Effects of stigma on HIV prevention behaviors and uptake of health services

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The role of relationships in HIV prevention among young women in Africa
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What is Stigma?

- A social process in which individuals with certain attributes or behaviors lose social value.

- Examples of stigmatized health conditions:
  - HIV and AIDS
  - Tuberculosis
  - Obesity
  - Mental illness
  - Substance abuse disorders
Dimensions of stigma

- Anticipated stigma (fears)
- Perceptions of community norms
- Experienced, enacted or observed stigma (discrimination)
- Internalized or self stigma
Special Vulnerability of Women of Reproductive Age

– Often 1st person in the family to be tested for HIV due to contact with reproductive health services → blame
– Gender norms/relations that penalize women for promiscuity → blame
– Low relationship power
– Socio-economic vulnerability
A framework for the effects of stigma on HIV prevention and health

Stigma

Psycho-social effects:
- Fear
- Denial
- Blame
- Guilt
- Shame
- Secrecy
- Silence
- Negative attitudes

Behavioral Consequences:
- Avoidance of HIV testing
- Lack of use of preventive measures
- Lack of disclosure
- Delay in care
- Avoidance of health services
- Not taking meds
- Discrimination
- Violence

Effects on health:
- Poor mental health
- Mortality and morbidity
- Adverse health consequences of violence
- Transmission of infections

*Adapted from Kumar et al., Culture, Health and Sexuality, 2009.*
Examples of HIV-Related Stigma Experienced by Pregnant Women

• Anticipated stigma:
  – A focus group participant in Soweto reported, “I didn’t book at an antenatal clinic because I was afraid that they would test me for HIV, so I avoided it as I told myself that I might be found to have this disease.”
  
  (Laher, Cescon et al. 2011)

• Perceived community stigma:
  – In a study of participants in a PMTCT program in Malawi, half had dropped out of the program, citing reasons including “involuntary HIV disclosure and negative community reactions”

  (Chinkonde, Sundby et al. 2009)
Intersectional Stigma

Overlapping Stigmas Experienced by Poor Women in Marginalized Racial/Ethnic Groups Living with HIV

- HIV-related stigma
- Racial/ethnic group stigma
- Poverty stigma
- Pregnant with HIV stigma

* Multiple experiences of stigma and discrimination

Evidence for the Effects of Stigma on Women’s HIV Prevention Behaviors in SSA

• Stigma and risky sexual behavior
• Stigma and PrEP use
• Stigma and uptake of HIV testing
• Stigma and use of essential reproductive health services
• Stigma and prevention of mother-to-child transmission (PMTCT)
Stigma and Risky Sex

• Stigma may cause women to fear asking their partners to use a condom (as they could be assumed to be HIV-infected)
  – In South Africa, “condom stigma” (linked to HIV-related stigma) was one of the strongest predictors of non-condom use (Chandran et al., *BMC Public Health*, 2012)
  – Among adults on ART in Uganda, internalized stigma was significantly associated with simultaneous viremia and sexual transmission risk behavior (Siedner et al., *AIDS*, 2014)
Stigma and PrEP non-adherence

• Taking PrEP may raise suspicion that one is HIV-infected and thus women fear stigma.
  – Qualitative study of the VOICE Trial found that women feared stigma if others saw that they were taking ARVs (PrEP). (Van der Straten, et al., *PLoS One*, 2014)
  – In Kenya, stigma was also cited as a cause for non-adherence in a PrEP trial: “…like my family, I explained that I am attending a study but they don’t [believe] that I am attending a study, they just thinking I am HIV positive and I am hiding it.” (Van der Elst, *AIDS Behav*, 2012)
The MAMAS Study
Maternity in Migori and AIDS Stigma Study

(PI: Janet M. Turan)

Investigating the relationships between women’s perceptions and experiences of HIV-related stigma and their use of essential maternity and HIV services in rural Kenya

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MAMAS Results on Refusal of HIV testing during Pregnancy*

• Pregnant women who anticipated male partner stigma were more than twice as likely to refuse HIV testing, after adjusting for other individual-level predictors
  – Odds Ratio=2.10, 95% CI: 1.15-3.85, p=.016

• Other variables in the model:
  – Anticipated stigma from other family members (ns)
  – Anticipated stigma from other people (ns)
  – Total perceived community stigma score (ns)
  – Knowing someone with HIV (OR =.52)
  – Lack of knowledge of male partner’s HIV testing status (OR=1.77)

* Turan et al., AIDS & Behavior, 2011
Use of Essential Maternity Services

• Fears about lack of confidentiality, unwanted disclosure, and HIV-related stigma may cause some women to avoid ANC clinics and childbirth in a health facility.

• Illustrative finding from MAMAS:
  – In rural Kenya, women with higher perceptions of HIV-related stigma at baseline were subsequently less likely to deliver in a health facility with a skilled attendant, even after adjusting for other known predictors of health facility delivery (AOR=0.44, 95% CI:0.22-0.88).

Turan et al., PLoS Medicine, 2012
GLOBAL UPDATE

Stigma of H.I.V. Is a Barrier to Prenatal Care

By DONALD G. McNEIL Jr.
Published: August 27, 2012
Disclosure and Use of ANC and Facility Birth Services

* Spangler et al., manuscript under review
Stigma and discrimination affect each step in the PMTCT cascade*

1. Attend ANC clinic
2. Be (a) offered and (b) accept HIV testing
3. Undergo CD4 and clinical stage assessment
4. Enroll in a PMTCT/HIV treatment program
5. Adhere to ART during pregnancy
6. Give birth with a skilled attendant
7. Follow safe infant feeding practices
8. Bring infant for HIV testing and return for results
9. Adhere to maternal/infant ART after birth

Interventions to Address Anticipated Stigma and Increase Use of HIV Prevention

• Interventions to positively engage male partners and other family members may reduce fears and experiences of stigma
  – Home-based couples intervention to increase couple HIV counseling and testing (CHCT) and safe disclosure in Kenya (Turan, NIMH R34, ongoing)

• Community-wide stigma reduction efforts
Interventions to Address Anticipated Stigma and Increase Use of HIV Prevention

• Interventions to reduce stigma and discrimination in healthcare settings can help health workers to identify and address women’s fears of stigma
  – HIV stigma-reduction intervention with medical students in Puerto Rico (Varas-Diaz et al., JIAS, 2013)
  – Stigma workshops with nurses and PLHIV in 5 African countries (Uys et al., AIDS Pt Care STDS, 2009)
  – Workshops with Public Opinion Leaders (POLs) in hospitals in China (Li et al., AJPH, 2013)
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