



HIV Status Disclosure to Sexual Partners: Rates, Barriers and Outcomes for Women



This information sheet summarizes some of the key findings of a new WHO document *Gender Dimensions of HIV Status Disclosure to Sexual Partners: Rates, Barriers and Outcomes*. It synthesizes current information available on HIV status disclosure to sexual partners in terms of rates, barriers, and outcomes among women. The full paper also addresses research gaps, and programmatic and policy strategies that have been adopted to overcome these barriers and support individuals through the disclosure process.

1. Background

The prevention and control of HIV infection depends on the success of strategies to prevent new infections and treat currently infected individuals. HIV testing and counselling serves as both a critical prevention and treatment tool in the control of the HIV epidemic. Within HIV testing and counselling programmes, emphasis is placed on the importance of HIV status disclosure among HIV-infected clients, particularly to their sexual partners.

Disclosure is an important public health goal for a number of different reasons. First, disclosure may motivate sexual partners to seek testing, change behaviour and ultimately decrease transmission of HIV. In addition, disclosure has a number of potential benefits for the individual including increased opportunities for social support, improved access to necessary medical care including antiretroviral treatment, increased opportunities to discuss and implement HIV risk reduction with partners, and increased opportunities to plan for the future.

Along with these benefits, however, HIV status disclosure to sexual partners has a number of potential risks for the individual including loss of economic support, blame, abandonment, physical and emotional abuse, discrimination, and disruption of family relationships.

2. Methods

All published abstracts and journal articles from January 1990 to December 2001 identified through a search of five medical and social science electronic databases: PubMed, the National Library of Medicine's (NLM) Gateway database, Psych INFO, LILACS, and Sociologic Abstracts were reviewed. Four HIV-related journals (AIDS Care, AIDS, AIDS and Behavior, and AIDS Education and Prevention) were targeted and the relevant articles found were searched for any additional references. The terms used during the computer-based searches include HIV testing and counselling and disclosure, HIV VCT and disclosure, and HIV serostatus and disclosure.

To have been eligible for review, the article must have included data on the rates, barriers or outcomes of HIV serostatus disclosure. Several of the authors were contacted personally to clarify some of the findings and provide updates on current research. Sixty-nine articles were reviewed for the overall paper of which 41 focused on women. Of these, 22 articles were from the USA and 19 from developing countries (17 from sub-Saharan Africa and two from Southeast Asia).



To read the full report of this summary, go to <http://www.who.int/gender/documents/en/>

3. Key findings

3.1 Rates of HIV status disclosure

Among studies in the developed world, rates of HIV status disclosure to sexual partners ranged between 42% to 100%, depending in large part on the type of partner to whom the person disclosed. The lowest rates of disclosure were reported among past partners or current casual partners.

The rates of disclosure in studies from developing countries were notably lower than rates reported from the developed world. The rates ranged from 16.7% to 86%. Among the studies that reported disclosure rates to current and/or steady partners the average rate of disclosure was 49%, considerably less than the average rate reported from studies conducted in developed countries (79%). The lowest rates were among pregnant women tested in antenatal care (ANC) in sub-Saharan Africa (16.7%-32%). In addition, larger proportions of studies from developing countries reported women that did not share their HIV test results with anyone (10%-78%) as compared to women in developed country studies (3%-10%).

Studies from both developed and developing country settings found that disclosure rates to sexual partners tend to increase over time. Results from both settings also found discrepancies between intention to disclose and actual disclosure behaviour, with actual disclosure rates lower than intended disclosure rates.

3.2 Barriers to HIV status disclosure

The most common barriers to disclosure that were mentioned included:

- fear of abandonment, closely tied to fear of loss of economic support from partners,
- fear of rejection/discrimination,
- fear of violence,
- fear of upsetting family members, and
- fear of accusations of infidelity.

Factors that motivated people to disclose to partners, family and friends included:

- sense of ethical responsibility/concern for partner's health, failing health/severity of illness, and
- need for social support to cope with diagnosis

to alleviate the stress associated with non-disclosure, and to facilitate HIV-preventive behaviour.

Implications of findings

- ✓ **More research is needed to identify disclosure factors so counselling tools can be developed to identify individuals least likely to disclose and counsel them accordingly.**
- ✓ **Multiple opportunities for disclosure counselling are important to provide ongoing support throughout the disclosure process.**
- ✓ **Counselling strategies need to be gender-specific and culturally appropriate to the target audience.**
- ✓ **Counsellors should not use intention to disclose as a predictor of future disclosure behaviour.**

3.3 Outcomes of HIV status disclosure

In most studies from both developing and developed country settings, HIV status disclosure to sexual partners was associated with positive outcomes including increased social support, acceptance, kindness, decreased anxiety and depression, and strengthening of relationships.

While fear of negative outcomes was a major reported barrier to HIV status disclosure, most individuals who choose to disclose reported experiencing positive social outcomes as a result of disclosure including support and understanding from partners.

Negative outcomes included blame, abandonment, anger, violence, stigma, and depression and were less commonly reported among those who disclose than positive outcomes. However, it is important to note that those who choose not to disclose may well be those who are most likely to have negative outcomes.

In studies that looked at violence as an outcome of HIV status disclosure for women who chose to disclose, violent outcomes were reported more often by women in sub-Saharan Africa (3.5% to 14.6%), than by women in USA studies (0.4%-4%). The highest rates of disclosure-related violence were reported among women in ANC. HIV-infected women in sero-discordant couples were the most likely to experience violence as a result of disclosure.

4. Research needed

There is a need to carry out further research to:

- a) improve our understanding of the issues related to uptake, barriers and outcomes of HIV testing and counselling, and
- b) to develop and test different models for optimizing the use of voluntary testing and counselling in a way that ensures that people, particularly women, are not put at risk.

This involves exploring ways in which to address issues of disclosure and identifying those women who may be at risk of partner violence.

4.1 Research to understand better the barriers and outcomes of HIV status disclosure to sexual partners

More research is needed to answer a number of outstanding questions including:

- Information from regions outside the USA and sub-Saharan Africa to understand variations in rates, barriers and outcomes across different cultural settings.
- Information to understand the implications of disclosure and support required when testing and counselling is undertaken in different circumstances (e.g. ANC, Voluntary Testing and Counselling (VCT) clinics, Sexually Transmitted Infections (STIs) clinics).
- Issues of disclosure among youth/adolescents.
- Issues of disclosure among injection drug-using partnerships.
- Research that broadens the definition/scope of disclosure to understand the long-term implications of disclosure on relationships and to understand how access to various treatment and care options becoming more widely available contribute to perceived motivations for HIV testing and counselling and disclosure.
- To describe the process and length of time that people require to disclose results to sexual partners.

4.2 Research to guide programmatic approaches and responses

Interventions research is needed to:

- Help guide programmes on the most effective ways of involving men in HIV testing and counselling programmes for women/most effective ways of promoting couples' counselling.
- Develop more effective 'screening' tools that counsellors can use to identify women least likely to disclose and most likely to experience negative outcomes as a result of disclosure.
- Understand a feasible scope of responsibilities for HIV testing and counselling programmes, in settings where referral services for women in violent relationships are not available.
- Determine whether broader-based initiatives such as community-based stigma reduction interventions have an impact on uptake of HIV testing and disclosure rates.
- Document how HIV/AIDS support groups are currently dealing with disclosure to gain insights for how to strengthen and expand such initiatives.
- Test possible models for incorporating interventions to address violence against women within HIV testing and counselling settings.

Implications of findings

- ✓ **Promoting couple counselling may help women to overcome the barriers that they face to seeking VCT services.**
- ✓ **Community-based programmes are needed to reduce stigma associated with HIV.**
- ✓ **Behaviour rehearsal techniques in HIV testing and counselling programmes can assist women to develop the skills they need to disclose results to sexual partners.**
- ✓ **Social support, for example, through support groups or ongoing counselling, may help HIV-infected individuals to overcome the barriers to disclosure.**

5. Policy and Programmatic Recommendations

There is a range of different programme and policy approaches that have been recommended to increase HIV status disclosure rates and support individuals through the disclosure process. These recommended approaches can be organized into four general areas which are summarized below.

5.1 Identification and referral for intimate partner violence in HIV testing and counselling

HIV testing and counselling provides a useful setting for discussing barriers to HIV status disclosure that individual clients may perceive. If women disclose they are experiencing violence or mention the fear of violence during the post-test counselling session as a reason that they are afraid to disclose their HIV status to their partners, HIV counsellors should:

- a) address this when discussing disclosure, and
- b) be prepared to refer these women to domestic violence services in communities where they are available.

A group in the USA is developing a study to evaluate the effectiveness of using peer advocates in the HIV testing and counselling process to identify women who are in abusive relationships, inform them of the potential risk for escalating violence, counsel them in ways to protect themselves and refer them to other domestic violence services¹.

5.2 Cross-training HIV and domestic violence staff

Cross-training HIV and domestic violence staff in the dynamics of the two epidemics may be an effective strategy to sensitize providers who are in direct contact with women who are affected by both epidemics.

This cross-training could involve providing VCT staff information on the dynamics of domestic violence that may ultimately help them to identify and refer women who are living in violent relationships, thereby diminishing the risk of negative outcomes of HIV status disclosure. For example, a programme in South Africa² provided nurses with a one week training programme on VCT that included a discussion on domestic violence. Because referral services for domestic violence were not available, the training emphasized providing a non-judgemental and supportive approach to women in abusive relationships, and allowing women themselves to make decisions regarding the

safety and feasibility of disclosing to partners.

5.3 HIV counselling approaches

HIV counsellors can strengthen communication skills and increase perceived self-efficacy for disclosure through the use of role-plays, scenarios and other behavioural rehearsal techniques. The development of support groups for infected women provides another avenue for ongoing support that may help women work through their disclosure processes. In addition, a mediated form of disclosure, in which either the counsellor mediates the disclosure between couples in the clinic or the client identifies a trusted family member or friend to mediate the disclosure process in the home, offers a potentially effective and culturally sensitive approach to supporting women.

Finally, encouraging couples to undergo HIV testing and counselling together may help to bypass many of the barriers associated with disclosure and may also facilitate sustained behaviour change among couples.

5.4 Community-based initiatives to empower women and minimize HIV-related stigma

Recognizing that some of the barriers women face in sharing HIV test results with their partners have their roots in underlying gender norms and social attitudes about HIV/AIDS, there have been calls for initiatives to address these broader issues.

Women's empowerment programmes are an example of an intervention that tries to shift gender norms and ultimately facilitate HIV status disclosure to sexual partners. Community-based programmes to reduce stigma associated with HIV/AIDS is another approach that has been suggested in order to encourage HIV testing and facilitate HIV status disclosure.

Community-based programmes that seek to change gender norms and improve communication between partners and spouses, such as *Stepping Stones*³ could also lead to an increase in disclosure and better outcomes for women and families.

¹ Gielen AC, personal communication, 27 February 2002.

² RADAR (Rural AIDS and Development Action Research Programme). <http://www.witz.ac.za/radar/Home.htm>

³ *Stepping Stones* is a participatory training programme which aims to prevent HIV infection by empowering participants to increase control over their sexual and emotional relationships particularly by challenging gender norms. It was developed by the *Strategies for Hope* project. <http://www.statshope.org>

