Southern California Sexual Health Collaborative

Implications of HIV-Stigma on Health:
From Local to Global

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What is Stigma?

- Defined by sociologist & writer Erving Goffman
- “Stigma: Notes on the Management of Spoiled Identity” (1963)
- “…an attribute that is deeply discrediting”
- “…an individual who might have been received easily in normal social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us.”
Stigma in the Context of HIV/AIDS

- Prejudice & Discrimination
- Negative Perceptions & Attitudes
- Abuse & Neglect
- Maltreatment

...directed towards people living with HIV & AIDS and the groups and communities they associate with
Local & Global Impacts of HIV-Stigma

- Reduced Adherence to ARVs
- Greater HIV Symptomatology
- Missed Clinic Visits
- Decreased Access to Services (ex. social support, PreP, PEP)
- Reduced Sero-status Disclosure
- Avoidance of Healthcare
- Decreased HIV Testing
- Decreased Negotiation of Safe Sex Practices
- Mental Health Pathologies (ex. depression, anxiety, suicidal ideation)
Reducing HIV/AIDS-related Stigma through PhotoVoice: A Road to Policy Change

- Received funding from University of California Global Health Institute (UCGHI)
- Obtained IRB approval from UCI/USC IRBs
- Informed Consent & Photo Release Forms Signed
- Recruited 10 women of color living with HIV/AIDS from LAC+USC Medical Center
- Photojournalist trained participants on PhotoVoice, photography ethics, and digital camera use
PhotoVoice Study (cont)

- Participants asked to critically reflect on experiences with HIV-stigma
- To take photos that bring reflections to life
- To record meanings of 10-15 photos in a contextual journal & assign a caption to each
- Submit photographs to study staff in preparation for focus group discussions (FGDs) and structured interviews
PhotoVoice Study...Preliminary Findings

Reasons why HIV Stigma Exists

• Ignorance & Lack of Education
• Taboos about Sex
• Social Conditioning/Cultural Myths
• Personal Fears & Misdirected Shame

Effects of HIV Stigma

• Fear of Dating & Social Relationships
• Stress & Isolation
• Chronic sadness & depression
• Loss of hope for the future
• Feelings of shame & dirtiness
• Waiting to Die

Actions Needed to Reduce HIV Stigma

• Education of Healthcare Workers
• Youth Empowerment & Outreach
• Women’s Empowerment
• Involvement of HIV community & the Church
• Practical and Consistent Education (e.g. safe sex, stigma, compassion)
• Dissemination of HIV Facts by Public Health & Medical Officials
Participant Photos of HIV/AIDS-Stigma
“HIV-Stigma makes you feel like a shadow!”
“Drowning my joy!”
“My cocktail is not like your cocktail!”
"I am HIV positive!"
“Taking labels off HIV pill bottles!”
“Caged lion at heart...always covered by this disease!”
“HIV-Stigma & Decay”
“HIV and broken...takes life away!”
“Pennies are more valuable than me!”
“Isolation...waiting to die!”
“Contagious!”
“They made me feel like garbage!”
“Doctors should know better!”
Participant Experiences with PhotoVoice

- Study was emotional
- Recalling stigma was difficult and painful
- PhotoVoice study led to:
  - Making peace with diagnosis
  - Wanting to advocate for others
  - Feeling stronger to continue fighting
  - Emergence of new coping skills
- Photography is personal but powerful
- Confident that photos will reach and educate
Next Steps...Taking Action

◆ Building a portable gallery to exhibit photos in settings where stigma is pervasive (Ex. hospitals/clinics, churches, and schools) to **EDUCATE, EMPOWER, & INSPIRE POLICY CHANGE**

◆ 1st presentation hosted by study participants is scheduled for February, 2014 for clinical healthcare workers LAC+USC Medical Center

◆ Design larger studies testing the efficacy of PhotoVoice as an educational tool for HIV-stigma reduction
Community-based Organization (CBO) role in HIV testing

• Provider practices, low income, and stigma are common barriers for HIV testing
  • Also for HIV positive individuals to receive care and continue treatment

• Clinics that cater to particular communities are a potentially important way to remove barriers for those individuals to learn about their STI status

• Marginalized or underrepresented groups face less stigma among people who share similar personal experiences and feel part of a community
  • MSM may be at particular risk for stigma
Visual Story of HIV-stigma: Peru

• Gay men’s CBO in Lima, Peru (Epicentro)

“Peru was recently voted as the most Homophobic country in Latin America”


• Opens up door to stigma globally
64 countries: adult consensual same-sex conduct is legal and protective laws are in place

115 countries: adult consensual same-sex conduct is not a criminal offense

78 countries: adult consensual same-sex conduct is criminalized

7 countries: adult consensual same-sex conduct is illegal and punishable by death

Source: UNAIDS, 2013
Global Problem: Nigeria

- Over 3.4 million Nigerians live with HIV, making Nigeria the country with the second largest population of people LWHA
- MSM and transgender people represent less than 1% of Nigerians but over 10% of new HIV infections
- Providing targeted services is therefore essential to end AIDS in Nigeria
Nigeria in the news

• Last month
  • President Goodluck Jonathan signs **same sex marriage prohibition bill** into law
    • Lynching, stoning MSM

• Among the first publicly affected by the new law, Ibrahim recently confessed to sodomy 7 years ago-with the principal of his high school
• Judge spared him death sentence by stoning since the crime occurred so many years earlier
• Others tortured into providing a list of 170 gay men
Nigeria-new legislation

- The Same Sex Marriage (Prohibition) Act prohibits same sex marriage or civil union, and carries up to 14 years imprisonment
  - Up to **10 years imprisonment** for any persons who "support the registration of gay clubs, societies, organizations, processions or meetings".
  - This provision poses a threat to HIV organizations providing services to the LGBTI population.
Nigeria: HIV Implications

• Nigeria no policy for HIV treatment and care in prisons
  • Death sentence or prison for HIV positive MSM arrested
• Health providers for MSM also criminalized
• People who spoke for LGBTI rights at the Biomedical HIV Prevention Conference in November in Abuja-now in hiding
  • One day to the next
• U.N. Secretary-General Ban Ki-moon has said the Nigerian law could fuel prejudice and violence and risks obstructing an effective HIV/AIDS response.
Stigma Trumps Prevention Options and Reachable Goals !!!!

zero new HIV infections
zero discrimination
zero AIDS-related deaths
Note: PMTCT, Screening transfusions, Harm reduction, Universal precautions, etc. have not been included – this is focused on reducing sexual transmission.
Small Group Discussion

• Starting with a reflection by our CAB panelists
  • Perspectives on Peru video
  • PhotoVoice Study Results
  • Using PhotoVoice as methodological tool for anti-stigma education
  • HIV stigma training in medical settings
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