# Cultural Competence in HIV/AIDS-Related Stigma: Have You 'ASKED' The Right Questions?

**Awareness:** Are you aware of the presence and incidence of HIV/AIDS-related stigma and discrimination?

**Skill:** Do you know the skill of conducting a cultural assessment, in a sensitive manner ?

**Knowledge:** Are you knowledgeable about factors contributing to HIV/AIDS-related stigma, the negative consequences of stigma on health care and interventions and at least three culturally responsive strategies to combat HIV/AIDS-related stigma?

**Encounters:** Do you seek out sacred encounters with people living with HIV/AIDS and are you committed to resolving HIV/AIDS-related stigma in a culturally sensitive manner?

**Desire:** Do you really “want to” become culturally competent with people living with HIV/AIDS and reduce HIV/AIDS-related stigma?



# HIV Stigma -- Case Study

## (Part 2)

Both Sara and Mary returned two weeks later for their result. Both agreed to provide support for each other. Mary, on receiving the result that she was HIV positive jumped up from her chair screaming “No!” and inadvertently knocked over the chair in which Sara was seated. Sara hit her head on the edge of the table which resulted in a gnash; then she passed out. Sara was subsequently hospitalized. Sara’s parents brought her a change of clothes and were still in the room talking with her the next morning when three residents accompanied the attending, Dr. Sampson, during rounds. They entered Sara’s room and the attending nodded curtly to Sara and her family and read Sara’s chart. He informed the residents that Sara is HIV positive. Overhearing this, Sara began to sob. “Uh,” replied Dr. Sampson, “I did not realize that you spoke English.” “She is an American,” her father said and he added, “She was born and raised here.”

# Quote

*"Science has yet to find a cure for AIDS. But there is a cure for discrimination in the health sector. It can be found in the thousands of health workers in the Americas."*

# References

- *AVERTting HIV/AIDS* (AVERT) (2011). HIV & AIDS Stigma. <http://www.avert.org/hiv-aids-stigma.htm>
- Castro, A. & Farmer, P. (2005). Understanding and Addressing AIDS-Related Stigma: From Anthropological Theory to Clinical Practice in Haiti. *AJPH*, 95:53–59.
- Chan, K., Yang, Y., Zhang, K. and Reidpath, D. (2007). Disentangling the Stigma of HIV/AIDS from the Stigmas of Drugs Use, Commercial Sex and Commercial Blood Donation – A Factorial Survey of Medical Students in China. *BMC Public Health*, 7:280.
- Engender**Health**. (2004) Reducing Stigma and Discrimination Related to HIV and AIDS: Training for Health Care Workers. <http://www.engenderhealth.org/pubs/hiv-aids-sti/reducing-stigma.php>
- Gobind, J. & Ukpere, W. (2012). Curtailing the Stigma Associated with HIV/AIDS Through Mandatory Testing: A Management Perspective. *African Journal of Business Management*, 6 (44), 11118-11127).
- Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. NY: Anchor Books.
- Harare. (2005). *Guidelines for Reducing Stigma and Discrimination and Enhancing Care and Support for People Living with HIV and AIDS*; <http://www.sanaso.org.zw/Guidelines%20for%20Reducing%20Stigma%20&%20Descrimination.htm>

# References

- Human Rights Watch. (2003). *Locked Doors: The Human Rights of People Living with HIV/AIDS in China*. <http://www.unhcr.org/refworld/docid/3fe478e27.html>
- Kidd, R. and Clay, S. Chiiya, C. (2007). Understanding and Challenging Stigma: Tool Kit for Action. Academy for Educational Development, International Center for Research on Women and International HIV/AIDS Alliance <http://www.icrw.org/files/images/Understanding-and-challenging-HIV-stigma-Introduction-and-Module-A.pdf>
- Kleinman, A., Eisenburg, L. & Good, B., (1978). Culture, Illness and Care: Clinical Lessons from Anthropologic and Cross-Cultural Research. *Ann. Inter. Medicine*, 88:251-258.
- Link, B., and Phelan. J. (2001). Conceptualizing Stigma. *Annual Review Sociol.* 27:363–85.
- Mahajan, A. et al. (2008). Stigma in the HIV/AIDS Epidemic: A Review of the Literature and Recommendations for the Way Forward. *AIDS*, 22(Suppl 2): S67–S79.
- Naughton, J. (2012). "HIV-Related Stigmatization in Treatment Settings: Effects on Patient Comfort, Risk Disclosure, and Treatment Decisions.". *Psychology - Dissertations*. Paper 171.
- Ogden, J & Nyblade, L. (2005). *Common at Its Core: HIV-Related Stigma Across Contexts* International Center for Research on Women.
- Pan Health Organization. (2003). Understanding & Responding to HIV/AIDS-related Stigma in the Health Sector. <http://www.paho.org/English/AD/FCH/AI/stigma.htm>

# References

- Smart, R. (2009). *HIV/AIDS-Related Stigma and Discrimination*. [http://www.iiep.unesco.org/fileadmin/user\\_upload/Cap\\_Dev\\_Training/pdf/1\\_4.pdf](http://www.iiep.unesco.org/fileadmin/user_upload/Cap_Dev_Training/pdf/1_4.pdf)
- Snyder, M., Omoto, A. and Crain, A. Punished for Their Good Deeds: Stigmatization for AIDS Volunteers. *Am Behav Scientist*, 42(7),175-192.
- UNAIDS Programme Coordinating Board. (2010). *Reduce Stigma and Discrimination and Increase Access to Justice in All National Responses to HIV epidemic*: 26th Meeting of the UNAIDS Programme Coordinating Board Geneva, Switzerland.
- UNAIDS. (2000). HIV and AIDS-Related Stigmatization, Discrimination and Denial: Form, Context and Determinants (Research studies from Uganda and India); Best Practices Collection. [http://www.unaids.org/en/media/unaids/contentassets/dataimport/publications/irc-pub01/jc316-uganda-india\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/publications/irc-pub01/jc316-uganda-india_en.pdf)
- WHO. (2008). *Towards Universal Access: Scaling up Priority HIV/AIDS Interventions in the Health Sector*: Progress Report 2008.
- Pulerwitz, J. & MacQuarrie, K. (2005). *HIV-Related Stigma Understanding, Measuring it and Testing the Impact of Programmatic Responses*. <http://www.docstoc.com/docs/68756998/Borders-for-Invitations>
- Sayles J et al. (2009). The Association of Stigma with Self-Reported Access to Medical Care and Antiretroviral Therapy Adherence in Persons Living with HIV/AIDS. *Journal of General Internal Medicine*. 24(10).



# AETC-NMC

AIDS Education and Training Center  
National Multicultural Center

---

HOWARD UNIVERSITY COLLEGE OF MEDICINE

1840 7<sup>th</sup> Street NW, 2<sup>nd</sup> Floor  
Washington, DC 20001  
202-865-8146 (Office)  
202-667-1382 (Fax)

[www.AETCNMC.org](http://www.AETCNMC.org)