Stigma, gender inequality and disclosure: impact on adherence

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ViiV Healthcare

SA/HIV/0003/17
I am a full time employee of ViiV Healthcare
4000 HIV patients
Number of people who accessed HIV care by exposure category and ethnicity: United Kingdom, 2006 - 2015

- White men who have sex with men
- Non-white men who have sex with men
- White heterosexuals
- Black African heterosexuals
- All other heterosexuals
- People who inject drugs
- Other/not known

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UK HIV continuum of care: progress against UNAIDS target, 2015

- People living with HIV: 100%
- People diagnosed with HIV: 90%
- On treatment: 83%
- Virally suppressed: 78%

Comparison with UNAIDS 90:90:90 target:
- People living with HIV: 87%
- People diagnosed with HIV: 96%
- On treatment: 94%
- Virally suppressed: 73%
Goffman 1963

‘ an undesired differentness from what we had anticipated ’

.....that reduced the bearer ‘in our minds from a whole and usual person to a tainted, discounted one’
HIV related stigma

Socially shared attitudes, beliefs, or actions that promote and perpetuate the devalued status of people living with or affected by HIV

Factors contributing to HIV/AIDS related stigma

- HIV/AIDS seen as a life-threatening disease
- People are afraid of contracting HIV
- The association between HIV and behaviours (such as sex between men and injecting drug use) that are already stigmatised in many societies
- People with HIV/AIDS thought responsible for contracting it
- Religious or moral beliefs that lead some people to conclude that having HIV/AIDS is the result of a moral fault (such as promiscuity or “deviant” sex) that deserves punishment.

Types of stigma

• Enacted: experience of social rejection, abuse, violence, abandonment, loss of job
• Anticipated/perceived: concern that the above will happen
• Felt/normative: an individuals perception of stigma levels within communities
• Internalised: inner endorsement of those views (self blame, shame, guilt)
Types of stigma

• Vicarious: hearing stories of other people being stigmatised and discriminated against

• By association: being a family member, work colleague, or caring for someone who is stigmatised

• Layered: several stigmatising characteristics
  – Homosexual, injection drug user, sex-worker, transsexual, single mother, immigrant, widow, mental health
Helen

28 years old

Married
2 young children

Parents-in-law live with them

Tests HIV+ve

Not previously tested for HIV

Run a small food stall
PARTNER

- Allows for partner/family testing
- Allows for condom use
- May facilitate clinic attendance
- May facilitate adherence
- May provide support

BUT many women fear:
- Stigma
- Discrimination
- Violence
- Abandonment
“You need to tell your partner your HIV status so he can be tested”

“You need to use condoms”
The condom is an ‘intruder’ in marriage: evidence from rural Malawi

Chimbri AM et al. Social Science & Medicine 2007;64(5):1102-1116

• Analysis of Malawi Demographics & Health Surveys 1992 & 2000
• Plus semi-structured interviews 3 rural districts
• Assess peoples perceptions of the compatibility of condoms within marriage
• Major findings:
  – Condom use negligible within marriage
  – All discussion around condoms in both men and women is in the context of preventing STD/HIV in extra-marital relationships
  – Initiating a discussion around condom use for preventing an infection in marriage is like bringing an intruder into the home
PARTNER

- May need to prioritise husband and children
- May need to prioritise work/earnings
- May need to rely on husband for transport to clinic
- May require his permission to attend/take/change medication
Disclosure
Encouraging partner to test
Suggesting condom use
Appointment attendance
Escalation of pre-existing IPV
Inability to leave

Intimate partner violence (IPV) and HIV

Figure 4. Illustrative maps of Africa showing: (a) IPV prevalence, (b) DALYs attributable to HIV, and (c) Depression prevalence in HIV positive women.
Listen to us, learn from us, work alongside us”

“UK findings from a global participatory survey among women living with HIV

- 95 women
- 79.6% experienced violence
- 83% depression and rejection
  - Self blame 78%
  - Anxiety 77%
  - Insomnia 75%
  - Very low self esteem 70%
  - Loneliness 70%
Lifetime IPV = 52%

Correlation between women living with HIV & domestic abuse

Common quotes from women:

“He will take my children away”
“If I leave all my family will know about my HIV”
“I will be cursed by black magic”
“He will kill me if I leave”
“If I leave no one else will want me”
“I am so ill that he looks after me, takes me to my appointments and looks after the money”

Personal communication Paula Evenden Dragonfly
## Summary of main forms of abuse

<table>
<thead>
<tr>
<th>Coercion and threats</th>
<th>Emotional abuse</th>
<th>Isolation</th>
<th>Financial abuse</th>
<th>Male privilege</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disclosure of HIV, report to welfare, immigration services, take the children</td>
<td>Putting her down, playing mind games, blackmail, HIV being main focus for emotional abuse</td>
<td>Controlling what she does, who she sees and talks to</td>
<td>Perpetrator controls all the money does not give her access to her own bank account</td>
<td>Treating her like a slave and being the dominant male</td>
</tr>
</tbody>
</table>

*Personal communication Paula Evenden, Dragonfly Collaborative*
HIV/AIDS Related Stigma and Discrimination against PLWHA in Nigerian population

• \( \sim 50\% \) PLWHIV should be ashamed of themselves\(^1\)
• \( \sim 53\% \) PLWHIV should be blamed for bringing disease to community\(^1\)
• \( \sim 50\% \) would buy vegetables from vendor with HIV\(^1\)

Gender-based attitudes, HIV misconceptions and feelings towards marginalized groups are associated with stigmatisation in Mumbai, India

• \( 73\% \) PLWHIV should be denied the right to marry\(^2\)
• \( 82\% \) PLWHIV should be denied the right to have children\(^2\)

Community patterns of stigma towards persons living with HIV: a population-based latent class analysis from rural Vietnam

• \( 70\% \) not safe for a child to play with someone with HIV\(^3\)
• \( 50\% \) PLWHIV should be isolated\(^3\)

A qualitative analysis of the barriers and facilitator to receiving care in a prevention of mother-to-child program in Nkhoma Malawi

• Transportation & cost\(^4\)
• Community discrimination and gossip\(^4\)
• Leaders refusing to give fertiliser coupons\(^4\)
• Negative experience of HCPs\(^4\)

N= 3258 patients in UK

<table>
<thead>
<tr>
<th>Risk group</th>
<th>Disclosed to nobody</th>
<th>Disclosed to friends</th>
<th>Disclosed to family</th>
</tr>
</thead>
<tbody>
<tr>
<td>MSM</td>
<td>5.0 %</td>
<td>85.8%</td>
<td>59.9%</td>
</tr>
<tr>
<td>Heterosexual</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>♂</td>
<td>16.6%</td>
<td>44.1%</td>
<td>61.1%</td>
</tr>
<tr>
<td>♀</td>
<td>15.7%</td>
<td>57.5%</td>
<td>67.1%</td>
</tr>
</tbody>
</table>

Facilitators and barriers to treatment adherence within PMTCT programs in Malawi
- Fear of disclosure to husbands\(^1\)
- Poor interaction with some HCPs\(^1\)

Fundamental concerns of women living with HIV around the implementation of Option B+
- Lack of informed consent\(^2\)
- Involuntary or coercive HIV testing\(^2\)
- Limited treatment options\(^2\)
- Termination of pregnancy\(^2\)
- Coerced sterilisation\(^2\)
- Pressure to start treatment\(^2\)

Understanding HIV-related stigma among Indonesian nurses
- Stigmatising attitudes significantly predicted by:\(^3\)
  - Education
  - HIV training
  - Perceived workplace stigma
  - Religiosity
  - Islamic religious identification

Prevalence and drivers of HIV stigma among health providers in urban India: implications for interventions
- N=305 doctors\(^4\)
- 13% HCPs should have the right to refuse to treat PLWHIV
- 55% HIV positive women should not be allowed to have children
- ~40% PLWHIV should not be allowed to marry

UK Experience

HIV-positive African women’s engagement with HIV care in the UK during pregnancy

8/15 women described negative experience of maternity care

“I could hear the midwife outside telling the other one to be careful as I was ‘high, high risk’

“When I think about the experiences I had… I wanted four or five kids. Now I said to my husband ‘no, this is the end of it’.

UK Stigma Index – 2015

• 378 women
• 34% worried about being treated differently by GP
• 5% felt their treatment had been delayed or refused
• 15% avoided seeking care

Source: Tariq et al. BHIVA 2014: abstract P136
Stigma, an important source of dissatisfaction of health workers in HIV response in Vietnam

Pham et al BMC Health Services Research 2012;12:474

• Perceived risk of being infected through contact with PLWHIV
• Negative attitudes towards key populations at risk in society (‘social evils’)
• Stigmatization of PLWHIV
• Stigmatization of professionals because of association with HIV
Structural community factors and sub-optimal engagement in HIV care among low-income women in the deep south of the USA

Walcott et al, Cult Health Sex 2016:18(6)682-94

- 46 women
- Employed 10.9%
- > 2 living children
- Annual income < $11000.00
- Ever missed HIV medication due to lack of food 21.7%
- Ever missed HIV doctors’ appointment due to transportation challenges 39.1%
“if you have a choice between feeding yourself and your family and going to a routine healthcare provider for a checkup, you feed your family”

“my biggest issue is getting back and forth to the clinic”

“I do not have enough money to get to the clinic…so therefore I am going to stretch my meds and only take 3-4 times this week”

“If I come in and see somebody from my hometown I’m most likely to come in and walk out”

“can’t afford to ride the bus…don’t want to tell their family they are going to the doctor, because the family is going to say, well why are you going to the doctor? And they don’t want to say”
May decline ART

Hide medication

Only take medication when alone

Difficulty getting to the clinic

Worried about being seen at the clinic

Unable to take it at mealtimes
Virological failure reduced with HIV-serostatus disclosure, extra baseline weight and rising CD4 cells among HIV-positive adults in Northwestern Uganda

Detectable Viral Load in Late pregnancy among women in the Rwanda Option B+ PMTCT Program: Enrollment results from the Kabeho study

• Rwanda – option B+
• 608 women in 14 facilities
• 56.7% on TDF/3TC/EFV
• 50% had detectable VL in T3 or 2/52 pp
• 37.7% of women on HAART >36/12 had detectable VL at enrolment
• 19/46 (41%) with available genotype had major NRTI/NNRTI resistance

Detectable Viral Load in Late pregnancy among women in the Rwanda Option B+ PMTCT Program: Enrollment results from the Kabeho study

- Detectable VL at enrolment significantly associated with:
  - Gravidity O.R. 0.9 (0.84-0.97)
  - No education O.R. 2.25 (1.37-3.70)
  - Non disclosure O.R. 1.97 (1.21-3.21)
  - Side-effects O.R. 2.63 (1.72-4.03)

Table 3 Multivariable logistic regression analysis of risk factors associated with mother-to-child transmission of HIV at 6 weeks and at 6 months of life

<table>
<thead>
<tr>
<th>Variables</th>
<th>HIV infection at 6 weeks (1)</th>
<th>HIV infection at 6 months (2)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>adjusted OR [95% CI]</td>
<td>adjusted OR [95% CI]</td>
</tr>
<tr>
<td>Mother's age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;=24</td>
<td>1.22 [0.41 - 3.64]</td>
<td>1.43 [0.53 - 3.89]</td>
</tr>
<tr>
<td>&gt;24</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>not currently married</td>
<td>1.42 [0.42 - 4.79]</td>
<td>1.55 [0.49 - 4.90]</td>
</tr>
<tr>
<td>currently married</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Education attainment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>none/primary</td>
<td>1.09 [0.29 - 4.08]</td>
<td>1.09 [0.33 - 3.63]</td>
</tr>
<tr>
<td>secondary/university education</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Wealth index</td>
<td></td>
<td></td>
</tr>
<tr>
<td>poorest</td>
<td>2.07 [0.31 - 14.01]</td>
<td>1.37 [0.27 - 7.01]</td>
</tr>
<tr>
<td>second</td>
<td>0.77 [0.07 - 8.16]</td>
<td>0.39 [0.05 - 3.44]</td>
</tr>
<tr>
<td>middle</td>
<td>0.82 [0.11 - 5.90]</td>
<td>0.53 [0.09 - 2.94]</td>
</tr>
<tr>
<td>fourth</td>
<td>1.33 [0.21 - 8.32]</td>
<td>1.05 [0.23 - 4.91]</td>
</tr>
<tr>
<td>richest</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Parity

<table>
<thead>
<tr>
<th></th>
<th>adjusted OR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>primiparous</td>
<td>1.97 [0.65 - 5.94]</td>
</tr>
<tr>
<td>multiparous</td>
<td>2.33 [0.84 - 6.41]</td>
</tr>
</tbody>
</table>

Disclosed HIV status to partner

<table>
<thead>
<tr>
<th></th>
<th>adjusted OR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>4.68* [1.39 - 15.77]</td>
</tr>
<tr>
<td>Yes</td>
<td>3.41** [1.09 - 10.65]</td>
</tr>
</tbody>
</table>

Place of delivery

<table>
<thead>
<tr>
<th></th>
<th>adjusted OR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>home</td>
<td>2.98 [0.42 - 17.17]</td>
</tr>
<tr>
<td>health facility</td>
<td>2.21 [0.33 - 14.88]</td>
</tr>
</tbody>
</table>

child's sex

<table>
<thead>
<tr>
<th></th>
<th>adjusted OR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>1.27 [0.49 - 3.34]</td>
</tr>
<tr>
<td>Female</td>
<td>1.21 [0.49 - 2.98]</td>
</tr>
</tbody>
</table>

Type of feeding for the child during first 6 months of life

<table>
<thead>
<tr>
<th></th>
<th>adjusted OR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>mixed feeding</td>
<td>5.55 [0.40 - 74.82]</td>
</tr>
<tr>
<td>artificial feeding</td>
<td>9.64* [0.96 - 96.62]</td>
</tr>
<tr>
<td>exclusive breastfeeding</td>
<td>2.45 [0.39 - 15.24]</td>
</tr>
<tr>
<td>1.99 [0.36 - 11.10]</td>
<td></td>
</tr>
</tbody>
</table>

Mode of delivery

<table>
<thead>
<tr>
<th></th>
<th>adjusted OR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>vaginal/instrument assisted</td>
<td>0.66 [0.17 - 2.57]</td>
</tr>
<tr>
<td>cesarean section</td>
<td>0.91 [0.24 - 3.40]</td>
</tr>
</tbody>
</table>
Depression
Change in patterns of HIV status disclosure in the HAART era and association of HIV status disclosure with depression level among women

Liu C AIDS Care 2017 April 1:1-7

- Women’s Interagency HIV Study (WIHS)
- 202 women, 102 diagnosed pre-HAART, 100 post-HAART
- Investigated:
  - Patterns of disclosure
  - Association between disclosure and depression
- No change in comfort level or time to disclosure to family or friends
- Less likely to disclose to family in HAART era
- Longer time to disclosure associated with depression
Stigma and isolation

- US study of 98 African-American women with HIV:\(^3\)
  - Stigma negatively related to disclosure, psychological wellbeing and psychosocial functioning

- London study of 62 African women with HIV:\(^2\)
  - Perceived and actual stigma cited as a barrier to accessing health care and volunteer agencies
  - Resilience strengthened by religious belief

Mechanisms for the Negative Effects of Internalized HIV-Related Stigma on Antiretroviral Therapy Adherence in Women: The Mediating Roles of Social Isolation and Depression. (WIHS)

Adapted from Turan B et al J Acquir Immune Defic Syndr. 2016 Jun 1;72(2):198-205. doi: 10.1097/QAI.0000000000000948
Reduced adherence

Non-disclosure

Secrecy

Depression

Reduced adherence
Reduced adherence

- Secrecy
- Depression
- Non-disclosure
- Adolescent
Additional challenges for Adolescents with HIV

- Lost parents/siblings
- Cognitive impairment
- Challenges of teenage years
- Exploring sexuality/negotiating safe sex
- Gender inequality
- Fluid friendships
- Social media
- Less control over disclosure
- Medication fatigue
- Lack of routine
Episodic medication adherence in adolescents and young adults with perinatally acquired HIV

Adapted from Hawkins A AIDS Care 2016;28,NO S1, 68-75

- AALPHI study in UK
- 29 young people with HIV, aged 14-22 years, 17 female
- Non-adherence significantly associated with:
  - Weekend days (Friday-Sunday)
  - Lack of routine
  - Being out of the home
- 11 had not disclosed to anyone
Factors associated with depression among adolescents living with HIV in Malawi

Adapted from Kim MH BMC Psychiatry 2015;15:264

- 562 ALWHIV 12-18 yrs 56.1% female

- Prevalence of depression was 18.9%
- Significantly associated with:
  - Female gender
  - Less schooling
  - Death in family/household
  - Failing a school term/class
  - Having a boyfriend/girlfriend
  - Non-disclosure
  - More severe immunosuppression
  - Bullied for taking medication
High self-reported non-adherence to antiretroviral therapy amongst adolescents living with HIV in Malawi: barriers and associated factors


- 519 ALWHIV (12-18 yrs) 56% female
- 30% missed ART doses in past week
- 45% in past month
- Reported barriers:
  - Forgetting 39%
  - Busy 11%
  - Depressed/overwhelmed 6%
  - Feeling stigmatized by people outside (5%) and within (3%) the home
Adherence & depression/disclosure in adolescents

• 89 Thai youth (14-16 yrs) *Kang Eint J STD AIDS 2015;26(8):534-41*
  – Negative association between depression and adherence

  – Stigma and discrimination by friends and family associated with non-adherence
  – Less disclosure associated with non-adherence
  – Depression strongly associated with non-adherence
Reduced adherence
Non-disclosure
Secrecy
Depression
Adolescent
Summary

• Stigma and discrimination towards PLWHIV remain highly prevalent
• Gender inequality issues are an added burden for women
• Disclosure remains one of the biggest challenges for women living with HIV
• Non-disclosure adds to the significant mental health burden associated with HIV
• Non-disclosure and depression impact on adherence
Potential solutions?

• Individual level
  – Peer support
  – Counselling/mental health support
  – Partner involvement
  – Adherence support

• Community level
  – Education
  – Public health campaign

• Health care setting
  – Education of health care professionals
Potential solutions?

• Medication
  – Simpler medication
  – Tolerable
  – High genetic barrier
  – Novel ways of delivery
    • Long –acting injectables
    • Implants

• Prevention

• CURE!!!!