

# HIV and Disclosure

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Mike Silverman MD, FRCP, FACP

Western University, London

NOT AN ETHICS EXPERT- Just OLD

# Zero sum games

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- Not comfortable- advocates against virus
- No other figure worth our protection- Infection Control Practitioners to much lesser extent
- Litigators- like this- Sharks (ultimate zero sum eat or starve) no medical sharks
- CMPA- Avoid lawsuits- patients unlikely to sue successfully re: disclosure- judges and juries unsympathetic and will identify with HIV uninfected partner- Recipient of transmission more likely to be victor in suit as compassion

# Clergy?

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- Rabbi and Minister- “I’m glad this isn’t my problem”

# Medical Approach

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- Primum non-nocere
- Patient harm: we try to understand; pt estimating risk from partner- we are 3<sup>rd</sup> hand estimators so harder to estimate than pt
- Likelihood of transmission- some estimates but can we make choice on risk for someone else without their consent? Lotterey tickets?
- Easy choice- “Punt” to public health as neutral persons to balance risks and **sometimes** do anonymous disclosure (often no way to be anonymous)



# Why not strongly encourage disclosure?

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- In North America- failure to disclose and yet having sex without a condom with high viral load= assault
- Generally men charged as far more likely to be infected- be the “index partner” in couple

# In Africa usually women find out first

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- Mostly via antenatal clinics
- Infected at younger age and so get sick earlier
- Do they disclose?

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- fear of accusations of infidelity, abandonment, discrimination and violence
  - Generally ~75% of women in sub-Saharan africa identified in pregnancy do not disclose to their partners (higher disclosure rates during VCT. ?From less fear of abandonment than while pregnant?) or More “empowered” women come for VCT



# Literature review of Disclosure Studies by WHO

**Bull World Health Organ vol.82 no.4 Geneva Apr. 2004**

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- women of lower socioeconomic status had a higher disclosure rate than women of higher socioeconomic status (Not just money/power)
  - Younger and more educated women MORE likely to disclose
  - Longer relationship (>2years) more likely to disclose

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- majority of the studies reported positive outcomes related to disclosure
  - Women reported receiving kindness, understanding or acceptance following disclosure in three of the studies.
  - disclosure was not associated with the break-up of marriages. In fact, four of the studies reported that *most* marriages survived disclosure

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Negative outcomes following status disclosure blame, abandonment, violence, anger, stigma and depression. Ranging from 4% to 28%.

The proportion of women reporting violence as a reaction to disclosure ranged from 3.5% to 14.6%. The true incidence of violence related to HIV status disclosure was hard to determine, as there were no base rates of violence

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- In Tanzania: 46.4% of women who did not disclose their HIV status to their partners reported that fear of divorce was a major barrier to disclosure, but 91.7% of women who did disclose their results reported that their relationship continued afterwards (Kilewo C Journal of acquired Immunodeficiency syndromes 2001).
  - In Kinshasa: 63% of women who did not disclose their HIV status reported fear of divorce as the major barrier, yet, 12 months after disclosure, no woman in the study reported divorce or separation (Heyward W AIDS 1993).

# What does this mean?

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- 1) only women who are confident in the safety and strength of their relationship actually disclose their results, and women who are less confident choose not to.

OR

- 2) It could also mean that women perceive the risk of a negative outcome to be more likely than it is in fact.

# SO?

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- 75% likelihood that she will not disclose
- Implications
- Implications for Him?
  - 1) he may get infected (use of condoms rises with disclosure)
  - 2) no opportunity for PReP
  - 3) If he is positive he won't find out or get treatment

# Implications for her

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- 1) hard for her to take *PMTCT* for prevention of transmission *or her own health*: as trying to keep secret- poor adherence- higher transmission. Many women will not make decisions such as taking HAART without husbands “permission”, and can’t get this.
- 2) difficult to discuss family planning etc..
- 3) stress on relationship of HUGE secret- including guilt that she may be putting him at risk



# Alternative don't test?

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- 45% transmission rate to infant
- Mothers at high risk of being positive (by definition unsafe sex to get pregnant, and transmission during pregnancy even higher) so opportunity for access to care missed

Encourage/ (force via medical disclosure) all women to disclose (North American solution)

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- Zimbabwe pt “Z”