HIV and Women: The wider perspective.

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Overview

- Women and HIV: a complex set of vulnerabilities
- The differing impact of HIV on women
- Women living with HIV: strengths and resources
- The rights of women: HIV as one of many inequalities
- Women’s leadership

Women are vulnerable to HIV

- Biological, social and cultural reasons
- Young women: infection rates double those of young men globally
- South Africa: 12% new HIV infections could be avoided if women not subject to sexual abuse
- Asia: 50m women at risk of HIV from intimate partners

Source: Women out loud UNAIDS 2012
Women’s vulnerability: Testing and diagnosis

18,000 people in the UK living with HIV are unaware of their infection
The proportion of people diagnosed late in the UK is far too high at 40%
Women who are NOT pregnant are more likely to be diagnosed late
Increasing numbers of new infections in older women

Public Health England: HIV report 2015:
http://www.aidsmap.com/Tales-of-the-late-diagnosed/page/2572026/
People living with HIV in the UK: 2014

Presumed Route of Acquisition

- MSM: 38,480 Diagnosed, 6,490 Undiagnosed
- Heterosexual: 42,880 Diagnosed, 11,160 Undiagnosed
- Women: 26,690 Diagnosed, 6,000 Undiagnosed

Continuum of care of adults living with HIV: United Kingdom, 2013

- HIV infected (n=107,000) 100%
- HIV diagnosed (n=80,900) 76%
- Retained in care (n=76,800) 72%
- On treatment (n=72,700) 68%
- Undetectable VL (VL<200, n=68,700) 64%

Data extracted from PHE: HIV in the UK: Situation Report 2015
What stops women testing?

- Fear of disclosure 1-3
- Stigma of a positive result 3-5
- Practicalities: Distance, Access, Entitlement 3,7
- Poverty 5
- Emotional and psychological factors 6
- No Provider Offer 8: Older women. Not pregnant


Helping Women to Test
Testing men

- Seroconversion in pregnancy and during breastfeeding is associated with vertical transmission.
- Repeat testing for women in “high risk” partnership
- Challenges of engaging men in antenatal settings
- Testing in ultrasound setting feasible and acceptable

Dhairyawan R et al. Sex Transm Infect 2012; 88 :184

Women with HIV are vulnerable

- In high and low income countries: studies link HIV with intimate partner violence

- Women living with HIV are at greater risk of poor mental health compared with men living with HIV

“HIV is not just affecting me but my two little boys… I can’t talk to them and explain what’s really happening to my life and that takes me straight to depression all the time”

Source: PositivelyUK 2013. States of Mind
Inequalities: Women and HIV

• The experience of living with HIV frequently cuts across many other inequalities experienced by women: economic, social, marginalised groups/behaviours

• In high-income countries, women living with HIV may frequently be from migrant populations, compounding other risks to wellbeing (fear of immigration status, job insecurity, isolation, being far from family and friends)

• A woman living with HIV may know her rights and how to report violations, but may not feel empowered to report/take action

Women with HIV : Impact of Treatment

• Virological control overall may be less good for women, with greater risk of viral rebound than men

• Time to virological suppression may be longer for women than men

• Women living with HIV tend to be more likely to discontinue and switch medication than men
A person centred approach

Care must vary depending on the unique needs and personal circumstances of each woman . . .

Family issues

Pregnancy

Stage of HIV journey

Violence or sexual abuse

Culture or religion

Age

Sexual issues

Medical history

Support

Immigration

Co-morbid problems (e.g. alcoholism, drug use, depression)

Language and understanding

Child-bearing potential

Acceptance of diagnosis

Socio-economic factors

Family life and reproductive decision making

• The impact of HIV on existing relationships and sex life
• Making new relationships
• Fertility, getting pregnant
• Managing sero – different relationships
• Contraceptive options for women with HIV
The power of peer support

- Women coming together to support one another
- Shared experiences, mutual respect, welcoming environments, improved understanding
- Evaluations: improves ability of women to make healthcare decisions, negotiate safer sex, feel more confident, report better health

Dr Alice Welbourn describing SHE programme of peer support

One Thousand Women

- Aim to develop a social movement to improve the mental and sexual health of Black, Asian and Minority Ethnic (BAME) Women
- Collaboration between The Afiya Trust and NAZ.
- Utilises social and professional networks of women to reach other BAME women
- Peer-to-peer network for learning and development of BME women to promote health and wellbeing and increase individual and community leadership
Faith and spirituality

- Faith as a major source of support
- Faith leaders may be unwilling to acknowledge HIV
- The role of prayer in healing and impact of use of ARVs
- Education programmes for church leaders

Talking About HIV

- Talking to other people with and about HIV is a beneficial process

BUT

- Women living with HIV are less likely to tell other people about their HIV than men
- Women may not tell health care providers about their HIV infection for fear of discrimination or refusal of care for their family as well as for themselves
The impact of stigma

- Women living with HIV say that fear of disclosing their status (to partners, to community, to healthcare providers, to employers) is a barrier to accessing HIV prevention and treatment.

- Women experience stigma in healthcare settings and fear lack of confidentiality.

- Stigma effectively silences the voices of women.

Fighting stigma: having a voice

“HIV is a virus. It is not a moral issue... It doesn’t define who I am. It’s got nothing to do with my personality, my values, my beliefs, the way I live my life. It’s a virus. So stop the stigma and stop moralising”

Source: [http://positivelyuk.org/wearepositive/](http://positivelyuk.org/wearepositive/)
Women, HIV and Language

- Words can inflict inadvertent damage
- Put people first
  - People living with HIV instead of HIV-infected or HIV-positive person
- Comprehensive prevention of vertical transmission instead of MTCT
- Avoid the word “infection” and its derivatives


The Power of Women with HIV

- Examples of empowerment through mentoring, peer support
- Successful leadership of organisations that advocate for the rights of women living with HIV
Meaningful Participation

The Greater Involvement of People Living with HIV (GIPA)

“Working together …..will enable us to create ‘services to fit people’ rather than ‘people to fit services’”

Eg BHIVA Guideline process

Women living with HIV: leaders

• Women account for half of all adults living with HIV

• Women living with HIV are already leaders: delivering HIV testing, treatment, care, advocacy, monitoring

• Their expertise helps to ensure that treatment and care respect women’s human rights

Source: Women out loud. UNAIDS 2012
The Future: Research, Women and HIV

Supporting Women with HIV Information Network. A UK & Ireland based network promoting research & collaboration to improve the lives of women living with HIV.

@SWIFT_women

Thank you

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Women living with HIV: leaders

- How can we ensure that this leadership and expertise is even more tightly embedded in guidelines, in policies? Women specific guidelines?

- Women living with HIV have to shape the services that are most relevant to them

- Finally, we need women leading more profound change: gender equality, sexual and reproductive rights, reducing stigma and discrimination

Rights: a cornerstone

Human rights can help “hold to account our governments, public and private healthcare services, our communities, employers, neighbours, faith groups, children’s schools and even our own partners and families”

Source: SHE Know Your Rights http://www.shetoshe.org/know-your-rights/
Activism: then and now

- Activism has changed since ART: ‘from protest to involvement’

- What does that look like: engagement with and partnerships between:
  - patients and their doctors
  - people living with HIV, and people writing guidelines for HIV care

- What have we lost? What have we gained?


Our work is not done. This week alone...

- Over 3600 children died this week from HIV
- Over 25,000 adults died this week from HIV
- Over 4,600 babies were infected with HIV
- Over 36,500 adults were infected, of which more than 7000 were young women

Birx D: Presentation at IAPAC conference London 2014
Fighting stigma: having a voice

“What can we do, as people living with HIV to end stigma? I believe that one of the most powerful tools we have is to talk about HIV. We cannot expect HIV stigma to just disappear...change happens when those who are directly affected. Stand up and demand to be treated with respect and dignity”

Silvia Petretti advocate for rights of people living with HIV

Supporting and leading

- Examples of empowerment through mentoring, peer support

- Successful leadership of organisations that advocate for the rights of women living with HIV
Prevention of Infant HIV Infection: Aiming for zero transmission

A multidisciplinary conference for obstetricians, gynaecologists, HIV physicians and allied healthcare professionals

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