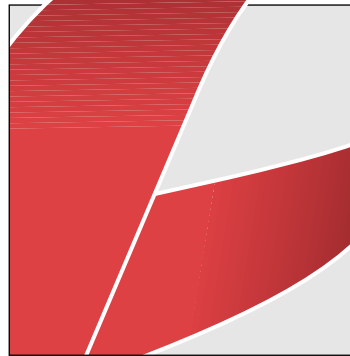
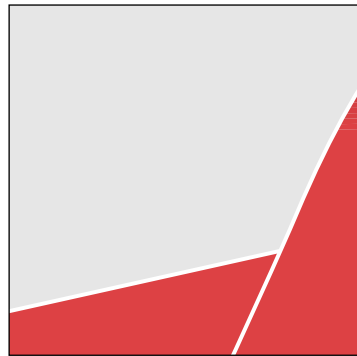


Counselling and voluntary HIV testing for pregnant women in high HIV prevalence countries

Elements and issues



Joint United Nations Programme on HIV/AIDS
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in high HIV prevalence
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Counselling and voluntary HIV testing for pregnant women in high HIV prevalence countries

Elements and issues

1. Introduction

For many years, little was known about preventing transmission of HIV infection from mother to child. Recently, however, many advances have been made in developing effective and affordable interventions that reduce the likelihood that a woman will pass HIV on to her baby.

The two most important interventions—the provision of antiretroviral drugs and the avoidance of breastfeeding—only apply to HIV-positive women. Both therefore require that a woman know whether she is infected by HIV. And yet in developing countries, where 95% of mother-to-child infections take place, there are very few counselling and testing services that allow a woman to find out her HIV status.

HIV counselling and testing in relation to pregnancy and other reproductive health services may prove a valuable entry point for provision of counselling and voluntary testing to the wider community of healthy and asymptomatic women and their partners. Some reproductive health settings such as STI (sexually transmitted infection) clinics, paediatric services and family planning clinics may provide an opportunity to offer testing to potential mothers and fathers of further children, while antenatal services will allow testing to be offered to women already pregnant and their partners.

Counselling and voluntary testing for HIV have benefits beyond the prevention of transmission from mother to child. Counselling services have been slow to gain acceptance in many countries, especially where HIV is heavily stigmatized and access to services and support for the HIV-infected is limited. Indeed, HIV testing has often been used as a diagnostic tool to confirm symptomatic AIDS. But a growing number of studies attests to the value of counselling and voluntary HIV testing in largely healthy populations. These services have been shown to contribute to an increase in safe behaviour at the individual level, and are likely also to reduce the ignorance, fear and stigma associated with HIV infection in the population at large.

Few countries have actively promoted counselling services and few have yet developed clear national guidelines on the provision of counselling and voluntary HIV testing in reproductive health service settings. However, service provision does not grind to a halt just because there are no clear guidelines. That means that facility managers have to make difficult decisions without guidelines, and often with incomplete information. This document aims to provide guidance on the counselling and HIV testing for managers of antenatal clinics and other pregnancy-related services, whether they are public, private or non-profit. It may also be used as a basis for discussions in developing a national policy in this increasingly important area.

The document gives an overview of the magnitude of the problem of HIV transmission from mother to child. It then focuses on the benefits of coun-

selling and voluntary HIV testing in the context of pregnancy, and discusses the content of such counselling. Operational issues and potential difficulties in setting up and maintaining such a service are explored.

2. Mother-to-child transmission of HIV: an overview

- HIV can be passed from mother to child in the womb, during childbirth or through breastfeeding.
- With no interventions, reported transmission rates ranged from 13% to 32% in industrialized countries, and from 25% to 48% in developing countries.
- Avoiding breastfeeding can cut the risk of transmission to between 20% and 25%.
- Prophylactic use of an antiretroviral regimen is just one component of a prevention-of-mother-to-child-transmission programme.
- Recommended antiretroviral drug regimens for preventing mother-to-child transmission include: zidovudine (ZDV) alone, ZDV + Lamivudine (3TC), and Nevirapine.
- The mechanisms by which these regimens provide protection against mother-to-child HIV transmission include decrease of viral replication in the mother and/or prophylaxis of the infant during and after exposure to the virus.
- A WHO Technical Consultation in October 2000 concluded that the benefit of these drugs in reducing mother-to-child HIV transmission greatly outweighs any potential adverse effects of drug exposure or concerns related to development of drug resistance.
- The most complex effective regimen includes antepartum/intrapartum/postpartum ZDV, while the simplest effective regimen includes single-dose intrapartum/postpartum nevirapine.
- For women receiving prophylactic regimens that include an antepartum component and who have received less than two weeks of ZDV antepartum treatment, prophylaxis with six weeks' treatment of ZDV for the infant, intrapartum/postpartum ZDV + 3TC, or the two-dose nevirapine regimen may be considered.
- There is currently no justification to restrict the use of any of these regimens to pilot project or research settings. The local choice of which antiretroviral prophylactic regimen to include in the standard package of care should be determined by issues of feasibility, efficacy and cost.
- In recent years, the use of nevirapine has attracted considerable attention because of its low cost and ease of use in MTCT-prevention programmes. The regimen of nevirapine used for MTCT prevention is a single 200mg oral tablet to be taken by

the mother at the onset of labour and a single oral dose of nevirapine in suspension (2mg/kg) to be given to the newborn within 72 hours of birth. Nevirapine and zidovudine were included in the WHO *Model List of Essential Drugs* in 1999, solely for the indication of MTCT prevention of HIV.

- Delivery by Caesarean section in women has been shown to reduce the risk of transmission too. This procedure is difficult to undertake safely where health infrastructure is limited. The risks associated with sepsis following this operation are greater in HIV-infected than in HIV-negative women.
- Vitamin supplementation, cleansing of the birth canal and avoiding invasive procedures during delivery may all help reduce the risk of transmission of HIV from mother to child. Since the presence of other STIs may increase the risk of a woman passing HIV infection on to her child, screening and treatment of STIs other than HIV may also reduce transmission rates. Research on these interventions continues. However, they are relatively cheap and beneficial to all women, regardless of their HIV status.

3. Why reduce mother-to-child transmission of HIV?

For most people working in maternal and child health, the answer to this question is self-evident. However, it is worth reviewing just how much illness and death could be averted by reducing transmission from mother to child.

- Some 4.3 million children under the age of 15 have died of AIDS since the beginning of the epidemic. Over 90% were infected by their mother at birth or during breastfeeding.
- Another 1.4 million children are currently living with HIV, and 1600 more are infected every day. Almost all of those new child infections are in developing countries, with 90% in sub-Saharan Africa alone.
- AIDS deaths are reversing gains in child health and survival. Forecasts for Zimbabwe in 2010, for example, show that AIDS is expected to push the infant mortality rate 138% higher and the under-five mortality rate 304% higher than they would have been in the absence of AIDS. In Côte d'Ivoire, child mortality will rise by over two-thirds.
- Caring for HIV-infected children carries heavy costs for families and health systems. In Soweto, South Africa, for example, one-third of paediatric hospital admissions are HIV-related.

Sick children, healthy children and orphans

Another concern is the idea that introducing this strategy for the prevention of MTCT might exacerbate the problem of orphaned children, increasing the burden of care on families and society. It is widely assumed that children born to HIV-infected mothers do not survive long enough to become orphans. But this

is a misconception: even in the absence of intervention, the great majority are still alive at their fifth birthday and beyond, and are highly likely to survive their infected mothers. The most likely effect of introducing the strategy, therefore, will be that of altering the ratio of HIV-infected orphans to uninfected orphans.

The intervention does not, therefore, significantly affect the need for societies to make provision for their orphaned children. However, from the point of view of planning for care and allocating resources, it is important to recognize that, with measures to reduce MTCT, many fewer orphaned children will be HIV-infected and in need of medical care and support, many of them long-term. It is also worth noting that improving perinatal care and diagnosing HIV infection in order to permit early access to care may prolong the life of mothers and their partners. Thus, their children will have the care of their mothers and be spared the misery and vulnerability of orphanhood for longer.

The stigma of dead children

In many societies where children are highly prized, a woman who bears unhealthy children or whose children repeatedly die faces ostracism within the family and the community. This stigma can be avoided through interventions and family support that help her to bear and raise healthy children.

4. Counselling and voluntary HIV testing: a prerequisite for action

The most effective interventions to reduce transmission from mother to child depend upon a woman knowing her HIV status, and that, in turn, depends upon the availability of information, counselling and voluntary testing services.

It is not necessary to wait until the full range of services is on offer before integrating HIV-related information, counselling and voluntary HIV testing into routine pregnancy care. At the very least, women can be provided with information about reducing their and their partner's exposure to HIV infection, and about avoiding unwanted pregnancies. Health professionals can also ensure services before and during delivery that minimize the child's exposure to HIV infection.

Pre-test information and counselling and post-test counselling will differ according to the needs of the client. The following sections discuss issues that should be considered in pre-test counselling for individuals and couples. The post-test information and counselling needs of HIV-positive and HIV-negative women and their partners are discussed separately.

4.1 Pre-test information and counselling

Pre-test information and counselling: a summary

- Information about the sexual transmission of HIV and how to prevent it
- Information about transmission of HIV from mother to child, and possible interventions
- Information about the HIV-testing process
- Assurance of confidentiality and discussion of shared confidentiality and couple counselling
- The implications of a negative test result, including information on how to remain HIV-negative, promotion of breastfeeding and family planning
- The implications of a positive test result, including costs and benefits of potential interventions, promotion of safe infant feeding practices and family planning, a discussion of their own, their family's and their child's survival and the possible exposure to stigma
- Counselling for risk assessment.

There is a great deal that women (and their partners) need to know before deciding whether or not to be tested for HIV. Much of it is straightforward information that can be imparted in groups. Reaching a decision is, however, not easy. After basic information has been given, most people will need counselling at an individual level to help them assess their level of risk and consider the implications of a positive or negative result in their own situation, before deciding whether or not to be tested.

Pre-test counselling has sometimes been dismissed as relatively unimportant; it is sometimes skipped entirely or performed by rote in a way that leaves no room for interaction or discussion of the implications of testing in relation to an individual's own health, reproductive, marital or social situation. This is partly because the bulk of experience comes from dedicated counselling and testing centres, to which most clients come only after they have already made the decision to be tested. At reproductive health facilities, the situation is very different. Many women and their partners have never considered being tested. Indeed, some have only very limited knowledge about HIV and AIDS. In these situations, it is likely that the quality of pre-test information and counselling will be a determining factor in whether or not people choose to take a HIV test. For pregnant women, this decision is likely to affect the interventions available to them and, therefore, their chances of bearing and raising a healthy child.

Men attending reproductive health services (including STI services) should receive counselling about HIV transmission and prevention. This information should include a discussion about transmission from mother to child. Counselling about fertility decisions and contraceptive services should be given. Pre-test counselling should stress the benefits of couple counselling. Since the vast majority of clients for reproductive health services continue to be women, however, this paper will focus on the counselling and information needs of women attending reproductive health services.

Information about HIV transmission and prevention

Since a child cannot be infected by a HIV-negative mother, the most effective way of avoiding HIV transmission from mother to child is to prevent new HIV infections among potential mothers. The starting point for all pre-test information and counselling should therefore be basic information about HIV transmission and prevention. Young women and men presenting at reproductive health services should all receive information about the sexual transmission of HIV and how to prevent it as well as information about the transmission of the virus from mother to child. Helping HIV-positive couples to avoid an unwanted pregnancy will also cut the likely number of new infections.

Information about the HIV test and confidentiality

Clients at reproductive health services should be given information about the HIV testing procedure itself, including the accuracy of the tests, confirmatory procedures, and the window period for antibody development. Practical details about blood sampling, the cost of a test and the length of time until results are available should be discussed.

Clients must be told clearly that a HIV test is entirely voluntary. While interventions such as the provision of ZDV or breast-milk substitutes cannot be provided to women whose HIV status is not known, refusing a test should not affect access to other standard antenatal care or reproductive health services.

It is vital that clients understand that HIV test results will be entirely confidential. Women must know and believe that they alone control disclosure of their test results to themselves, to other health staff, or to their partners, families or friends. Results will not be revealed to anyone else (including other health-care providers) without the client's permission.

Counsellors should also discuss shared confidentiality and the benefits of couple counselling. Access to some effective interventions to reduce HIV transmission may depend upon the support of a partner. Counsellors should offer to refer women and their partners to other counselling and testing services in cases where a man, for cultural or other reasons, is unlikely to attend the health facility providing services to his wife or partner.

Counselling to assess the risk of infection

In pre-test counselling, individuals should be given an opportunity to assess their own risk of infection, together with a counsellor.

There is currently some evidence that, in highly stigmatized societies, women who believe themselves to be at high risk of infection are less likely than low-risk women to choose to be tested for HIV infection or to come back for their test results. Since the potential benefits of knowing one's HIV status in the context of childbearing are greater for HIV-infected women, counsellors should take particular care to explain the benefits to women whose self-assessment suggests that they are at elevated risk of being HIV-infected.

The benefits of a HIV test and the implications of the results

Unless women and their partners fully understand the benefits of a HIV test, they are unlikely to choose to have one. A discussion of the benefits of testing is necessarily linked to a discussion about the implications of a positive or negative result.

A negative result allows an individual to act to avoid infection in the future. It will also allow a woman to breastfeed, confident in the knowledge that it is best for her child.

The implications of a positive result will depend upon the interventions available. Information about existing interventions to reduce transmission of HIV from a HIV-positive mother to her children should be given during pre-test counselling to help women (with or without their partners) weigh up the potential costs and benefits of having a test. Women should be told that, in the absence of any intervention, less than half the babies born to HIV-positive women will contract the virus from their mother. Intervention can reduce that amount to less than 10%. However, it should be clear to a woman that the most effective interventions cannot be made available to women whose HIV status is not known.

Clients should also be told that a positive result will allow them to make important decisions about their own lifestyle, nutrition and health care—decisions that may have a major impact on their survival, even in places where antiretroviral combination treatments are not available.

The potential downside of HIV testing

Clients must be given clear information about the potential downside of HIV testing. Where interventions are unavailable or where a woman or a couple judges them to be unaffordable, clients may decide that the benefits of testing are limited. Where breastfeeding is universal, privacy is limited and breast-milk substitutes are expensive, it may be impossible for a HIV-positive woman to choose alternatives to breastfeeding without advertising her HIV status to her family or community. Counsellors should discuss with a woman the likelihood that she will be ostracized, divorced or otherwise discriminated against if her HIV status is revealed. It may be that the risks of disclosure of HIV status to the broader welfare of both mother and infant far outweigh the likely benefits of HIV testing. Counsellors should discuss these issues with clients individually. Whatever the counsellor's own assessment, however, testing should always be offered to women, and support provided while they make their decision as to whether to be tested or not.

The decision to be tested for HIV will never be easy. But because there are now clear benefits to knowing one's HIV status during pregnancy, counselling and HIV testing in reproductive health settings provide perhaps the greatest incentive for women and their partners to take the difficult decision to find out their HIV status.

4.2 Post-test information and counselling for HIV-negative women

Information and counselling for HIV-negative women: a summary

- Information to prevent future HIV infections
- High risk of transmission to infant if newly HIV-infected during pregnancy or breastfeeding
- Importance of sustained and exclusive breastfeeding for infant health

In even the highest HIV prevalence countries, most pregnant women are not HIV-infected. For some, the process of testing will raise important and personal issues about sexual and domestic relationships that may need to be resolved through further discussion (perhaps with the partner). A negative result should never be presumed to indicate a lack of anxiety or of a need for further counselling. Information and counselling for HIV-negative women should concentrate on preventing future infection.

Preventing future infections

Where couples have been tested together and both are negative, information given in pre-test counselling about prevention of sexual transmission of HIV should be reinforced and the particular importance of avoiding infection during pregnancy and breastfeeding should be stressed.

Research in Malawi suggests that women may be at high risk of HIV infection soon after childbirth. This may be because their husbands or partners have sex with other partners during a woman's pregnancy or the abstinence that often follows it, becoming infected at that time and passing on the new infection as soon as sexual relations with the new mother resume. This represents a double danger if the mother is still breastfeeding, since there is a very high likelihood of transmitting infection to the infant when the mother carries the high viral load associated with new HIV infections.

When a partner is infected, or when his serological status is not known, the importance of prevention information and counselling is greater still. Information on where to get condoms and other contraceptive means should be given.

Ensuring healthy feeding practices

A negative test result also creates an opportunity for the active promotion of exclusive and sustained breastfeeding among HIV-negative mothers.

4.3 Post-test information and counselling for HIV-positive women

Information and counselling for HIV-positive women: a summary

- Information on how to prevent future HIV re-infections
- Information about therapy options, including costs
- Counselling about feeding options, including health benefits and risks of breastfeeding, costs of replacement, exposure to stigma and need for contraception
- Information and counselling about future fertility
- Information about preventing HIV transmission to uninfected sexual partners
- Counselling about shared confidentiality
- Information and referral for support, services and positive living

A positive test result gives providers of pregnancy-related services the opportunity to offer a range of information and services that can help a woman make choices about her own health and behaviour and her family's.

Information and counselling about therapy

Obviously, a positive test result is a prerequisite for the two interventions thought to be most effective in reducing transmission of HIV from mother to child: antiretroviral therapy and avoidance or abbreviation of breastfeeding. Where antiretroviral therapy is available, counsellors should explain its benefits and the importance of adherence to the regimen. They should also make clear that, while research continues, it is thought that the benefits of antiretroviral drugs may be diminished if a woman goes on to breastfeed her infant. Unless antiretroviral drugs are provided free, counsellors should discuss the cost of the therapy and help a woman assess her family's ability to bear the cost of a full regimen.

Information and counselling about infant feeding

Full information about infant feeding options is essential for all HIV-positive mothers-to-be, regardless of whether antiretroviral drugs are available. Pregnant women should be reminded that less than half all babies born to HIV-positive mothers and breastfed will be infected with HIV. Of those that do become infected, at least a third are likely to have contracted the infection while being breastfed. Women should also understand that breastfeeding protects against a wide range of other childhood diseases. Women should be given information about the alternatives to breastmilk, and what two years of substitute feeding is likely to cost. The importance of access to clean water, fuel and feeding implements if they choose substitutes to breastmilk should also be discussed.

Counsellors should discuss the possibility that choosing substitute feeding might label a woman as HIV-positive in the eyes of her family or her community. Counsellors should help a woman analyse her social situation and family resources and weigh up the best feeding option for her baby. A mother must decide what the best option is in her own situation; counsellors should provide all possible support for a woman's decision.

Information and counselling about fertility regulation

In many high HIV prevalence countries, bearing healthy children provides social status and access to family resources—access denied to women whose HIV-infected children sicken and die. To that extent, interventions to reduce HIV transmission from mother to child can help a woman consolidate her social position, despite her HIV infection.

While women and couples should be free to make their own decisions about child-bearing, counsellors should ensure that women are aware of the risks inherent in any future pregnancies, as well as the risk of passing on the virus during unprotected sex. Counsellors should make it clear that even where interventions are available, all pregnancy carries some risk of HIV transmission from mother to child. And the risk of transmission grows as the mother's infection progresses, so it is likely to grow from one pregnancy to the next. What is more, the effectiveness of anti-retroviral therapy in successive pregnancies is unknown.

Women who choose to avoid pregnancy in the future because of their HIV infection should be referred to family planning services. Women who choose two years of replacement feeding should also receive advice on contraception to replace the birth-spacing effect of breastfeeding. If they choose to bear more children, they should be encouraged to delay the pregnancy for at least two years.

Counselling about shared confidentiality

While health service providers must guarantee confidentiality of test results, they should recognize that the burden of secrecy can be detrimental to people's ability to live positively with their infection. Counsellors should help HIV-positive clients decide with whom, if anyone, to share information about their status. Counsellors should never themselves disclose test results to anyone else except at the express request of the client.

Counsellors should discuss the potential pluses and minuses of sharing test results with other people. Sharing a positive test result with a partner may expose a woman to ostracism. It may, on the other hand, allow her to make otherwise impossible choices about childbearing and care. Sharing results with other family members can provide psychological support as well as necessary care and help in planning for the future. Sharing results with other health care workers can ensure that a woman receives the best information and care possible for herself and her child over the course of her pregnancy and eventually her illness. Sharing results with other HIV-positive people in support groups can contribute to knowledge and coping skills.

Information to prevent the further spread of HIV

Information on preventing the sexual transmission of HIV is every bit as important for HIV-positive as for HIV-negative clients. Staff counselling HIV-infected women should reinforce information provided in pre-test counselling, stressing the risk of passing infection on to present and future sexual partners, discussing negotiation of safer sex with those partners and providing information about sources of free or affordable condoms.

Information about the natural history of HIV infection, well-being and care

In many countries, a positive HIV test result is equated in people's minds with near-immediate sickness and death. Correcting this misconception is an important aspect of counselling. Counsellors should discuss the natural history of HIV infection, including the long latency period and common opportunistic infections.

Counselling and voluntary testing services attached to reproductive health services are an important entry point to the continuum of care. Counsellors in reproductive care settings are unlikely to be able to provide as much follow-up counselling or support as clients need. Counsellors at reproductive health facilities should therefore provide referrals to support groups or other sources of information about care and about living positively with HIV.

4.4 The benefits of information, counselling and voluntary HIV testing for different clients in reproductive health settings: a summary

Potential mothers and fathers

Counselling and voluntary HIV testing can help women and men who may be considering starting or expanding their families to:

- weigh up the risks and advantages of a pregnancy
- make choices about contraception
- make choices about preventing future HIV infection, including condom use

Pregnant women who test HIV-negative

Counselling a woman following a negative test can help her

- understand and maintain safe behaviour to avoid future infection
- breastfeed for the greatest health of the infant

Pregnant women who test HIV-positive

Counselling a woman following a positive test can help her

- decide whether to share her HIV status with anyone and, if so, with whom
- choose to terminate her pregnancy where safe, legal and available
- choose to benefit from antiretroviral therapy where available
- understand infant feeding options and choose that which is best in her circumstances
- learn more about HIV infection and its implications for her health
- access support groups and health services that promote positive living
- make choices about sexual behaviour and future fertility



Partners of pregnant women

Counselling and voluntary testing of partners of pregnant women helps couples

- support one another in decisions about care and infant feeding
- make decisions about future fertility
- choose behaviours that reduce the risk of contracting or spreading HIV

The wider community

Widespread availability and use of counselling and voluntary testing for HIV in a community can

- reduce fear, ignorance and stigma surrounding HIV
- stimulate a community response in support of those needing care
- contribute to an environment supportive of safer sexual behaviour
- reduce spillover of artificial feeding to HIV-negative mothers

5. Operational considerations

Providing counselling and voluntary testing for HIV in pregnancy-related services is easier said than done. While such services are clearly desirable wherever interventions to prevent HIV infection in infants and sexual partners of pregnant women can be offered, they will add to the cost of antenatal and reproductive health services.

This section of the document considers what is necessary in order to provide such services, and makes recommendations about staff training, counselling options and test types. It tries to focus on the feasible, rather than the ideal.

5.1 Staffing

In most developing countries, specialist counsellors are in short supply. And there is unlikely to be enough money available to train and hire as many specialist counsellors as would be needed in the context of routine antenatal care.

It is recommended, rather, that existing reproductive health staff be trained in the basics of counselling and testing for HIV. They are already familiar with many of the issues surrounding reproductive health and infant feeding. Training existing staff to provide additional advice on HIV care and prevention in the context of pregnancy may be easier than training professional counsellors to deal with all the medical questions that may arise around the subject of reproductive health and childbearing. However, extra staff will probably need to be hired to cope with the extra volume of work created by providing counselling and HIV testing services.

The work of providing information and counselling should be diffused as efficiently as possible throughout the hierarchy of care, according to the particular needs of each client. Much of the routine provision of basic information about HIV transmission, prevention and testing for example, can be done in groups and carried out by staff with little special training in counselling. For more complex issues—analysis of resources in helping HIV-infected mothers reach feeding decisions, or counselling of discordant

couples, for example—specialized counsellors may be needed and discussion with clients on a one-to-one basis will be essential. Regular staff should be able to refer those in need to progressively more specialized levels of counselling. The more specialized counselling may be provided by dedicated voluntary counselling and testing centres outside the reproductive health facility. Facility managers will need to identify services to which they can refer clients, and would be well advised to discuss their clients' needs with key staff in those services.

Health workers will need additional training in all the basic areas of pre- and post-test counselling if they are to provide useful HIV-related counselling to women contemplating a test or digesting its results. In addition, they may need extra training to help them deal non-judgementally with clients in often difficult situations. Perhaps most importantly, health workers need a rigorous understanding of the importance of confidentiality.

5.2 Types of information and counselling

Counselling needs vary according to the situation. It is often not necessary (and more often still not affordable) to impart all the necessary information to each woman in individualized in-depth pre and post test counselling sessions. The majority of women who test HIV-negative need less individualized post-test counselling than women who test positive, for example.

These varying needs should be taken into account in designing counselling and testing services. The reality is that, if counselling and testing for HIV are to become a routine part of already overstretched reproductive health services in low-resource, high-fertility countries, the degree of individualized attention provided is likely to fall short of the ideal.

Routine information that is relevant to all women and their partners regardless of HIV status may be imparted in group sessions. This is especially true of information provided before a test. Individualized counselling will be needed in order to answer specific questions that arise from the information, as well as to help women weigh up their particular situations and arrive at a decision about testing. A client should always be able to communicate in private her decision about whether or not to be tested.

Some post-test information, such as reinforced prevention information relevant to all clients regardless of HIV status, can also be given in groups. However the balance between general information needs and counselling needs is different for clients who have chosen to undergo a test and are receiving their results.

Pregnant women who are HIV-infected may need considerable individualized attention to help them arrive at decisions based on information imparted in groups. All women who test HIV-positive should receive individual counselling to help them reach important decisions about therapy, infant feeding, sharing their status and other aspects of living with infection.

Information on video

Obviously, human interaction and especially individualized attention are the ideals in providing information about HIV as well as in counselling clients. But limitations of time, money, space and personnel are likely to make these the exception rather than the norm in reproductive health settings in developing countries.

Much of the basic information people need when making decisions about sexual behaviour and fertility in the context of HIV does not vary according to context. Basic information about HIV infection, prevention, therapy and infant feeding can be imparted successfully on video, as experience in antenatal clinics in Thailand has shown. These videos have the advantage that their accuracy is assured and they are guaranteed to be informative and non-judgemental—not always the case where individual counsellors are involved.

Where information is imparted by video (or in group counselling sessions), people must always be given the opportunity to ask questions and discuss individual problems and circumstances in private with a trained counsellor.

Obviously, this option is not open to sites that have no electricity or video equipment, and is unlikely to be necessary or desirable in low-volume sites. Service providers will have to weigh up the one-time cost of video equipment versus the recurrent costs of counsellors' salaries and make decisions accordingly.

Couple counselling

Ideally, women and their partners should go through the whole pre-test counselling, testing procedure and post-test counselling together. However, since men very rarely accompany their wives or partners at reproductive health facilities, this is unlikely to happen unless efforts are made, where culturally appropriate, to make reproductive health-care settings male-friendly.

It is recommended that counsellors discuss the benefits of couple counselling with women during pre-test counselling sessions. Those women who would like to be counselled and tested together with their partners should be catered for or referred to specialized counselling and testing services. In the latter situation, a mechanism must exist for communicating test results to the original service providers, with the consent of the couple and without breaching confidentiality.

5.3 Types of testing

Visiting a clinic often requires considerable travel time and expense. Adding to this burden by requiring a woman who has chosen to be tested to return for her HIV test results may be unhelpful. It is likely to result in a high proportion of women not returning to collect their results—a waste of time and resources from the point of view of the service provider. In addition, sending specimens to a laboratory for testing can lead to lost samples and uncertain quality control.

Reliable rapid test kits for on-the-spot testing of HIV are now widely available at prices similar to laboratory test kits. These kits do not need highly trained staff or sophisticated laboratory equipment, although most do require refrigeration. Training clinic staff to use these kits can cut down on the time and paperwork involved in sending specimens for lab testing, and can avoid doubling travel time for clients. In terms of quality, they have been shown to be as reliable on a national level as laboratory testing services.

There are, however, some difficulties associated with rapid test kits. Firstly, on-the-spot testing may provide more opportunities for breaches of confidentiality than outside laboratory testing. The need to maintain confidentiality should be central to all staff training around testing and counselling for HIV.

Secondly, it is possible that women will feel obliged to undergo a test offered on the spot, without having thoroughly thought through the consequences. They may also want to discuss the implications of testing with their partners, and opt for couple counselling and testing. It is therefore suggested that women be told about rapid testing during the pre-test counselling, and then be given the opportunity to make an appointment to come back at a convenient time if they decide they want to go ahead with the test. More information on rapid tests is available in WHO's *Weekly Epidemiological Record* (1998, **73**:321–326).

6. Cost considerations

Since counselling and voluntary testing for HIV has so rarely been offered as a routine part of pregnancy-related services in developing countries, there are few data upon which to base discussions of cost.

Even the cost of therapy is uncertain in this rapidly developing field. Prices range from US\$0 to US\$4 for nevirapine (one dose to the mother and one dose to the infant), depending on whether or not there is access to the nevirapine donation programme; about US\$50 for one month's course of zidovudine for prevention of MTCT in developing countries, to US\$300 for a course of zidovudine given from week 14 of pregnancy to the mother and for 6 weeks to the infant. The short-course therapy for a full zidovudine/3TC regimen, as in the Petra study, would cost about US\$60.

The cost of breastmilk substitutes varies considerably from country to country (from US\$60 to US\$450 per 6 months)¹. Often, high import duties on infant formula milk considerably raise the price to the consumer. Additional costs associated with the use of breastmilk substitutes are the costs of fuel, clean water, clean implements and preparation time.

There is virtually no information at all to quantify non-monetary costs and benefits associated with interventions to reduce HIV transmission from mother to child—costs such as increased stigma or improved child survival. (In this section, 'costs' refers only to monetary costs.)

Some work has been done to investigate the costs of providing counselling and voluntary testing, although not in reproductive health settings. The cost

¹ *HIV and Infant Feeding: A guide for health care managers and supervisors.*
UNAIDS/98.4

per person counselled ranges between US\$4 and 12. The majority of that is spent on training and salaries for staff. Since it is suggested here that as much counselling as possible be done by regular staff in reproductive health settings, the cost may be expected to be rather low.

What is clear is that the costs will be shared between service providers and their clients. The extent to which service providers pass costs on to their clients will depend on many factors, including market demand.

Costs and benefits to pregnant women and their families

In most low-income countries, HIV-positive pregnant women and their families will not be able to bear the bulk of the monetary costs associated with drug interventions to reduce transmission of HIV to their infants, unless this is subsidized or provided at no cost. In addition to the cost of therapy, the cost of replacement feeding, and the time, water, fuel and implements needed to prepare and deliver them, should be taken into account.

Women may also have to pay for testing and post-test counselling, and the demand for these services will certainly be influenced by the cost.

The major financial return for a family in averting the transmission of HIV from mother to child is the savings in medical bills and care for sick children, and funeral costs. The non-monetary benefits of bearing and raising a healthy child are incalculable.

Costs and benefits to the service provider

If providers of pregnancy-related services are to integrate counselling and voluntary testing for HIV into their routine work, they will have to absorb most of the costs of establishing the service.

The bulk of those costs are likely to be in staff training, and in the recruitment of staff to help with the extra workload implicit in providing an integrated counselling and testing service. Test kits must be procured or laboratory services contracted; these costs may or may not be passed on to the client, although the service is unlikely to be sustainable unless some cost recovery is planned for. Some investment will also be required in setting up systems to ensure the confidential treatment of HIV-related data.

Where health services are provided by the public sector, a return can be expected in terms of lower costs of caring for HIV-infected children. This is especially the case in countries where health services are routinely provided free to infants and children under the age of five.

List of documents on MTCT available through the UNAIDS Information Centre or through UNAIDS' website (www.unaids.org):

General information

UNAIDS. *HIV Transmission from Mother to Child*, Technical Update, Geneva, UNAIDS, October 1998.

Prevention of HIV Transmission from Mother to Child: Planning for Programme Implementation, Report from a Meeting, Geneva, 23-24 March 1998, UNAIDS.

Prevention of HIV Transmission from Mother to Child: Strategic Options, Geneva, UNAIDS, 1999.

UNAIDS. *AIDS 5 Years since ICPD: Emerging issues and challenges for women, young people and infants*, UNAIDS Discussion Document, Geneva, UNAIDS, 1999.

HIV counselling and testing

The importance of simple/rapid assays in HIV testing: WHO/UNAIDS recommendations. *Weekly Epidemiological Record*, 1998, **73**:321-328.

Antiretroviral treatments

WHO, *Prevention of mother-to-child transmission of HIV: selection and use of nevirapine*. Technical Notes. Geneva, WHO/HIV_AIDS/2001.3, WHO/RHR/01.21

New Data on the Prevention of Mother-to-Child Transmission of HIV and their Policy Implications: Conclusions and recommendations. Geneva, 11-13 October 2000. http://www.unaids.org/publications/documents/mtct/MTCT_Consultation_Report.org

Gray G et al. *The PETRA study: early and late efficacy of three short ZDV/3TC combination regimens to prevent mother-to-child transmission of HIV-1*. XIII International AIDS Conference Durban, South Africa, - 9-14 July 2000 Abstract LbOr5 <http://www.aegis.com/conferences/13WAC/LbOr5.html>

WHO/UNAIDS recommendations on the safe and effective use of short-course ZDV for prevention of mother-to-child transmission of HIV. *Weekly Epidemiological Record*, 1998, **73**:313-320.

UNAIDS, WHO. *Guidance modules on antiretroviral treatments. Module 6: The use of antiretroviral drugs to reduce mother-to-child transmission of HIV*. Geneva, UNAIDS/WHO, 1998, UNAIDS/98.7.

HIV and infant feeding

UNICEF, UNAIDS, WHO. *HIV and Infant Feeding: A review of HIV transmission through breastfeeding*. Geneva, UNAIDS, 1998, UNAIDS/98.5.

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HIV and Infant Feeding: A UNAIDS/UNICEF/WHO policy statement. Geneva, UNAIDS, 1997.

Planning, implementation and monitoring and evaluation

Vertical Transmission of HIV—A rapid assessment guide, 1998.

Local Monitoring and Evaluation of the Integrated Prevention of Mother-to-Child HIV Transmission in Low-Income Countries, 1999.

MTCT prevention in Asia

Thaineua V et al. From research to practice: use of short-course zidovudine to prevent mother-to-child HIV transmission in the context of routine health care in Northern Thailand. *South East Asian Journal of Tropical Medicine and Public Health*, 1998.

MTCT prevention in Latin America

Prevention of vertical transmission of HIV. Report from a workshop, Buenos Aires, 29-31 July 1998.

MTCT prevention in Africa

The Zimbabwe Mother-to-Child HIV Transmission Prevention Project: Situation Analysis.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) is the leading advocate for global action on HIV/AIDS. It brings together seven UN agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO) and the World Bank.

UNAIDS both mobilizes the responses to the epidemic of its seven cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV on all fronts: medical, public health, social, economic, cultural, political and human rights. UNAIDS works with a broad range of partners—governmental and NGO, business, scientific and lay—to share knowledge, skills and best practice across boundaries.

At one time, little was known about preventing mother-to-child transmission of HIV. However, the recent development of effective and affordable interventions reduces the likelihood that a woman will pass HIV on to her baby. The two most important interventions are the provision of antiretroviral drugs and the avoidance of breastfeeding—both of which require that a woman know her HIV status. Yet developing countries, where 95% of mother-to-child infections occur, have few counselling and testing services to help women access this information. Counselling and voluntary testing for HIV also contribute to an increase in safe behaviour at the individual level, and are likely to reduce the ignorance, fear and stigma associated with HIV infection in the population at large.

This document provides guidance on counselling and HIV testing for managers of pregnancy-related services. It offers an overview of mother-to-child transmission of HIV, focusing on the benefits of counselling and voluntary HIV testing in the context of pregnancy, and discussing the content of such counselling. Operational issues and potential difficulties in setting up and maintaining such a service are also explored.



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