

Gender Dimensions of HIV Status Disclosure to Sexual Partners:

Rates Barriers and Outcomes



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World Health Organization

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A Review Paper

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I. Introduction

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 a critical prevention and treatment tool in the control of the HIV epidemic. Voluntary HIV testing and counselling (VCT) can effectively reduce risk behaviours among individuals at risk for HIV (1). HIV testing and counselling is also a critical component of prevention strategies to reduce transmission of HIV from mother to child (2-4). Unless pregnant women are willing to be tested and counselled for HIV, the encouraging advances made in the use of drugs to reduce perinatal transmission will be meaningless. HIV testing and counselling also offers the opportunity to identify HIV-infected individuals and channel them into treatment programmes. Through the early identification of the infection, its management can be substantially improved (5,6) .

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 may facilitate other health behaviours that may improve the management of HIV. For example, women who disclose their status to partners may be more likely to participate in programmes for prevention of HIV transmission from mothers to their infants. Through disclosure of her status, a woman may receive support from her family or others in her social network and may also be able to access available support services. By adequately addressing the emotional, social, and practical sequelae of her positive status she may be more willing to adopt and maintain health behaviours such as cessation of breastfeeding or adherence to treatment regimens.

It has now been recognized, however, that there are a number of barriers that HIV-infected individuals face when sharing their test results with friends, family and, most importantly, sexual partners. There is considerable interest in finding strategies to encourage disclosure because of the public health benefits that may accrue from the disclosure of HIV status. The purpose of this review paper is

to synthesize the current information available on HIV status disclosure in terms of the rates, barriers and outcomes of HIV status disclosure among HIV-infected individuals. Particular emphasis is placed on women's experiences with disclosure to sexual partners. Through a comprehensive review of the literature and a solicitation of experiences and input from researchers and practitioners in the field, the report aims to identify the major barriers and describe programmatic and policy strategies that have been adopted to address these barriers and support women through the disclosure process. The report ends with a section on recommendations for ways to move forward to increase disclosure rates and the support available to women who would like to disclose their HIV status to their sexual partners safely.

Methodology: This document is based on a review of all published abstracts and journal articles from January 1990 to December 2001 identified through a comprehensive search of five medical and social science electronic databases including: PubMed, the National Library of Medicine's (NLM) Gateway database, Psych INFO, LILACS, and Sociologic Abstracts. The four HIV related journals: *AIDS Care*, *AIDS*, *AIDS and Behavior*, and *AIDS Education and Prevention* were also searched by hand. Any article that qualified during these searches was then retrieved from the library and the bibliography 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. The reviewers also contacted several of the authors personally to clarify some of the findings and to update ourselves on current research. The 69 articles reviewed in this paper include 25 articles from sub-Saharan Africa, 40 articles from the United States of America (USA), three articles from Southeast Asia, and two articles from Western Europe. The articles varied greatly in terms of their sample size, study design, and methods of data collection. In addition, these studies targeted a wide variety of populations including pregnant women, men who have sex with men, health care providers, injecting drug users, and STD clinic attendees.

II. Background

1. Benefits of HIV status disclosure to sexual partners

In addition to the public health benefits of disclosure that include expanded awareness of risk that may lead to decreased sexual risk-taking and ultimately decreased transmission of HIV, there are also potential benefits to the individual who chooses to share results with his/her sexual partners.

Disclosure of HIV status to sexual partners may lead to:

- ◆ Increased opportunities for instrumental and expressive social support
- ◆ Improved access to necessary medical treatment and care
- ◆ Increased opportunities to discuss and implement HIV risk reduction with partners
- ◆ Increased opportunities to plan for the future carefully and thoughtfully

2. Risks of HIV status disclosure to sexual partners

The individual benefits that women may receive from sharing HIV test results with their partners need to be balanced against the potential risks that an individual woman may face if she discloses. The potential risks of HIV status disclosure to sexual partners include:

- ◆ Loss of economic support
- ◆ Blame
- ◆ Abandonment
- ◆ Physical and emotional abuse
- ◆ Discrimination
- ◆ Disruption of family relationships

Another potential risk of disclosure is the possibility that children may face violence or abandonment as a result of their parent's disclosure of their positive status whether or not the children are also HIV-positive.

3. The process of HIV status disclosure

Most studies that have examined HIV status disclosure describe the outcome rather than the process of disclosure. Kimberly (7) has developed a useful framework to describe the decision-making process for disclosure. The framework outlines a six-step process that includes dilemmas, barriers and decisions at each step.

- ◆ The first step is adjustment to the diagnosis. At this stage in the disclosure process, individuals may need help adjusting to their diagnosis and reaching a level of personal acceptance.
- ◆ The second step involves an evaluation of personal disclosure skills. Individuals need to evaluate whether they possess the skills necessary for telling others.
- ◆ The third step involves evaluating the appropriateness of disclosing to a potential recipient. This process involves taking inventory of one's social network and deciding on an individual basis who should be told, taking into account certain criteria such as role and physical distance from that recipient.
- ◆ The fourth step is evaluating the circumstances for disclosure. There may be certain circumstances that prohibit disclosure to certain individuals.
- ◆ The fifth step in the process involves anticipating the reactions of the potential recipients. Individuals need to weigh these anticipated reactions against the anticipated benefits of disclosure to each individual.
- ◆ Finally –the sixth step– individuals identify their motivation for disclosure to each recipient.

By expanding our definition of disclosure from the outcome to the process, we can acknowledge and appreciate the numerous factors that influence the decision to disclose, including individual psychological state, personal communication skills and communication patterns, anticipated reactions and individual motivations for disclosure. We can also think of multiple levels of interventions to help support individuals through the process.

Summary of findings

- ✓ **Rates of disclosure to sexual partners are higher among women in the developed world (average 71%; range: 42%-100%) compared to women in the developing world (average 52%; range: 16%-86%).**
- ✓ **Disclosure rates to sexual partners increase over time.**
- ✓ **There are cultural factors that influence the patterns of self-disclosure to sexual partners and other social network members.**
- ✓ **Women often disclose to multiple categories of people.**
- ✓ **There is a core group of people who choose not to disclose HIV test results to anyone (3%-10% in the USA and 10%-78% in developing countries).**
- ✓ **There is a disparity between intention to disclose and actual disclosure.**

When directly comparing rates of disclosure across different studies one must be aware of how disclosure was defined and measured. The majority of studies on HIV status disclosure have measured disclosure as a dichotomous variable (disclosed/did not disclose to specified targets). Other studies however, have measured disclosure in terms of number of people to whom the individual disclosed or per cent of the total social network members to whom the individual disclosed.

There is also considerable variation across different studies in the timing of disclosure measurement. Some studies measured HIV status disclosure shortly after diagnosis (8-12) while others did so at defined periods after diagnosis but generally within two years (13-17) and finally, some studies measured disclosure among HIV-infected individuals who had known about their HIV status for more than two years (18-20). Among the studies that considered disclosure at more than one time period following diagnosis, authors reported a substantial increase, in some cases a doubling, of disclosure rates over time. Therefore, when comparing the rates of disclosure across studies there is a need to take into account the time frame since diagnosis.

Finally, there was variation in the targets of disclosure among the studies. The majority of studies report on HIV status disclosure to sexual partners. However, some studied disclosure only to steady or primary partners including spouses, while others reported on disclosure to the last sexual partner, and still others reported on disclosure to multiple categories of partners. Many studies also reported on HIV status disclosure to friends and families and a smaller number of studies reported on disclosure to others including health care providers, neighbours, bosses, and co-workers. For the purpose of this report we have focused on disclosure rates to sexual partners and, whenever possible, we identify how 'sexual partner' is defined within each study.

1. Studies from the developed world

Among the fifteen studies based in the United States of America (USA) that report HIV status disclosure rates to sexual partners, six reported on samples of women only, three reported disclosure rates among homosexual men and the remaining six studies included both men and women in their sample. Fourteen of the fifteen studies recruited their participants from clinic-based settings. All fifteen reported disclosure rates to sexual partners and some studies included multiple categories of sexual partners such as current, past, casual and steady partners. The period of time that lapsed between diagnosis and assessment of disclosure ranged from two months to 13 years. There was also one study from France that looked at HIV status disclosure to sexual partners among HIV-positive patients attending treatment services at an HIV clinic in Paris, France.

The disclosure rates to sexual partners were quite high, ranging between 42% to 100%, depending in large part on the type of sexual partner to whom the person disclosed. The lowest rates of disclosure were reported among past partners or current casual partners. Among the studies that reported disclosure rates to current and/or steady sexual partners the average rate of disclosure was 79%. There was variation in rates of HIV status disclosure to sexual partners among different ethnic groups in the USA and in France. Armistead (19) reported a relatively lower percentage of women who disclosed to partners (56%) as compared to women from a study by Simoni (87%) and men from a study by Hays (98%). In a study among ethnically diverse HIV-infected women, Simoni (21) found that Spanish-speaking Latinas reported lower rates of disclosure than English-speaking Latinas, African-

Americans and Anglo-Americans. In a study from France, Bungener (22) found a similar trend with 69% of HIV-infected women of European descent informing at least one member of their family of their status as compared to only 38% of women of African descent ($p=.0003$). This suggests that there may be important cultural factors that impact the patterns of self-disclosure to sexual partners.

In general, women disclosed to multiple categories of people. Gielen (23), for example, reports that 82% of the women she studied shared results with multiple categories of individuals. However, there was considerable variation among the USA studies in the patterns of disclosure to social network members in addition to the sexual partner. Armistead (19) found that among the African-American women interviewed in her study, the highest rates of disclosure were reported to mothers, as compared to studies by Simoni (21) and Hays (24) in which they reported that disclosure rates to non-family members were higher. Similarly, among the women of Latin origin studied by Comer (2000) the highest rates of disclosure were reported among family (55%) and friends (25%). A study by Lee (25) was the only study to report disclosure of HIV status among HIV-infected youth. The authors found that 87% of the 350 youth enrolled in the study disclosed to at least one family member. Among the young men 93% reported that they disclosed to friends as compared to 79% of the young women. Among the young women with three or fewer partners since the time of diagnosis 63% informed all partners of results as compared to only 9% of the young women who reported four or more partners.

Few studies assessed the length of time from diagnosis to disclosure. Levy (26) found that among the patients from an outpatient clinic in Paris, France, less than half (42.5%) disclosed to their partner immediately after diagnosis, 21% disclosed within one month of diagnosis and 24% waited more than one year to disclose. Women tended to share results with their sexual partners immediately after diagnosis more often than men (53% vs. 32.5%, $p=.003$).

Across studies there remained percentages of individuals who reportedly did not share their HIV test results with anyone since the time of their diagnosis. Gielen (23) reports 3%, Kilmarx (27) reports 11%, Simoni (28) 10% and Lester (29) reports that 67% of individuals in his sample had not disclosed to any friend and 25% had not disclosed to any family member.

2. Studies from the developing world

Studies of HIV status disclosure rates to sexual partners from the developing world include 11 studies from sub-Saharan Africa (one from Burkina Faso, two from Kenya, three from Rwanda, and five from the United Republic of Tanzania), and one reporting disclosure rates from a multi-country study in Kenya, Tobago, and the United Republic of Tanzania. There were no published studies from other regions of the developing world that reported rates of HIV status disclosure to sexual partners. Six of the studies reported rates of disclosure among women who were enrolled in HIV perinatal transmission trials and the remaining three studies reported rates of disclosure among other clinic-based populations. The assessment period for disclosure ranged from two weeks to almost four years.

The rates of disclosure among the studies from the developing world 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 the developed world (79%).

The patterns of disclosure to social network members in addition to the sexual partner varied. The study from the United Republic of Tanzania by MacNeil (10) reported that six months after diagnosis, individuals were most likely to share results with their parents (49.4%), followed by spouses (24.7%) and then sexual partners (18.8%). From another study in the United Republic of Tanzania, Lie (30) also found that HIV-positive individuals primarily chose an individual of the same sex and same generation with whom to share results. Kilewo (16), however, reports lower disclosure rates to family members (5.6%) as compared to partners (16.7%) among women enrolled in an HIV perinatal transmission trial.

Only a few of the studies reported on disclosure rates at multiple assessment points. The study from the United Republic of Tanzania by Antelman (15) found that disclosure to sexual partners increased from 22% within two months of diagnosis to 41% after nearly four years. MacNeil (10) reports that disclosure rates to sexual partners increased from 5.8% at baseline to 18.8% six months after diagno-

sis. Van der Straten (17) reports that 77% of the HIV-positive women they followed shared results with partners within one year of diagnosis and this percentage increased to 79% among women followed two years after diagnosis.

Intention to disclose HIV test results was measured in *lieu of* or in addition to actual disclosure rates in a few studies. There are discrepancies between intention and actual disclosure behaviour.

However, due to the small number of studies that have assessed both, it is difficult to describe any clear pattern between the two. Among pregnant women in Rwanda, Ladner (8) found that during pretest counselling 50.9% of women said they planned to tell their partners their HIV test results. Among the women who returned for the post-test counselling 84.9% reported that they shared results with their partner. It is possible that the women who were least likely to disclose did not return for their results and therefore the rates of disclosure are among those women who were most motivated to disclose in the first place. In another study among childbearing women in Kinshasa Heyward (31) found that 47% of the HIV-infected women said they intended to tell their partners of their results. The investigators did not measure disclosure rates; however, they did note that only 2.2% of the women brought their partner back to the clinic for testing. Rakwar (32) reported that 90% of the women that they talked with in an STD clinic said they would tell their partners their results if they were HIV-infected. The investigators in this study did not measure actual disclosure rates.

A large proportion of individuals from the developing world studies reported that they did not share their HIV test results with anyone as compared to the developed world studies. 10% of women from Thailand had not shared results with anyone (33). Similarly, 17% of HIV+ women from a VCT clinic in the United Republic of Tanzania (34), 50% of HIV+ women from rural South Africa (35), 16% of participants from rural Tanzania (36) and 77.8% of the HIV+ pregnant women from urban Tanzania (16) had not shared results with anyone.

Most of the studies that were reviewed are based in clinic settings and therefore may not be representative of all situations in which VCT is provided. Therefore, we cannot necessarily generalize these findings to other environments in which VCT may be provided.

Implications of findings

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

Summary of findings

- ✓ **The most common barriers to disclosure included fear of abandonment, fear of rejection/discrimination, fear of violence, and fear of upsetting family members.**
- ✓ **Length of time since diagnosis and severity of illness were positively associated with disclosure.**
- ✓ **Factors that motivated people to disclose to partners, family and friends included a sense of ethical responsibility, failing health, social support, minimizing stress associated with non-disclosure, and disclosure as a way to facilitate HIV preventive behaviour.**

Among the studies that described barriers to HIV status disclosure there were two different ways that the barriers were assessed. Either study participants were asked directly about the perceived barriers to disclosure or, through multivariate analysis, the investigators identified the correlates associated with disclosure and non-disclosure of HIV test results. Barriers were primarily described for disclosure to sexual partners and, to a lesser degree, disclosure to other categories of recipients including family, friends, and others. The most common barriers to disclosure that were mentioned by participants included fear of abandonment, fear of rejection/discrimination, fear of violence, fear of upsetting family members and fear of accusations of infidelity. The factors associated with disclosure that were assessed through multivariate analysis included ethnicity, severity of disease, age and education. When exploring the barriers to disclosure that are reported in different studies it is important to keep in mind the context in which the participants were offered HIV testing. It is likely that the barriers that individuals face when deciding to share their results with their partner will vary depending on the circumstances under which they were tested. For example, barriers to disclosure will be different for women who were tested in an antenatal care context as compared to women in HIV VCT clinics. Maman (37) describes the extensive decision-making process that women who present to VCT clinics have gone through to get tested. The women at VCT clinics are generally motivated to test by their high perception of risk for HIV, they have often thought about testing for a long period of time prior to being tested and many have talked with their partner about HIV risk and HIV testing

prior to being tested. In contrast, it may reasonably be assumed that women from antenatal clinics have generally not thought about HIV testing prior to being offered the opportunity as part of their antenatal care, and as such most of these women have not talked with their partner prior to deciding whether to test. Therefore, the barriers that these women face when deciding whether or not to share results with their sexual partners may be more extensive.

1. Fear of abandonment

Fear of abandonment was the major barrier that was mentioned most often by participants from studies both in the developed and developing world. For studies among women, particularly in developing countries, fear of abandonment was closely tied to fear of loss of economic support from a partner. Thirteen of the 14 studies conducted in developing countries with women reported that fear of abandonment and loss of economic support were major barriers to disclosing HIV status to sexual partners. In these settings where resources are extremely scarce and women's access to resources independent of their partner is uncommon, it is not surprising that fear of losing instrumental support from a partner is a major consideration when deciding whether to share results or not. The absence of social security and health insurance in most African countries also make women dependent on their partner and family for their health care, therefore women may choose not to disclose their HIV status in order to benefit from family support. However, a study by Antelman et al. (15) conducted in the United Republic of Tanzania did not support the hypothesis that women who are more economically dependent on their partner are less likely to disclose. They found that women of lower socioeconomic status (SES) were more likely to disclose. Their study population was of low SES, so it is possible that they were unable to detect an association that actually exists between SES and disclosure due to lack of variability.

2. Fear of rejection/discrimination

In addition to fearing abandonment and loss of economic support, several studies found that fear of social isolation and discrimination was another important barrier to disclosure of HIV status. Study participants feared discrimination and social isolation from family members and from the wider public. Fear of discrimination can be further defined as fear of social discrimination leading to social isolation and lack of support and fear of socioeconomic discrimination which may lead to problems with

jobs, housing, insurance and other practical socioeconomic considerations. In a study among HIV-infected women in the USA by Moneyham et al. (38) the authors found that concerns of discrimination were a major barrier to disclosure, particularly in situations where disclosure involved people that participants felt had power over some aspect of their lives such as work or needed resources. The concern regarding socioeconomic discrimination was mentioned more often in studies conducted in the developed world than in those from the developing world. Participants from studies in the developed world mentioned concern over social discrimination more often than they described fears of socioeconomic discrimination. Fear of loss of confidentiality was closely tied to fear of discrimination in all studies. The loss of confidentiality represented potential exposure to discrimination.

3. Fear of violence

Fear of violence was mentioned by women as a barrier to disclosure in about one quarter of all studies. Some studies specifically probed for fear of violence as a barrier to disclosure, and in others fear of conflict and violence was spontaneously mentioned by women. Fear of violence was mentioned less often as a barrier to disclosure in developed world studies compared to studies from the developing world. Gielen (23) found that 12% of the HIV-infected women included in her study in Baltimore, USA, reported fear of violence as a barrier to disclosure. From developing countries, 16% of the women studied by Kilewo (16) in the United Republic of Tanzania, 19% of the women studied by Farquhar in Kenya (39) and 51% of the women studied by Rakwar in Kenya (32) indicated that fear of violence was a major barrier to sharing HIV test results. In a study among pregnant women in Burkina Faso, Nebie (40) reported that fear of domestic violence was the only identifiable reason why women chose not to share test results with their partner.

4. Fear of upsetting family members

Concern for others was a barrier that was mentioned in several studies. The two studies from the USA that involved Asian/Pacific Islander Americans found that fear of upsetting and shaming family was the major barrier to disclosure (41, 42). Yoshioka (41) found that among HIV-infected men there were three major barriers to disclosure of HIV status to family members including:

1. protection of family from shame
2. protection of family from obligation to help
3. avoidance of communication about highly personal information

Chin (42) found that fear of burdening or disappointing others was a major barrier among the Asian/Pacific Islander women that she studied. In the study from Thailand by Bennetts (33) three quarters of the women (77%) felt that HIV was a disease of which their family would be ashamed.

Lack of disclosure and shame were both associated with high levels of worry about HIV. All three studies describe cultural attributes of Asian communities that explain why shaming and disappointing family is a major concern for HIV-infected individuals. From the United Republic of Tanzania, 17% of the HIV-infected pregnant women studied by Antelman (15) reported that their reason for non-disclosure was the desire to avoid upsetting others.

5. Severity of illness

Severity of disease was associated with disclosure to partners, family and friends. As symptoms of the disease become more pronounced, HIV-infected individuals are more likely to share results with others. Armistead (19) found that among African-American women, the stage of disease was predictive of disclosure to fathers and friends, but not to sexual partners. Other studies have found a direct relationship between severity of the disease and disclosure. Among men of Latin-American origin, Mason (43) found that severity of disease was an independent predictor of disclosure to partners. Jeffe (44) found a direct relationship between severity of disease and disclosure to medical providers. Mansergh (45) also found that disclosure was lower among asymptomatic men than symptomatic men.

6. Motivators for disclosure

To counterbalance the barriers some studies also reported on the factors that motivated individuals to disclose to their partners and to other members of their social network. The reasons for disclosing differed depending on the individual to whom the person was disclosing. Simoni (21) found that ethical responsibility and concern for partner's health was the major reason cited for disclosing to sexual partners, whereas seeking social support was the primary reason for disclosure to friends and family.

Increasing social support was also mentioned as a major reason for disclosure to partners, family, friends and medical providers in the study by MacNeil (10).

In addition to the social factors that may play a role in motivating individuals to disclose, a couple of studies also reported on the role that counselling may play in facilitating disclosure. De Rosa (11) found that rates of disclosure increased with the number of times that a health professional discussed issues of disclosure at the HIV clinic where they received care. Men who were counselled both at post-test counselling and at their current HIV clinic were nearly twice as likely to have disclosed to all sexual partners than men not counselled at both sites. In a qualitative study conducted at a voluntary counselling and testing clinic in the United Republic of Tanzania, Maman (36) found that men and women mentioned the important role that counsellors played in their decision to disclose.

Implications of findings

- ✓ **Efforts to promote couple counselling may help women to overcome the barriers that they face to seeking voluntary testing and counselling services.**
- ✓ **Community-based programmes are needed to reduce stigma associated with HIV.**
- ✓ **Behaviour rehearsal techniques in HIV testing and counselling programmes can assist women 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.**

A small number of papers were reviewed that describe barriers to HIV testing. There were five studies from the USA (46-50), three studies from sub-Saharan Africa (51-53) and one review paper (54). All but one of the studies (51) discuss barriers to HIV testing among pregnant women. The study by Nyblade is the only one to assess the barriers to HIV testing among a community-based sample of individuals, some of whom had been tested for HIV and others who had not. Most of the studies report both the rates and barriers of accepting HIV testing and returning for HIV test results. Among pregnant women from the USA, the most common barrier to accepting HIV testing was lack of perceived need for the test and fear of potential negative outcomes from testing and disclosure including stigmatization and discrimination. In the African studies, the acceptance of HIV testing was high; however, the return rate for results was significantly lower. In his review paper Cartoux (54) found that the median acceptability for VCT by pregnant women in developing countries was 95% (range 53%-99%). The return rates varied widely between sites (median 82%, range 33%-100%). In Nyblade's study (51) of community-based acceptability of HIV/VCT the factors associated with VCT participation were older age, positive HIV status and having sexual partners in the past five years. Lack of health care for HIV-positive persons is a disincentive to seek VCT as is the fear of stigma and discrimination.

Cartoux (52) specifically explored the impact of group versus individual pretest counselling on acceptability of HIV testing and return for results. His review found that the rates of returning for results were not related to the type of pretest counselling that was provided. They therefore argued for group pretest counselling in which the standard HIV pretest counselling session would be administered to a group as opposed to an individual, in resource-constrained settings. In contrast, Sorin (49), in a study conducted in the USA, found that for every five minute increase in the length of individual counselling the rate of acceptance for HIV testing more than doubled.

Summary of findings

- ✓ **Positive outcomes of HIV status disclosure to sexual partners were common.**
- ✓ **Positive outcomes included increased support, acceptance and kindness, decreased anxiety and strengthening of relationships.**
- ✓ **While fear of negative outcomes is a major barrier to HIV status disclosure the actual rate of reported negative outcomes affected a relatively small proportion of those who disclosed.**
- ✓ **Negative outcomes reported included blame, abandonment, anger, violence, stigma and depression.**
- ✓ **The reports of violence following disclosure were more common in studies conducted in the developing world.**
- ✓ **Women who reported violence as a result of disclosure in the USA tended to be low socioeconomic status (SES) women of colour with a history of violence in their relationships.**
- ✓ **HIV-infected women with a sero-discordant sexual partner may be at increased risk for violence following disclosure.**
- ✓ **Disclosure can lead to increased HIV preventive behaviours including condom use.**

1. Positive outcomes of disclosure

Most studies both in developing and developed countries reported that positive outcomes were common following disclosure. Of the 20 studies focused exclusively on women, 18 reported that the majority of women mentioned at least one positive outcome from disclosure. Positive outcomes reported by women included increased support, acceptance, and kindness. Disclosure was associated with less anxiety, fewer symptoms of depression, and increased social support (reported in 10 of 27 studies). Three studies also mentioned that disclosure caused the respondents to feel closer to their friends and family members or others in their social network. An important finding from both devel-

oped and developing country studies is that disclosure was not associated with the break-up of long-term relationships. In fact, six studies that reported on the effects of disclosure on marriage showed that most marriages survive disclosure.

2. Negative outcomes of disclosure

Of the 31 studies reporting on outcomes of disclosure, 26 mention negative outcomes. For the most part, these negative outcomes affected a small percentage of respondents. Negative outcomes included blame, abandonment, anger, violence, stigma, and depression. Two studies (13, 55) showed that unmarried sexual partners were the most likely to suffer a break-up in the relationship following disclosure. In the USA, studies by Gielen (56), Rothenberg (57), and Lester (29) showed that African-American women and other minorities were more likely to report negative consequences related to disclosure, including discrimination and physical assault.

Among studies that looked at violence as an outcome of HIV status disclosure, many found that violence was not a commonly reported outcome. Where violence was reported, the range was wide (average 12%; range: 3.2% to 45%). However the measure of violence was often inadequate. In addition, definitions of violence were almost always limited to physical assault and did not include other aspects of abuse such as threats and controlling behaviours.

In studies conducted in the USA, four of 20 studies reported that respondents experienced violence as a result of disclosure (average 8%; range: 3.2% to 24%). In a study conducted among HIV-positive women in Baltimore, USA, Gielen (58) found that 4% of women who reported any violence since time of diagnosis felt it was directly attributable to their HIV status. Gielen (58) also suggests that women with a history of physical or sexual abuse were more likely to suffer violence as a result of disclosure. Studies done in the USA show that violence as a result of disclosure is not limited to women. In a nationally representative sample of HIV-infected individuals undergoing medical care, Zierler (59) found that 10.3% of women reported violence since time of HIV diagnosis; 4.5% of men who have sex with men reported violence since the time of HIV diagnosis; and 3.2% of heterosexual men reported violence since the time of diagnosis.

In the developing world, the reports of violence were more common (average 11%; range: 3.5% to 23%). Five of the 12 studies conducted in the developing world report violence as an outcome of disclosure. Studies in South Africa seemed to have the most reports of violence. Grinstead (60) showed that HIV-positive women in sero-discordant couples where the man was HIV-negative were the most likely to experience violence. The rate of reported violence in these relationships was 13% as compared to no violence reported in sero-discordant relationships where the man was HIV-positive and the women HIV-negative. Of concern is the small but still significant number of women reporting that they were forced to leave their homes after disclosing their status. Programmes assisting these women should be implemented as most of these women rely on their partners for their livelihood.

The true risk of violence related to disclosure was hard to determine from these studies as there were no base rates of violence obtained at the beginning of the studies and measures of severity also varied. Therefore it is impossible to tell if the rate of violence increased or decreased after disclosure. Additionally, the definitions of violence differed greatly across studies and measures of severity also varied. Most studies did not define violence, and some only report on slapping and biting because it is not known what the term physical assault means in relation to slapping and biting. This makes the rates of violence post-disclosure difficult to assess and compare.

3. Disclosure to partners compared to family members and friends

Most studies did not describe the outcomes of disclosure by the recipient to whom the individual disclosed. Of the three studies that did, all showed that disclosure to mothers was associated with increased social support. Disclosure to fathers was more rare and generally occurred with disease progression. Fathers were also more likely than other family members to become angry or withdraw after disclosure. Disclosure to sexual partners was also frequently associated with emotional support. However, lovers were more likely to become angry and withdraw after disclosure than family members. All three studies reported that disclosure to friends resulted in increased social support and that friends were the most unlikely to become angry or withdraw after disclosure (13,10, 21).

4. Anticipated versus real outcomes

Several studies mentioned that fear of consequences like abandonment, violence, and discrimination were major barriers to disclosure. However, when the study participants who chose to disclose were asked the outcomes of disclosure, these fears were seldom realized. In Kilewo's (16) study from the United Republic of 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. However, 91.7% of women who did disclose their results reported that their relationship continued after disclosure. Heyward (31) found a similar trend in Kinshasa, Democratic Republic of the Congo, where 63% of women who did not disclose their HIV status reported fear of divorce as the major barrier. Yet at 12 months after disclosure, no women in the study reported divorce or separation. This finding can mean one of two things. First, only women who are confident in the strength of their relationship actually disclose their results and women who are less confident or have reasons to be concerned do not disclose their results. It could also mean that women perceive that the risk of a negative outcome is more likely than it is in reality.

5. Behaviour change as an outcome

Few studies examined the role that disclosure plays in changing sexual behaviour. Of the two studies that looked at the role of disclosure in changing behaviour, involving partners was found to lead to greater behaviour change. A study done by Niccolai (14) with 129 males and females enrolled in a behaviour modification programme found that after disclosure of status to partners, condoms were used 89.9% of the time compared to only 76.6% of the time with non-disclosure ($p=0.02$).

Similarly, Allen (61) found that among a cohort of 1458 childbearing women in Rwanda, involving the male partner in HIV testing and counselling was an independent predictor of condom use. Of the 26% of women whose partners were also tested, 55% used condoms compared to 28% of women whose partners were not tested. These findings suggest the need for encouraging disclosure when it is safe and feasible for the woman. Additionally, whenever possible women should be encouraged to bring their partners with them to voluntary testing and counselling clinics and the couples should be counselled together to facilitate disclosure in a safe environment.

Implications of findings

- ✓ **Promotion of couple counselling is an important step to facilitate positive outcomes and minimize negative outcomes.**
- ✓ **Research is needed to identify factors associated with negative outcomes of disclosure in order to develop better 'screening' tools for counsellors.**
- ✓ **Providing women with information that a history of violence may increase the likelihood that they will experience a negative outcome as a result of disclosure will help them to make informed decisions about disclosing.**
- ✓ **In settings that can support routine assessment of violence as part of the HIV testing and counselling protocol, it is necessary to accompany such a policy with training programmes that provide skills in how to ask about violence and how to refer women for additional services.**
- ✓ **Counsellors should assist women to determine whether fears of negative outcomes are grounded in reality or whether they can be overcome.**
- ✓ **Support groups may represent a key opportunity for discussing fears and concerns around disclosure as well as sharing disclosure strategies amongst peers.**

VII. HIV Status disclosure among men who have sex with men

(See TABLE 5/page 53)

A review of the literature found only three studies examining disclosure among men who have sex with men (MSM) (13, 24, 48). All three were conducted in the USA. No studies were found with men who have sex with men in developing country settings.

The three studies reviewed found that disclosure rates among men who have sex with men were quite high. Stempel (13) working with 93 HIV-positive men found that 82% of men had disclosed to a primary sexual partner, while 56% had disclosed to a new sexual partner. Hays (24), working with 163 HIV-positive men, found that 98% of asymptomatic men had disclosed to their lover or partner and all symptomatic men with AIDS had disclosed to their partners. Major barriers to disclosure reported by these men included not wanting to worry or upset others, fear of discrimination, fear of condemnation by family, fear of disrupting relationships –both familial and sexual– fear of losing friends, feeling that disclosure would be of limited benefit, and a desire to conceal their sexual orientation.

The results from these studies showed that for men who have sex with men disclosure acts as both a source of stress and a source of social support. Among the 163 HIV-positive men studied by Hays (24), disclosure to friends and significant others was associated with less anxiety; whereas, disclosure to mothers was often associated with depression. Similarly, Stempel (13), working with 93 homosexual men in San Francisco, found that 21% of long-term sexual partners and 17% of new sexual partners expressed unfavourable reactions to disclosure of HIV test results. Holt (62), meanwhile, found that disclosure among 40 HIV-positive homosexual and bisexual men was closely tied to the length of time since diagnosis. Immediately after diagnosis, individuals were more likely to choose not to disclose their status to anyone until they had time to come to terms with the diagnosis themselves. During the asymptomatic phase of the disease, men would eventually choose to disclose to partners to allow them to share the responsibility for safer sex. Disclosure during the symptomatic phase of the disease was more common and allowed the men to develop a social network of both practical and emotional support.

With only three studies looking at HIV status disclosure among men who have sex with men it is hard to make generalizations about the experiences of disclosure among this population. This lack of research highlights the need for studies to look at the special needs and concerns of this population in terms of disclosure, especially in developing country settings, where homosexuality is highly stigmatized.

VIII. HIV status disclosure among commercial sex workers and injecting drug users

Although HIV is widespread among commercial sex workers and injecting drug users in many settings, few studies looking at the disclosure experiences of these marginalized populations have been conducted. This review found no studies looking at HIV status disclosure among commercial sex workers.

Only one study looked at HIV status disclosure among injecting drug users. A study (63) in the USA with 161 injecting drug users found that participants who reported current drug use were less likely to disclose (OR=0.36) and that disclosure was positively associated with length of time since diagnosis, duration of relationship, and HIV status. The study also found that drug-using partners were at high risk for HIV infection because partners were unlikely to self-disclose their HIV status to other network members.

Further research is needed to understand the rates and barriers to disclosure for these vulnerable populations as well as the outcomes they experience following disclosure.

Commercial Sex Workers and Injecting Drug Users

- ✓ **Although HIV is widespread among commercial sex workers and intravenous drug users in many settings, few studies looking at the disclosure experiences of these marginalized populations have been conducted.**
- ✓ **This review found no studies looking at HIV status disclosure among commercial sex workers.**
- ✓ **Only one study (from the USA) looked at HIV status disclosure among injecting drug users.**
- ✓ **Further research is needed to understand the rates and barriers to disclosure for these vulnerable populations as well as the outcomes they experience following disclosure.**

IX. Policy and programme approaches

There is a limited range of different programme and policy approaches that have been recommended to increase HIV status disclosure rates and support individuals through the disclosure process. However, very few of these approaches have been rigorously evaluated. This section includes, where available, examples of these approaches. These recommended approaches can be organized into five general areas including:

- ◆ Identification and referral of domestic violence in HIV testing and counselling programmes
- ◆ Cross-training of HIV and domestic violence staff
- ◆ HIV counselling approaches
- ◆ Community-based initiatives to empower women and minimize HIV-related stigma
- ◆ Partner notification policies

1. Identification and referral of domestic violence in HIV testing and counselling programmes

HIV testing and counselling may provide a useful setting for identification and assessment of violence against women. Identification of violence within HIV voluntary testing and counselling programmes is justified by the fact that there is consistently, across different settings, a core group of women who report violence and other negative outcomes as a result of disclosure to sexual partners.

In 2000, a law was passed in New York State (USA), that among other things instituted domestic violence ‘screening’ at HIV post-test counselling sessions. As a result, the Department of Health has been involved in training both domestic violence and HIV providers. They developed a seven-step protocol for identification of domestic violence that is used by HIV counsellors (www.health.state.ny.us/nysdoh/rfa/hiv/protocol.htm). Domestic violence risk assessment is the standard of care in HIV testing and counselling in New York State, which means that a discussion of domestic violence is encouraged during pretest counselling and domestic violence risk assessment is a required component of post-test counselling of HIV-infected individuals.

Asking about violence without adequate skills to address the issues raised by women and without an effective referral network raises serious ethical concerns. Since HIV counsellors are already responsible for addressing a wide range of issues within their sessions with clients, it may be challenging for them to adequately address the issues surrounding domestic violence in their sessions with women. Therefore, an effective case management system that enables counsellors to refer clients to domestic violence services and follow-up with clients to ensure that they received the services that they needed is important. In Baltimore, Maryland, USA, Gielen and colleagues are 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 services (Gielen AC, personal communication, 27 February 2002).

2. Cross-training HIV/AIDS and domestic violence staff

Cross-training HIV/AIDS 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 that are affected by both epidemics. The Departments of Health in both New York State and California in the USA, have developed extensive training programmes for HIV counsellors and domestic violence providers.

In California, they have developed a training course for providers working in the field of HIV prevention to give them information on the dynamics of domestic violence and to build skills in screening and referral. They train case managers, nurses, and other health care workers who are working in HIV and STD programmes (Deborah Cohen, personal communication, 4 March 2002). New York State has been very proactive at developing policies and training staff to ask women about domestic violence in the context of HIV counselling, testing, referral and notification programmes. Following the legal requirement for domestic violence 'screening' in HIV testing and counselling, members of the New York State Department of Health have developed and facilitated training workshops to help HIV counsellors learn how to effectively 'screen' clients for domestic violence. In the standard HIV counselling training programmes offered by the state both the pretest and the post-test counselling sessions offer training in discussing and 'screening' for domestic violence. They have also developed a separate training workshop on domestic violence for people working in the field of HIV prevention

that includes information on defining violence, describing patterns of abuse, describing the intersections between HIV and violence, and developing effective responses to victims of domestic violence. They have developed another training manual to address issues of domestic violence within lesbian, gay, transgender and bisexual communities. Finally, they have facilitated training workshops for domestic violence providers that cover information on early care needs of individuals newly diagnosed with HIV, transmission of HIV in the shelter environment and providing domestic violence services that are sensitive to persons infected with HIV (Rachel Iverson, personal communication, 27 February 2002).

Similarly, in South Africa, RADAR (Rural AIDS and Development Action Research Programme) a National Department of Health TB/HIV pilot site, and WHO ProTEST site, has introduced VCT services into PHC clinics in rural Limpopo Province. Because prior research highlighted the importance of domestic violence as a problem affecting local communities and nurses alike, a cross-training approach was undertaken (see text box on page 28).

Incorporating gender and gender-based violence perspectives into a VCT training programme in South Africa¹

A one-week VCT training curriculum for nurses was developed by merging perspectives and approaches from domestic violence training materials with more traditional VCT training methodology. Role plays and other interactive methods explored how gender roles, gender inequalities, and domestic violence increase women's vulnerability to HIV infection. An HIV-positive facilitator was instrumental in conceptualizing and implementing the curriculum, and her own disclosure during the training was designed to sensitize nurses to the importance of confidentiality and the benefits and risks women face in disclosing their HIV status. 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. Evaluation of the programme included a review of services, in-depth interviews with trained nurses, and the use of "mock clients" to evaluate VCT from the client perspective (64). Over 40 healthcare workers (90% of nursing staff in the pilot sub-district) were trained, and over 350 HIV tests were performed in the first six months following training. More women than men had come for testing (2:1), and approximately 2/3 of tests' results were positive. Same day results were delivered in all cases, using a rapid HIV test. A mock client played the role of a woman in an abusive relationship in order to assess how and whether the nurse addressed this issue in the course of counselling. In most cases, nurses enquired about the risk of domestic violence, exhibited a non-judgemental and non-directive attitude, and did not pressure the client to disclose her positive status to her partner. Instead, follow-up visits for support and counselling were offered. In addition to raising awareness regarding domestic violence, the gender focus of the training heightened nurses' own perceptions of HIV risk: over 90% reported that they had spoken to their spouse about HIV since the training, and almost 1/3 had subsequently had an HIV test themselves. Thus, integrating domestic violence issues into VCT training has the potential to strengthen the immediacy and relevance of the issues for nurses themselves. This in turn can raise awareness about both the risks and benefits of disclosure for women, and improve the quality of VCT service delivery. In settings such as South Africa where women are known to be at high risk of both domestic violence and HIV, such training approaches may be particularly relevant.

¹For further information visit: <http://www.witz.ac.za/radar/Home.htm>

3. Counselling approaches

HIV counselling is an important point of contact that can be used to address barriers to HIV status disclosure by:

Using role plays and other behavioural rehearsal techniques: First, HIV counselling can be used to develop interpersonal communication skills among clients for HIV status disclosure. 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. These techniques not only help clients identify the communication challenges that they may face when disclosing to their sexual partners but also serve as an opportunity to develop a personal disclosure plan with the counsellor. Counsellors should proactively address fears of violence and abandonment, rather than waiting for women to bring this up.

Ongoing counselling and HIV support groups: Repeated opportunities for counselling on disclosure is another strategy that can be used in HIV/VCT programmes to try to increase rates of HIV status disclosure to sexual partners. De Rosa (11) found that rates of disclosure increased monotonically with the number of times that a health official at the HIV clinic where a person received care discussed the issue of disclosure. Men who were counselled both at post-test counselling and at their current HIV clinic were nearly twice as likely to have disclosed to all sexual partners than men not counselled at both sites. At a minimum, raising the issue of disclosure during both the pretest and the post-test counselling session is necessary in order to work through the barriers and develop a plan for disclosure to sexual partners. During the pretest counselling session the counsellor can help the client to think about the potential reaction of the partner, develop answers to potential questions that partners may have and to think about when and under what conditions results will be shared with partners. Pretest counselling can also be used to help clients think about the consequences of failing to disclose including infecting their partners, perinatal transmission, and difficulty in accessing medical and social support. During the post-test counselling session, counsellors can use the behavioural rehearsal techniques to discuss additional barriers and develop a specific disclosure plan. In situations where ongoing counselling may be an option, the opportunity to continue work-

ing with clients after the standard post-test counselling session is important. 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 to providing ongoing emotional support, such groups may provide a supportive environment for those who have already disclosed to share their experiences and strategies with peers, thereby providing a forum for openly discussing fears, benefits, anticipated outcomes, and real outcomes of disclosure.

New counselling approaches: New approaches to counselling may be needed to support clients through the disclosure process. 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. In many HIV testing and counselling settings women are already creating the opportunity for mediated disclosure through their own initiatives. Experience from Kenya, Uganda and the United Republic of Tanzania indicates that many women choose not to share results with their partner directly (Elizabeth Marum, personal communication, 7 March 2002). Rather they test first, then they return home and convince their partners to test again with them, without telling partners that they have already tested. When the couple returns to the HIV testing and counselling clinic the counsellors do not acknowledge that they have already counselled and tested the woman. The couple goes through the HIV testing and counselling process again and they share results with one another in the post-test session with the counsellor. Disclosing results in the context of the couples' session, with the counsellor guiding the process, is often easier than a woman trying to do it on her own. Alternatively, identifying a third party such as a family member or friend to be physically present with clients when they disclose to their partners is another potentially useful strategy to minimize negative reactions. In the United Republic of Tanzania, Maman and colleagues are currently pilot-testing the feasibility and acceptability of the mediated counselling approach in the context of an HIV VCT clinic (34).

Involving men in HIV testing and counselling: Finally, involving men in the process of HIV testing and counselling of women may help to bypass many of the barriers associated with disclosure and may also facilitate sustained behaviour change among couples due to the fact that men generally

have more control over the sexual decision-making within couples. There are few concrete recommendations and even fewer actual examples of strategies that have been used successfully to target men and recruit couples for HIV testing and counselling. In the context of perinatal HIV transmission, there is the added barrier to overcome the traditional lack of male involvement in women's reproductive health care. Some have suggested that promoting infant health as the responsibility of both the mother and the father may encourage more men to test for HIV during the antenatal period.

4. Broader community-based initiatives

Recognizing that some of the barriers women face in sharing HIV test results with their partners have their roots in underlying discriminatory gender norms and social attitudes about HIV/AIDS, there have been calls for initiatives to address these broader issues. Until the underlying power differentials in gender relations are addressed the specific problem of HIV and violence will continue (Zierler, personal communication, 1 February 2002). Programmes that target young men and boys to promote more equitable relational development are important. These programmes can provide young men with alternative strategies for conflict resolution and alternative norms of sexual behaviour. There are few examples of well-designed and evaluated programmes that target young men to change norms around sexual behaviour and violence. Maman and colleagues (34) are initiating an intervention study in Dar es Salaam, the United Republic of Tanzania, that combines drama-based communication together with peer support to reduce adolescent males' HIV risk behaviours and reduce partner violence, which will ultimately enable adolescent females to initiate HIV preventive behaviours. There may also be opportunities to work creatively with young couples to promote more dialogue about HIV risk and violence within their relationships.

Women's empowerment programmes are another means to try to shift gender norms and ultimately facilitate HIV status disclosure to sexual partners. There is an example of a creative empowerment programme that is effectively addressing the interface between HIV and violence among women in Rhode Island, USA (Kelly Smith, personal communication, 22 March 2002). (see text box on page 32). Microcredit programmes are another empowerment approach that may enable women to access independent sources of income. Access to resources may provide women with more latitude to challenge male decision-making within their relationships because they are not completely depend-

ent on financial support from their partners. Fear of abandonment and loss of financial support were the major reasons that women cited for not sharing HIV test results with their partners. Therefore, if women have access to independent sources of financial support then fear of financial loss should become less of a barrier to disclosure.

Community-based programmes to reduce stigma associated with HIV/AIDS is another approach that needs to be taken in conjunction with other efforts in order to encourage HIV testing and facilitate HIV status disclosure. Research has shown that AIDS stigma can have a variety of negative effects on HIV test-seeking behaviour, willingness to disclose HIV status, health care-seeking behaviour, quality of health care received and social support solicited and received (65). There are different approaches that have been used to try to reduce HIV-related stigma including information-based approaches, coping skills acquisition, counselling approaches and contact with affected groups (65).

Empowerment programme to address intersection of HIV and violence:

Sojourner House WomenCARES Programme

Sojourner House was one of Rhode Island's first domestic violence organizations founded in 1976. It is a non-profit organization whose mission is to end domestic violence. The organization focuses on empowering women through direct service, community education and through participation in the legislative and judicial system. In 1999 Sojourner House initiated the WomenCARES (Women Creating Awareness, Respect, Empowerment and Support) project which provides individual and group level interventions to help women of colour and teens identify, own and act to reduce their HIV and abuse risks. The project teaches safer sex skills to enhance clients' knowledge and willingness to set and attain risk behaviour change goals. They coordinate services with 56 community-based organizations to assure that clients have access to other assistance that they need in order to attain their risk reduction goals (housing, emergency food assistance, job training, health care, HIV testing, etc.). Via street outreach, staff and peer educators distribute safe sex supplies and harm reduction information. When participants join their risk reduction groups or enrol in the individual peer counselling, they learn and practice skill-building and role-playing exercises to enhance self-protection skill retention. Clients set and work toward risk reduction goals. They cross-train staff with community-based organization (CBO) partners to increase their collective ability to intervene effectively in domestic violence cases involving HIV risks.

For more information visit: <http://www.sojourner-house.org>

5. Partner notification policies

Ethical, legal and professional debates on different strategies to notify people of their risk for HIV have not been conclusive. Some individuals have advocated for a provider-referral approach in which the health care worker would elicit names of sexual contacts from the HIV-positive individuals and then notify those contacts directly of their risk for HIV infection (66, 67). Others have advocated for a patient-referral approach in which the decision to notify sexual partners of their risk for HIV is left up to the control of the HIV-infected individual (68, 69). Advocates of the provider-referral approach argue that such programmes may promote testing of undetected carriers of HIV and thus slow the spread of infection through this population. Advocates of the patient-referral approach argue that the involuntary disclosure of HIV status may discourage people from seeking HIV testing and may place HIV-infected individuals at risk for negative social outcomes including violence.

The World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) have instituted a policy on HIV status disclosure that seeks to protect the human rights of the individual (70). Protection of human rights, they argue, is essential to safeguard human dignity and to ensure an effective, rights-based response to HIV/AIDS. A rights-based response to HIV/AIDS requires that states enact anti-discrimination laws that protect people living with HIV/AIDS from discrimination in both the private and public domains. Additionally, states must work to ensure the privacy and confidentiality of all HIV-positive individuals. The principles of confidentiality and informed consent are necessary tools by which to protect both the uninfected and infected and should be respected by all.

In the USA only two states, New York and California, have enacted policies that seek to protect the human rights of the individual by incorporating domestic violence 'screening' within their counselling, testing, referral and partner notification systems (CTRPN). New York legislation implemented in June 2000 recognized identification of domestic violence and referral as a necessary component of HIV post-test counselling. The Department of Health in close collaboration with the New York Office for Prevention of Domestic Violence and community-based agencies and organizations took steps to advance the integration of routine enquiry for violence and HIV prevention services (see text

box on page 35). Similarly, the California Department of Health Services developed a policy which states that if partner notification puts the individual at risk for violence then the safety of the person must be secured before the intervention can take place (Catherine Baker, personal communication, 20 March 2002). If the client requests that notification not be conducted because of a partner's possible violent reaction then the notification must be deferred indefinitely. The provider must provide adequate documentation of the threat of domestic violence and must refer the client to domestic violence programmes. Included in the policy is the requirement that the notification providers must develop written resource listings for domestic violence services that are regularly updated. Policies like those developed in New York and California have limited impact if the persons who are expected to carry out the mandate, such as HIV counsellors, are not effectively trained to identify, respond to and refer clients who report violence. Both states have developed training programmes for HIV counsellors (see section on cross-training). The formal recognition of the link between partner notification and violence through policies like those adopted by New York and California have significant impact on the efforts to support women who face negative outcomes as a result of disclosure. These programmes should be considered as a possible model that can be adopted by other states and within other settings. However, screening for violence in settings where there are no support services available to refer female victims of domestic violence is insufficient and may be inappropriate. Therefore, in these settings –which may include many, if not most, developing countries– HIV counsellors may have to be trained to provide the relevant information about domestic violence and to be able to counsel and refer women themselves. This approach needs to be developed, further defined and rigorously evaluated before it can be promoted.

Policy approach to HIV status disclosure: New York State

In June 2000, New York State adopted a law that requires domestic violence screening during HIV post-test counselling for HIV-infected individuals. The actual steps in screening and referral are summarized in a structured protocol for HIV counsellors (<http://www.health.state.ny.us/nysdoh/rfa/hiv/protocol.htm>).

The provider raises the issue of domestic violence before partner names are elicited. Screening for violence occurs on a partner-by-partner basis for partners voluntarily identified and for any partners, including spouse(s) known to the provider. A referral for domestic violence services is made when any risk of domestic violence is identified. A provider may defer notification when risk of domestic violence would adversely affect the health and well-being of the HIV-infected individual, his or her children, someone close to him or her or a named partner. The local public health official, in consultation with the provider, can determine whether referrals for domestic violence services and other steps, such as development of a safety plan, are sufficient to allow notification to proceed. Decisions on partner notification should be revisited throughout the continuum of care. Guidelines for integrating domestic violence screening within HIV testing and counselling have been developed (<http://www.health.state.ny.us/nysdoh/rfa/hiv/guide.htm>).

These guidelines provide some background information on the link between HIV and violence and also provide suggestions on exactly how to carry out the policy within the pre and post-test counselling sessions. There is also a simple flow chart that outlines the steps to be taken in screening and referral (<http://www.health.state.ny.us/nysdoh/rfa/hiv/physchrt.pdf>). To support the implementation of the policy the Department of Health developed training programmes for HIV counsellors to develop skills in domestic violence screening and referral. Separate training programmes for screening and referral issues within lesbian, gay, transgender and bisexual communities have also been developed.

6. Research implications

There are a number of research questions that still need to be answered to understand better the barriers and outcomes of HIV status disclosure to sexual partners. Foremost, there is a dearth of information on the experiences with HIV status disclosure from regions outside of the USA and sub-Saharan Africa. Studies need to be conducted in other regions of the world to describe the variability in rates, barriers and outcomes of HIV status disclosure to sexual partners. There is a need to understand the implications of disclosure and the support required when VCT is undertaken in different circumstances (e.g. antenatal care, VCT clinics, STD clinics). More research needs to be conducted to explore the specific issues with regard to disclosure among adolescents. There is also a lack of information on HIV status disclosure to sexual and drug-using partners among injecting drug users. All of these studies should include reliable and tested measures of violence, including threats and controlling behaviours.

In terms of measurement, future research may benefit from broadening the assessment of disclosure by it being considered a process involving the conveying of a range of information over an extended period of time. Studies are needed that describe the process that women go through in deciding whether to disclose. Through qualitative interviews with HIV-infected women, Kimberly (7) developed a framework to describe the stages of HIV status disclosure to sexual partners among women in the USA. It would be useful to test this framework within different populations in the USA and to determine whether it has widespread applicability. Developing a similar framework to describe the decision-making process for women in developing countries would be very helpful. Additional studies are needed to describe more accurately the length of time that women need to share results with partners. Most of the studies that examined the outcomes of disclosure described the short-term impact of disclosure. It is important that longitudinal cohort studies be done that follow women over extended periods of time after disclosure to see what the long-term ramifications of disclosure are so that we can understand better the impact of disclosure on women's lives. As access to various treatment and care options (e.g. PMTCT programmes, home-based care, prevention of opportunistic infections, antiretroviral therapy) become more widely available in developing countries, it will be important to understand how these may contribute to perceived motivations for testing and coun-

selling, and disclosure. This, in turn, may highlight key strategies for overcoming barriers to disclosure which might otherwise limit access to such options.

While the descriptive information on HIV status disclosure is certainly not complete, the information that is available from the USA and sub-Saharan Africa does point to some programmatic approaches that should be evaluated through intervention research. Research is needed to guide programmes in effective ways of involving male partners in the HIV testing and counselling process of women. Research is needed to evaluate new HIV counselling strategies that are designed to increase rates of disclosure such as a mediated disclosure approach. Evaluating the effectiveness of behavioural rehearsal techniques, such as role-plays and scenarios, at developing skills for disclosure communication skills is also important. Documenting and understanding how HIV support groups are currently dealing with the issue of disclosure may lend important insights for how to strengthen and expand such initiatives. Research is needed to develop screening tools that HIV counsellors can use to identify individuals least likely to disclose and most likely to experience negative outcomes as a result of disclosure. Determining the effectiveness of identification and referral programmes for violence by intimate partners within settings that provide HIV testing and counselling is important in contexts where extensive referral services are available as well as in those contexts where referral services are not widely available. In settings where referral services for violence are not widely available, research is needed to identify strategies that HIV counsellors can use to support women and men who report violence within their relationships. Research is also needed to determine whether broader initiatives such as community-based programmes to empower women or reduce HIV/AIDS-related stigma are effective at reducing barriers to HIV testing and disclosure for women.

Table 1: Disclosure rates to sexual partners

Study	Population	Setting	Type of partner	Length of time since diagnosis	Rate of disclosure
Simoni, 2000 (28)	230 HIV+ women from outpatient clinics	New York City, USA	Husband or steady male or female sexual partner	Time since diagnosis ranged from three months to 13 years (median 4.09 years)	82% disclosed to partner
Stein, 1999 (12)	HIV+ individuals initiating care at an urban hospital (69% men)	Boston and Rhode Island, USA	All sexual partners	In the last six months	60% of participants disclosed to all sexual partners
Kalichman 1999 (71)	266 sexually active HIV+ individuals (203 men, 129 women)	USA	Most recent sexual partner	Had known of HIV status for at least six months	78% of men and 79% of women shared results with most recent sexual partner
De Rosa, 1998 (11)	692 HIV+ men from HMOs and public clinics	Los Angeles, USA	Sexual partners within the last two months	Within two months	92.6% of men reported disclosing to partners who were HIV+, 57% of men reported disclosing to partners who were negative
Stein, 1998 (72)	203 patients presenting for primary care	Urban hospital, USA	All sexual partners in past six months and spouse	During the last six months	60% disclosed to all sexual partners 78% disclosed to spouse/significant other
Kilmarx, 1998 (27)	142 HIV+ STD clinic patients	Baltimore, Miami, Newark, USA	Spouse or sexual partner	Known of HIV status for 6-24 months	89% of individuals had disclosed their HIV status to at least one other person 6 to 24 months after being tested 28% reported they had first disclosed to a sexual partner 31% reported they had first disclosed to a relative 29% reported they had first disclosed to neither a sexual partner or a relative
Marks, 1991 (73)	138 HIV+ men recruited from public clinic	Los Angeles, USA	Intimate lovers, casual partners and spouses	Tested seropositive within the last 18 months	Of the men who only had one sexual partner since diagnosis, 69% disclosed their status to that partner. Among those with 2-4 partners, 36% disclosed to at least one sexual partner. Among those with 5+ partners, 18% disclosed to at least one partner.
Armistead 1999 (19)	100 HIV+ African-American women recruited from HIV outpatient programme	New Orleans, USA	Partners (classified according to women's response)	Average length of time from diagnosis to disclosure to partner was 7.92 months (sd 17.41 months)	56% disclosed to their partners

Study	Population	Setting	Type of partner	Length of time since diagnosis	Rate of disclosure
Sowell, 1997 (20)	82 women enrolled in prospective study on impact of HIV / AIDS	Rural Georgia, USA	All sexual partners	29% asymptomatic, 23% symptomatic, 48% had AIDS	69% disclosed to all sexual partners 15% told some sexual partners 16.4% told no sexual partners
Lester, 1995 (29)	20 HIV+ mothers enrolled in a longitudinal study of the impact of HIV on families	California, USA	Current or recent male sexual partner	Not defined	100% of all sexually active HIV-positive women had disclosed their HIV status to current or recent male sexual partners 33% had disclosed to at least one friend 25% had told at least one family member
Rothenberg 1995 (74)	136 health care providers who work with HIV-infected female clients	Baltimore, USA	Partner not specifically defined	Disclosure in the past one year	74% of providers had clients who had disclosed to a partner in the past one year
Simoni, 1995 (21)	65 HIV+ women from outpatient clinic	Los Angeles, USA	Lover (person with whom they were emotionally but not necessarily sexually involved)	25% knew of status for one year or less 30% knew of status for 1-2 years 35% knew of status for 2-4 years	86.8% of individuals had disclosed to their 'lovers'
Perry, 1994 (75)	Community based sample of 129 HIV+ adults (95% men)	USA	Present steady partner, present casual partner, past steady partner, past casual partner	27.5 months +/- 14.5 months (at latest assessment)	77% present steady partner 42% present casual partner 70% past steady partner 47% past casual partner
Niccolai, 1999 (14)	299 HIV+ individuals enrolled in longitudinal behaviour modification programmes (48% women, 88% African American)	USA	Partner defined as the last person with whom the participant had sex	Within two months of disclosure and assessed every two months at follow-up visits	76% of participants disclosed to last sexual partner at baseline 26.9% reported non-disclosure to at least one sexual partner during follow-up
Levy, 1999 (26)	174 HIV+ patients in ambulatory HIV clinic	Paris, France	Any sexual partner, spouse, former sexual partner	42.5% disclosed immediately, 21% waited one month, 24% waited more than one year to disclose. Women disclosed immediately after learning status more often than men (53% versus 32.8%, p=.003)	35% disclosed to sexual partner (any), 11% disclosed to former sexual partner, 7.6% disclosed to spouse

Study	Population	Setting	Type of partner	Length of time since diagnosis	Rate of disclosure
Kilewo, 2001 (16)	1050 HIV+ pregnant women enrolled in perinatal transmission trial	United Republic of Tanzania	Sexual partner not specifically defined	Duration of follow-up was 18 months after diagnosis	16.7% disclosed to their sexual partner
Nebie, 2001 (40)	306 HIV+ pregnant women enrolled in perinatal transmission trial	Burkina Faso	Sexual partner not specifically defined	Median duration of follow-up for women who disclosed was 13.9 months	17.6% disclosed to sexual partner
Antelman, 2001 (15)	1078 HIV+ pregnant women enrolled in perinatal transmission trial	Dar es Salaam, United Republic of Tanzania	Sexual partner	Assessed within two months and after 46 months of follow-up	22% disclosed to partner within two months, 40% disclosed to partner after 46 months
Farquhar, 2000 (39)	104 HIV+ pregnant women attending antenatal clinic	Nairobi, Kenya	Partner not defined	Unknown	65% of women had informed partners of their HIV status 27% brought their partners in for HIV testing
Gaillard, 2000 (9)	331 HIV+ women enrolled in MTCT trial	Mombasa, Kenya	Partner (stable relationship which was 87.6% of the total sample)	Two months after diagnosis	32% (15.5% of those who had not disclosed said they intended to)
MacNeil, 1999 (10)	154 newly diagnosed HIV+ persons	Semi-urban Tanzania	Spouses and sexual partner	Three and six month follow-up	At three months 18.8% shared with spouse, 5.8% shared with sexual partner, at six months 24.7% shared with spouse, 12.3% shared with sexual partner
Ladner, 1996 (8)	1233 pregnant women screened for HIV in context of study on impact of HIV on pregnancy	Kigali, Rwanda	Partner not specifically defined	Two weeks after testing	84.9% had informed their partner that they were tested
Lie, 1996 (30)	611 HIV+ patients from two regional hospitals	United Republic of Tanzania	Partner not specifically defined	Duration not stated	86% shared HIV test results with their partner
Van der Straten, 1995 (17)	876 women recruited from outpatient and antenatal clinic (27% HIV+)	Kigali, Rwanda	One steady partner within last one year	One and two years after enrolling in study	77% reported discussing their HIV results with partner in past one year and 79% disclosed within two years; of the 47 HIV+ women who were asked about disclosure two years after diagnosis, 21% had not disclosed to their sexual partner

Study	Population	Setting	Type of partner	Length of time since diagnosis	Rate of disclosure
Maman, 2002 (34)	245 women from HIV VCT clinic (29.8% HIV+)	Dar es Salaam, United Republic of Tanzania	Primary partner (partner they have been together with for at least three months)	Three months after HIV testing	69% of HIV+ and 83% of HIV- women disclosed to partner
Keogh, 1994 (18)	47 women enrolled in prospective study on natural history of HIV infection	Kigali, Rwanda	Current or past sexual partner if woman is widowed or separated	Three years after diagnosis	79% of women disclosed to their sexual partner
Grinstead, 2001 (60)	3551 participants enrolled in study of HIV VCT	Dar es Salaam, Tanzania; Nairobi, Kenya, and Port of Spain, Trinidad	Spouses and sexual partner	Six months after diagnosis	Overall 76% disclosed to sexual partner 70% of those enrolled as individual and 91% of those enrolled as member of a couple; 52% of HIV+ individuals 79% of HIV- individuals

Table 2: Reported barriers to HIV status disclosure to sexual partners

Study	Population	% of study participants who HAD NOT disclosed to sexual partner	Barriers to disclosure
Kilmarx, 1998 (27)	142 HIV+ STD clinic patients from Baltimore, Miami and Newark who have known of HIV status for 6-24 months	4% had not disclosed to sexual partner	Emotional concerns Afraid of rejection
Yoshioka, 2001 (41)	16 HIV+ Asian men living in NE USA	Not reported	Protection of family from shame Protection of family from obligation to help Avoidance of communication related to sensitive information
Moneyham, 1996 (38)	19 HIV+ women from SE USA	Not reported	Fear of relationship termination Fear of discrimination Concerns about confidentiality
Rothenberg, 1995 (74)	136 health care providers who work with HIV-infected clients in Baltimore, USA	26% of the female patients of the providers had not disclosed in the past one year	Fear of physical violence (45%) Fear of abandonment (66%) Fear of emotional abuse (56%)
Gielen, 1997 (23)	50 HIV+ African-American women from USA	20% women had not disclosed to anyone 10% disclosed to sexual partner only 8% disclosed to family only	Fear of rejection and discrimination (22%) Fear of violence (12%)
Perry, 1994 (75)	129 HIV+ adults in USA (95% men)	58% had not disclosed to present casual sexual partner 23% had not disclosed to present steady sexual partner 53% had not disclosed to past casual sexual partner 30% had not disclosed to past steady sexual partner	Fear of exposure to sexual orientation Fear of rejection from partner
Simoni, 1995 (21)	65 women from outpatient HIV clinics in Los Angeles, USA	13.2% had not disclosed to lover	Fear of rejection Desire to maintain secrecy
Armistead, 1999 (19)	100 African-American women from New Orleans, USA	44 % had not disclosed to sexual partner	Fear of losing economic support from sexual partner
Chin, 1999 (42)	9 HIV+ Asian/Pacific Islander women from USA	20% of the total number of people in their networks were not informed of HIV status	Fear of stigmatization Fear of burdening or disappointing others Concerns about discrimination

Study	Population	% of study participants who HAD NOT disclosed to sexual partner	Barriers to disclosure
Maher, 2000 (76)	490 women from STD clinics in Newark and Miami, USA	1% of women felt that if they had HIV their sexual partner should not be informed	Declining an HIV test was not significantly related to any measure of partner violence and was not significantly associated with having previous experience with partner notification 24% of women said that they would have some fear of telling their partner their results if they were tested
De Rosa, 1998 (11)	692 HIV+ men, USA	43% of HIV- partners and 7.4% of HIV+ patients did not disclose to all partners	Rates of informing all sexual partners increased monotonically with number of times a health official at clinic discussed issue of disclosure
Stein, 1998 (72)	203 consecutive patients presenting for primary care at two urban hospitals in USA	22% of women and 48% of men had not disclosed to all sexual partners	Individuals with multiple partners, individuals without high spousal support, and blacks were less likely to disclose than whites and Hispanics
Mason, 1995 (43)	107 Spanish-speaking Latino men 85 English-speaking Latino men 206 white men from outpatient clinic in Los Angeles, USA	31.1% of Spanish speaking Latino men, 13% of English-speaking Latino men, and 3.6% of white men had not disclosed their HIV status to an intimate lover	Men with less education, less severe disease and shorter period of time since HIV testing were less likely to disclose
Jeffe, 2000 (44)	Convenience sample of 206 people living with AIDS in St. Louis, USA	31% reported had not disclosed to all applicable medical providers 9% did not disclose to any providers	Whites more likely to disclose to any providers than African-Americans. Those with lower CD4 counts more likely to disclose
Simoni, 2000 (28)	230 HIV+ women in New York City, USA	18% did not tell partners	The higher the T-cell count the more likely women were to disclose
Niccolai, 1999 (14)	229 HIV positive individuals enrolled in longitudinal study in USA	24% did not disclose to sexual partner at baseline 26.9% reported non-disclosure to at least one sexual partner at follow-up	In bivariate analysis non-African-American race, ($p=.04$), not using elicited drugs ($p=.002$), consistent condom use ($p=.0005$), using a condom during the last sexual act ($p=.04$) and having only one sexual partner ($p=.002$) were significantly associated with HIV status disclosure to sexual partners. Those who used condoms were 2.7 times more likely to disclose than those who reported inconsistent condom use
Levy, 1999 (26)	174 HIV+ patients (29.3% women) 44.5% single, 45.7% live with sexual partner, 21% primary school education in Paris, France.	65% did not disclose to sexual partner (any) 89% did not disclose to former sexual partner 92.4% did not disclose to spouse	Fear of rejection Fear of change in relationship Desire to protect others

Study	Population	% of study participants who HAD NOT disclosed to sexual partner	Barriers to disclosure
Gaillard, 2000 (9)	331 HIV+ women in Mombasa, Kenya	68% of women had not informed partner 76.1% said they never intended to disclose to partner 15.5% said they intend to disclose	Fear of partner's reaction (94.1%) <22 years of age was associated with higher disclosure rate
Sigxaxhe, 2000 (77)	28 HIV+ women participating in a pilot perinatal transmission trial in South Africa	Not reported	Fear of rejection Fear of discrimination Fear of verbal abuse Concerns about public ignorance of the disease
Ladner, 1996 (8)	1233 pregnant women screened for HIV in the context of study on impact of HIV on pregnancy in Kigali, Rwanda	Among 848 who returned for PTC, 15.1% of HIV+ women and 7.8% of HIV- women had not informed their partner that they were tested	Fear of family conflicts or expulsion from the marital home
Kyaddondo, 2000 (78)	Women from antenatal care in Kampala, Uganda	Not reported	Fear of breaking the relationship Fear of blame Fear of being sent away from home
Nebie, 2001 (40)	306 HIV+ pregnant women enrolled in perinatal trial in Burkina Faso	12.4% of women had not informed their partners	Fear of domestic violence
Kilewo, 2001 (16)	1050 HIV+ pregnant women enrolled in perinatal HIV study in Dar es Salaam, United Republic of Tanzania	83.3% had not shared HIV test results with their partners	Fear of stigma (46.4%) Fear of divorce (46.4%) Fear of violence (16.1%)
Rakwar, 1999 (32)	520 randomly selected women from an STD clinic in Nairobi, Kenya	10% of women said they would not tell their partner their HIV test results if they were positive	Fear of accusations of infidelity (63%) Fear of abandonment from partner (55%) Fear of violence from partner (51%)
MacNeil, 1999 (10)	154 newly diagnosed HIV-infected persons from semi-urban area of United Republic of Tanzania	Three months after testing, 94.2% had not shared with partner, 82.2% had not shared with spouse; at six months, 87.7% had not shared with partner; 75.3% had not shared with spouse	Fear of reprisals Fear of stigma Fear of loss of economic support

Study	Population	% of study participants who HAD NOT disclosed to sexual partner	Barriers to disclosure
Antelman, 2001 (15)	1078 HIV+ pregnant women enrolled in perinatal HIV trial in Dar es Salaam, the United Republic of Tanzania	78% of women had not disclosed to partners within two months of HIV testing 60% of women had disclosed to partners after nearly four years of follow-up	Fear of losing confidentiality (32%) Fear of social isolation (14%) Not wanting to worry others (17%) Fear of conflict with partners (15%) Just being afraid (11%) Monogamously married or cohabiting for less than two years Women working in low wage employment Women with multiple partners Women who didn't know anyone with HIV/AIDS Women who had previously disclosed to female relative
Heyward, 1993 (31)	364 women (187 HIV+, 177 HIV-) participating in a longitudinal perinatal transmission study in Kinshasa, Zaire	30% of women said they did not intend to notify partners (53% HIV+ and 6% HIV-)	Fear of divorce (63%) Fear of accusations of infidelity (86%)
Issiaka, 2001 (79)	79 HIV+ women involved in the therapeutic trial in Burkina Faso 79.7% lived with their sexual partner 63% had no personal income	78.4% had not shared results with their sexual partners	Fear of being rejected or abandoned (71.4%) Fear of being considered unfaithful (24%) Women who were educated shared results with their partners more often than women who were illiterate
Farquhar, 2000 (39)	104 HIV+ women who had been offered testing as part of prenatal care in Nairobi, Kenya	35% had not informed sexual partner	Fear of blame (54%) Fear of physical assault and abandonment (19%) Disclosure was associated with age <24 years and low SES
Pool, 2001 (80)	208 women attending maternity clinic in three rural sites participated in 24 focus group discussions in rural Uganda	Not reported	Fear of being accused as the source of infection Fear of accusations of infidelity Fear of separation
Bennetts, 1999 (33)	129 women enrolled in a perinatal transmission trial in Bangkok, Thailand	56% of women had not disclosed to anyone except for partner	Fear of shaming their family
Maman, 2002 (34)	15 women, 17 men and 15 couples who had been through HIV testing and counselling at VCT clinic in Dar es Salaam, Tanzania	31% of HIV+ women did not disclose results to their sexual partners	Fear of partner's reaction, particularly abandonment Lack of communication with partner prior to HIV testing
Keogh, 1994 (18)	47 HIV+ women enrolled in longitudinal study on natural history of HIV infection in Kigali, Rwanda	21% had not disclosed to their partner three years after diagnosis	Fear of rejection and blame Did not want to frighten partner Partner was sick

Table 3: Barriers to HIV testing

Study	Population	Acceptability of testing	Barriers to testing	Intervention implications
Cartoux, 1998 (54)	Survey of investigators from 13 perinatal transmission studies from West (3), East (7) Southern (2) Africa and Thailand (1)	Acceptance rate for VCT at pretest was high (92%, range 53-99.7%). Return rates varied among sites (median 82%, range 33-100%). In majority of sites the return rate of women diagnosed with HIV were below those found to be HIV-.	Clinics in which staff in charge of VCT also involved in general antenatal care, provided specific services for HIV and NGO support had higher overall acceptability.	Pretest group discussion is easier to implement than individual counselling. HIV VCT could be integrated into existing sessions of counselling regarding general antenatal and postnatal care. VCT with same day results represents an option to minimize failure to return.
Parra, 2001 (47)	413 pregnant women in South Texas, USA	15% of participants who had not previously been tested indicated that they would refuse HIV testing. 85% indicated that they would agree to be tested if recommended by a doctor.	Fear of being stigmatized, denial, fatalism and fear of rejection were barriers to testing mentioned by women. The most common barrier was fear of being viewed as having had many sexual partners.	Identifying reasons why women may not want to get tested will improve the educational and counselling strategies targeted at reducing the number of women who decline testing.
Siegel, 1998 (48)	84 African-American, Puerto Rican and white women enrolled in a larger study on HIV+ women's treatment behaviour and experiences in New York City, USA.	Few women made a thoughtful and planned decision to test. Several learned of status as a result of donating blood, physical exam for life insurance, in response to financial incentives and while in prison.	The most common barrier to testing was psychological, primarily denial and fear. Indifference was another less frequently mentioned barrier. Fear of having to disclose was another barrier that was mentioned.	There is a need to make testing more widely available and more public education around testing needs to take place.
Sahlu, 1999 (53)	751 factory workers enrolled in a cohort study of HIV infection progression, Addis Ababa, Ethiopia	98% of women and 99% of men said they wanted to know their HIV status at pre-test counselling. However, only 63% returned for post-test counselling within two months	Factors associated with failure to return include being manual workers, reporting recent casual sex, being married. Women were likely to return based on plans for the future rather than on past sexual exposure.	Not reported

Study	Population	Acceptability of testing	Barriers to testing	Intervention implications
Fernández, 2000 (50)	1357 women receiving prenatal care at public clinics in Florida, Connecticut and New York City, USA	85% of women accepted to be tested for HIV	Reasons for accepting test included belief that testing was a positive thing to do for the baby and/or mother's health and perception that provider strongly endorsed testing. Reasons for declining test include no perceived risk (20.7%), scheduling difficulties (15.6%), previous testing (11.7%) and no support by a provider (9%).	Rates of acceptance can be increased when women understand modes of vertical transmission, role of mediation in preventing transmission, belief that prenatal HIV identification can promote the health of mother and child and perception that providers strongly endorse testing. Considerable effort should be dedicated to increasing provider support for prenatal testing.
Sorin, 1996 (49)	1992 patient level information routinely collected from all postpartum women who met counselling eligibility criteria. 17 731 women, 2% were HIV+, New York, USA	34.4% agreed to be tested for HIV 50% of these women returned for their post-test results	Factors associated with agreeing to be tested: age less than 20, Hispanic, uninsured, sexual risk, no prenatal care, individual counselling length. Factors associated with return for results: STD during pregnancy, prenatal care at this hospital only, positive test result. For every five minute increase in the length of counselling session the odds of testing more than doubled.	Counsellor characteristics of empathy, warmth and genuineness are crucial for continuation rather than termination of initial counselling interview. These factors relate to whether client knowledge and risk perception are improved, leading to test acceptance. Counsellor awareness of client risks coupled with individualized and directive rather than neutral, universal approach to testing and counselling are essential in achieving acceptance and identifying infected women.
Cartoux, 1999 (52)	Pretest counselling offered to 3958 pregnant women (927 group, 3031 individual counselling) in two antenatal clinics in Burkina Faso	Acceptance of test improved with individual counselling though it was already high with group counselling (almost 90%)	The return rate for results was not related to the pretest technique and independent of HIV status.	At a public health level, group pretest counselling can be easily integrated into existing sessions of antenatal care counselling, routinely performed by current clinic staff.
Valdiserri, 1993 (81)	Records of 557 967 clients, representing more than 40% of all publicly funded HIV testing and counselling clients in USA from Jan-Dec., 1990	63% returned for post-test counselling, (62% women, 65% men)	People who were young, African-American, and pretest counselled in STD clinics were least likely to return for results. Factors strongly related to returning for results were MSM, HIV+ status, and female.	Approaches that encourage clients to gauge and accept their own risk of HIV accurately and realistically and that incorporate a specific plan to provide results and post-test counselling are likely to improve post-test counselling return rates, render these services more efficient and cost-effective and accelerate the subsequent adoption of self-protective behaviours.

Study	Population	Acceptability of testing	Barriers to testing	Intervention implications
<p>Nyblade, 2001 (51)</p>	<p>10 950 participants (4764 men, and 6186 women) enrolled in Rakai, Uganda community-randomized trial from 1994-1995, ages 15-59 years</p>	<p>Women significantly less likely to receive VCT than men (31.4% vs. 34.8%)</p>	<p>Younger age, HIV+ status, and having no sexual partners in the last five years was significantly associated with lower VCT participation. Lack of health care is a disincentive to seek VCT. Those most vulnerable to HIV were less likely to participate in VCT (younger men and women, women with two+ sexual partners in past five years, and HIV+ individuals).</p>	<p>There is a need to target VCT to ensure participation by high-risk individuals most in need of these services.</p>
<p>Royce, 2001 (46)</p>	<p>1362 representative par-turient women from seven hospitals in the USA</p>	<p>89.9% of women reported being offered HIV testing during prenatal visit 69.6% reported receiving an HIV test during prenatal visit</p>	<p>Women with insurance were three times more likely not to get tested than women with public funding. Proportions of women tested increased incrementally with the perception that the provider considered testing to be important. 6.6% of women said they were too worried to test, 1.8% said they feared discrimination, 1.5% said testing was contrary to their beliefs. 55.3% said they had no perceived need for the test.</p>	<p>There is a need to improve caregivers understanding of the importance of universal testing. As a society we should actively seek to mitigate the stigma associated with HIV.</p>

Table 4: Reported Outcomes of HIV Status Disclosure

Setting	Study	Population	Positive outcomes	Negative outcomes
Developed Country	Beevor, 1993 (82)	23 HIV+ and 23 HIV – women receiving care at a clinic in London, UK	57% of HIV+ women disclosed their status to their parents and reported that their parents were supportive	Not discussed
	Comer, 2000 (83)	176 HIV+ women from Los Angeles, USA 41% African-American, 32% Hispanic, 27% Caucasian	Disclosure leads to improved mental health for African and Caucasian-Americans	Disclosure leads to worse mental health outcomes among Hispanic-Americans
	Gielen, 1997 (23)	50 HIV+ women in Baltimore, USA 86% African-American 56% current or former IV drug users	76% of women reported acceptance, support, and understanding after disclosure	22% reported rejection, abandonment, or shame after disclosure 6% reported being physically assaulted after disclosure
	Gielen, 2000 (58)	257 HIV+ women in Baltimore, USA 92% African-American	56% of women reported no negative consequences as a result of disclosure	44% of women reported some negative outcomes relating to disclosure, including: 24% loss of friends, 23% insulted, 21% rejected by family, 4% physical or sexual assault. 4% of women who reported any violence since time of diagnosis felt it was directly attributable to their HIV status.
	Gielen, 2000 (56)	310 HIV+ women enrolled in an HIV primary care clinic at an urban teaching hospital in the USA	Many women reported positive outcomes from disclosure	45% reported experiencing emotional, physical, or sexual abuse some time after diagnosis 4% reported physical abuse following a disclosure event
	Mason, 1997 (84)	105 HIV+ African-American men and 264 HIV+ European-American men randomly sampled from two outpatient clinics in Los Angeles, USA	82% of all participants who informed their closest friend about their HIV status, reported that their friend frequently or always reacted in an emotionally supportive way	15% of men reported that their lovers ended the relationship after disclosure

Setting	Study	Population	Positive outcomes	Negative outcomes
Developed Country	Kilmarx, 1998 (27)	142 HIV+ STD clinic patients from Baltimore, Miami, and Newark, USA: 57% male, 43% female	Among those who had disclosed to their sexual partner, 52% said partner was very accepting and 32% said partner was somewhat accepting	Among those who had disclosed to their sexual partner: 4% reported the partner was indifferent 8% reported the partner was somewhat rejecting and, 4% reported the partner was very rejecting; 3.5% of participants reported losing their jobs after disclosure.
	Lester, 1995 (29)	20 HIV+ and 20 HIV- mothers in an urban poor USA population	Most of the women reported satisfaction with support from family and friends	35% of HIV+ women reported episodes of discrimination directly related to their HIV status
	Mansergh, 1995 (45)	684 HIV+ men from two HIV outpatient clinics in Los Angeles, USA	Men generally reported favourable reactions to disclosure	10.4% of respondents reported that their intimate partners left them after disclosure
	Marks, 1991 (73)	138 HIV+ men from a public HIV clinic in Los Angeles, USA	Disclosure to sero-negative partners generally led to protected sexual contact	Disclosure to sero-positive partners generally led to unprotected sexual contact
	Moneyham, 1996 (38)	19 HIV+ women from the South Eastern part of the United States, USA	Most patients were able to identify at least one positive experience resulting from disclosure	Not discussed
	Rothenberg, 1995 (57)	136 health care providers who work with HIV-infected clients in Baltimore, USA	Not discussed	24% of providers had at least one female patient who experienced violence following disclosure 37% of providers had a female patient who was abandoned following disclosure
	Semple, 1993 (55)	31 HIV+ women infected mainly from heterosexual contact from the USA	No reported marital break-ups or separations. Majority of husbands reacted with emotional support.	Among unmarried women with new partners, disclosing had either changed a good relationship in a negative way or made a poor relationship even worse, leading to a break-up in the relationship.

Setting	Study	Population	Positive outcomes	Negative outcomes
Developed Country	Serovich, 1998 (85)	13 HIV+ women from the USA	Women reported hope and comfort as some of the reactions following their disclosure of status to family members and sexual partners.	Most reactions after disclosure were emotional and included blame, fear, disbelief, anger, embarrassment, shock, worry, sorrow, and silence. No physically violent reactions were reported.
	Simoni, 1995 (21)	65 women from outpatient HIV clinics in Los Angeles, USA	The majority of women experienced supportive reactions from partners, family, and friends.	Not discussed
	Zierler, 2000 (59)	Nationally representative probability sample of 2684 HIV+ adults who were receiving medical care, USA	Not discussed	10.3% of women reported violence since time of HIV diagnosis 4.5% of men who have sex with men reported violence since time of HIV diagnosis 3.2% of heterosexual men reported violence since time of diagnosis
Developing Country	Bennetts, 1999 (33)	129 HIV+ women enrolled in a perinatal transmission trial in Bangkok, Thailand	72% of women were still in a relationship with their partner after disclosure.	28% separated from their partner or their partner died following disclosure
	Chin, 1999 (42)	9 HIV+ Asian-Pacific Islander women (Philippines, Cambodia, and Viet Nam)	Respondents indicated that they were closer (63%) or maintained the same level of closeness (34%) to members of their network to whom they disclosed.	Not discussed
	Finney, 2000 (86)	11 HIV+ women and 7 HIV+ and HIV- men living in metropolitan Durban, South Africa	Not discussed	All women experienced either physical abuse (hitting, punching, slapping, etc.) and/or psychological abuse (stigma, discrimination) related to disclosure.
	Gaillard, 2000 (9)	331 HIV+ African women interviewed two months after testing positive	73% of partners were understanding following disclosure	10.5% of the women's partners did not believe the results 9.3% had no comment 3.5% chased the woman out of the house 3.5% physically assaulted the woman following disclosure

Setting	Study	Population	Positive outcomes	Negative outcomes
Developing Country	Grinstead, 2001 (60)	3551 participants from the HIV Voluntary Testing and Counselling Efficacy Trials in Tanzania, Kenya, and Trinidad	Positive life events were common: 42% reported a strengthening of a sexual relationship 12% reported increased emotional support from employers	Negative life events were less frequent 27% reported a break-up of a sexual relationship 5% reported a break-up in the marriage 4.5% reported physical abuse by a sexual partner
	Heyward, 1993 (31)	187 HIV+ and 177 HIV – childbearing women at a public hospital in Kinshasa, Democratic Republic of the Congo	At 12 months no women reported divorce or separation following disclosure	Not discussed
	Issiaka, 2001 (79)	79 HIV+ women living in Burkina Faso	Informed partners were either indifferent (72%) or had an encouraging attitude (24%)	4% of the women reported a case of dispute without violence following disclosure
	Keogh, 1994 (18)	47 HIV+ women who were part of a prospective study in Kigali, Rwanda	62% reported a positive reaction (such as acceptance) following disclosure to their partners	17% reported a negative reaction (blame or anger) following disclosure to their partners 21% reported fear, disbelief, or shock as reactions following disclosure Slightly over a quarter of women reported their marriage deteriorated following disclosure
	Kilewo, 2001(16)	1050 HIV+ pregnant women enrolled in the PETRA study in Dar Es Salaam, United Republic of Tanzania	91.7% of women reported that their relationship continued after disclosing to their partners	14.6% of partners reacted violently following disclosure
	Matthews, 1999 (35)	88 HIV+ mothers attending an outpatient clinic in Cape Town, South Africa	19% of women who disclosed said their disclosure resulted in more kindness	27% of women reported at least one problem with disclosure 13% experienced violence from partners following disclosure 9% reported that their partner left them, and 3% said they were forced to move away from their home
	Nebie, 2001 (40)	306 HIV+ pregnant women enrolled in a perinatal trial in Burkina Faso	Most women remained with their partner after disclosure	Among 54 women who disclosed to their partner, only two actually separated from that partner following disclosure.
	Shah, 2000 (87)	52 HIV+ pregnant women from Mumbai and Sumerpur, India	Not discussed	13 out of 30 males who reported extramarital affairs still blamed the woman because she was diagnosed first. Six husbands left their wife, 12 women were beaten/abused by their in-laws, and 18 women were no longer allowed to do household activities.

Table 5: Rates, barriers, and outcomes of HIV status disclosure among men who have sex with men (MSM)

Study	Population	Disclosure rates	Barriers to disclosure	Outcomes of disclosure
Hays, 1993 (24)	163 HIV+ men participating in a longitudinal cohort study in the USA	98% of asymptomatic men had not disclosed to their lover/partner. All asymptomatic men and men with AIDS had disclosed to their partners.	Not wanting to worry or upset others Fear of discrimination Fear of disrupting relationships Feeling that disclosure would have no benefit Desire to conceal sexual orientation	Disclosure to friends and significant others was associated with less anxiety Disclosure to mother was associated with depression
Holt, 1998 (62)	40 homosexual and bisexual HIV+ men from the USA	All men in their sample had disclosed (part of eligibility criteria)	Fear of losing friends/sexual partners Fear of condemnation by family Fear that sexual orientation would be revealed	During the asymptomatic phase, disclosure to partners allowed the men to share responsibility. During the symptomatic phase, disclosure gave the men a social network.
Stempel, 1995 (13)	93 homosexual men participating in a larger cohort study in San Francisco, USA	82% disclosed to primary sexual partner, 56% disclosed to new sexual partner.	Fear of losing health insurance (82%) Fear of losing housing (47%) Fear of being perceived as AIDS carrier (61%) Fear of disrupting family relations (39%) Fear of disrupting sexual relations (21%)	21% of lovers and 17% of new sexual partners expressed unfavorable reactions to disclosure of HIV test results.

XI. BIBLIOGRAPHY

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