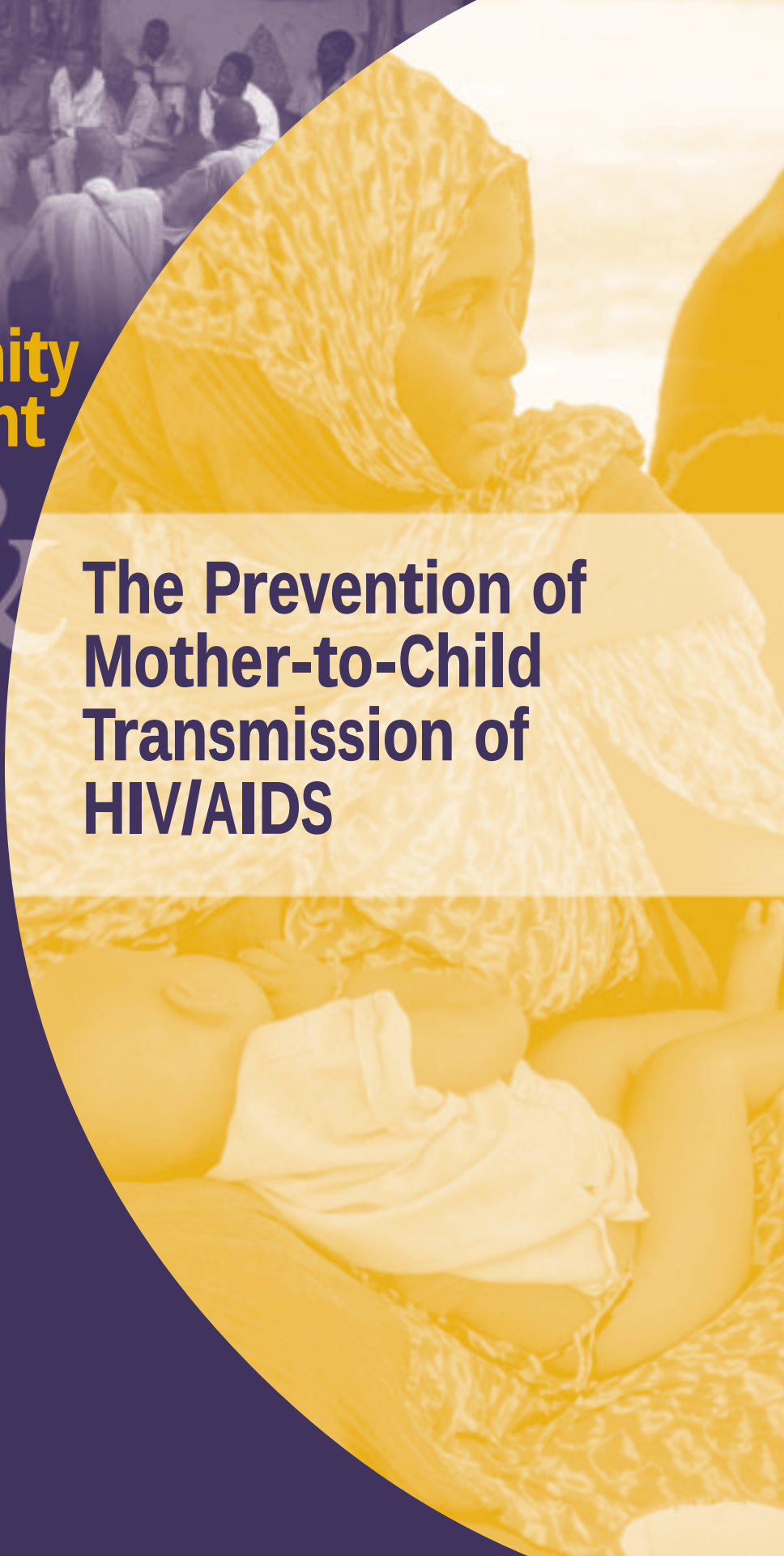
Community Involvement

&

The Prevention of Mother-to-Child Transmission of HIV/AIDS



ICRW
International Center for Research On Women

In 2001, approximately 800,000 children acquired HIV infection, the majority of them via mother-to-child-transmission (MTCT). Yet medical interventions currently available, if provided, could save the lives of 300,000 children per year. *To be most effective, medical treatments must be combined with educational efforts that inform communities about HIV/AIDS and reduce the stigma associated with it.*

Understanding Mother-to-Child-Transmission (MTCT) of HIV/AIDS

MTCT is the primary cause of HIV infection in children under 15. In 2001, 2.5 million babies were at risk of HIV infection through MTCT. However, transmission from an HIV-positive woman is a risk, *not* a certainty.

How is HIV transmitted?

HIV can be transmitted from mother to child during pregnancy, labor and delivery or through breastfeeding.

- Without treatment, the risk of MTCT during pregnancy, labor and delivery is about 15-30%.
- It is estimated that a child born uninfected to an HIV-positive mother has a 5-15% chance of acquiring the virus from her milk if exclusively breastfed; the risk of transmission is much higher if breastfeeding is mixed with other liquids or solids.

About 5,000 women are infected with HIV every day

MTCT and breastfeeding: keys to decisionmaking

The WHO and UNICEF recommend that mothers with HIV avoid breastfeeding entirely when replacement feeding is:

- Acceptable—is bottle-feeding accepted within the culture?
- Feasible—is refrigeration and sterilization equipment available?
- Affordable and sustainable—will there be a long-term supply of breast milk substitutes and a dependable system to ensure that infants will have sufficient quantities as long as needed?
- Safe—is the water supply safe for drinking?

As of December 2001, 17.6 million women were living with HIV/AIDS—nearly half of all adults infected with the virus

It is also important to consider the health of the mother and infant when deciding whether or not to breastfeed. For example, the risk of transmitting HIV/AIDS is higher if the infant has a mouth infection, if the mother has recently contracted HIV, or the disease is at an advanced stage in the mother.

However, replacement feeding must be considered in the context of other factors in the particular environment. In many developing countries, safe and accessible replacement feeding is rarely an option. The risk of illness or death of the infant due to improper use of breast milk substitutes (e.g., if mixed with unhygienic water or if over-diluted) might be greater than the risk of MTCT through breastfeeding. Even if a woman has access to safe breast milk substitutes and knows how to use them properly, her decision not to breastfeed might draw attention to her HIV status, putting her at risk of discrimination or even violence and abandonment by her family and community.

Should mothers choose to breastfeed, breastfeeding must occur *exclusively* during the first three to six months; anything other than breast milk in the infant's diet, including water, will increase the risk of transmission (*see box*). If mothers choose not to breastfeed from birth or to stop breastfeeding later, they should be provided with specific guidance and support for at least the first two years of the child's life to ensure adequate replacement feeding.

When Breastfeeding is the Safest Option for HIV-Positive Women

Evidence suggests that in the first three months, the risk of MTCT is actually *lower* if an HIV-positive mother feeds the baby *exclusively* with breast milk—that is, when an infant is given no other food or drink of any sort—than if she mixes breast milk with other liquids or solids. Why is this the case?

Consumption of cow's milk, allergic reactions to other foods, and infectious illnesses that can be introduced through food and drink other than breast milk can all damage the infant's digestive tract, making it easier for the virus to enter the bloodstream. Infants could therefore be doubly disadvantaged by being at higher risk of HIV transmission through HIV exposure from breastfeeding and by exposure to risks related to replacement feeding.

What are the Obstacles to Preventing MTCT?

Lack of access to treatments

Most HIV-positive children are born in developing countries. More than 95% of HIV-positive women in the world live in developing countries, along with an estimated 90% of all HIV-positive children.

In industrialized countries, the combination of anti-retroviral (ARV) drug treatments for the mother, along with other preventative measures such as delivery by caesarean section and counseling, has resulted in the near elimination of MTCT. While resource-poor countries have not yet experienced the same level of success, decreasing costs of ARVs over the past several years means that women in resource-poor countries can greatly reduce the risk of infection in their infants: treatments costing less than $5 per birth can reduce risk of transmission to infants by 50%.

However, accessibility is often still problematic; in spite of lower costs, ARVs are still out of reach or simply not available to many women in developing countries. Another common obstacle for such women is an inadequate health care system to properly administer ARVs.

The role of social factors

Even when ARVs are available, women who live in close-knit families and communities might choose not to protect themselves or their unborn children rather than risk rejection by their families and community if they are known or perceived to have HIV/AIDS. This fear of rejection is largely due to the stigma that is associated with the disease.

Fear of stigma and discrimination against people living with HIV/AIDS discourages some women from taking precautionary measures that can greatly reduce the risk of MTCT, such as testing to find out their HIV/AIDS status; seeking counseling if they are HIV-positive and pregnant; taking ARVs while pregnant; or choosing not to breastfeed.

"When you get AIDS you are ridiculed by society…You are ill-treated… People think you have been careless, promiscuous."

–young pregnant woman in Botswana

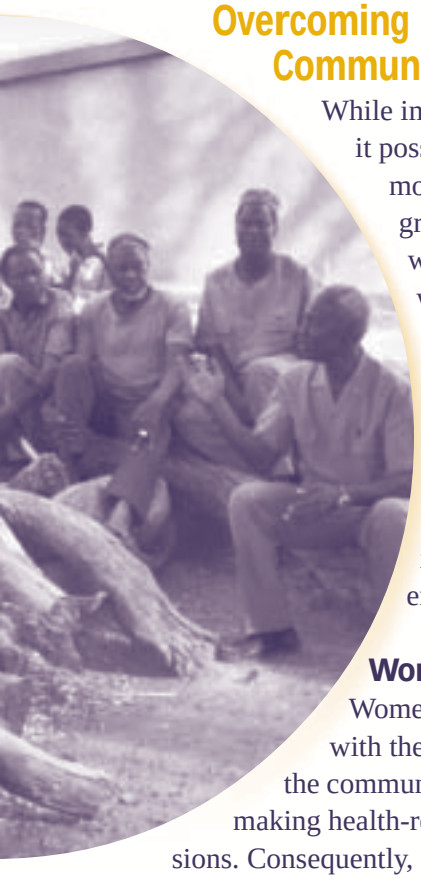
Emphasis of treatments for the child but not the mother

In large part, programs using ARVs for MTCT prevention have tended to focus only on the survival of children. This can result in a disincentive to pursue MTCT prevention options. While mothers often wish to protect their babies, their husbands and communities might not see the usefulness of a

In 2001, 1.8 million women became infected with HIV

treatment that protects babies but leaves the mothers to die. As one participant noted in Botswana and Zambia studies[1] on communities and MTCT, "…what is the point [of keeping the baby alive when]…there will be no mother to raise the baby?" Donors, recognizing this gap in treatment efforts, are now beginning to coordinate efforts to provide HIV-specific and other health care to mothers who participate in projects working to prevent MTCT.

Overcoming Obstacles: The Importance of Community Involvement



While important biomedical breakthroughs using ARVs make it possible to prevent most cases of HIV transmission from mother to child, the potential impact of ARVs will be greatly magnified—or diminished—depending on whether or not they are accepted in the communities which stand to benefit from them.

Because the transmission of HIV from infected mothers to their fetuses occurs within women's bodies, programs often are targeted at women only. Yet, interventions to reduce the risk of MTCT are not likely to succeed if they address women in isolation; successful interventions *must* involve the entire community.

Women's health, community decisions

Women often consult with their families and the community when making health-related decisions. Consequently, in order to succeed, programs to prevent MTCT must be able to provide information, education, services, and support to these significant others in women's lives. Without this, community members cannot provide guidance that will most effectively minimize the risk of MTCT.

The provision of education and information dissemination on HIV/AIDS should not be limited only to prenatal clinics. Limiting outreach work to prenatal clinics inevitably will exclude critical members of the community who do not use these clinics—men and community elders—from accessing vital information. Consequently, they will be less likely to have an accurate understanding of HIV/AIDS and MTCT. This enables stigma and misconceptions to persist, making it less likely that men and elders will be supportive of women seeking care.

[1] In 1999, Glaxo Smith Kline (formerly Glaxo Wellcome, Inc.) and UNAIDS jointly funded the International Center for Research on Women to lead two community-based research studies in Botswana and Zambia on the perspectives, needs, and preferences of women and communities regarding the mother-to-child-transmission of HIV.

The extent of misinformation among communities can be seen in findings from the Botswana and Zambia studies. For example, community members believed that if the mother was HIV-positive, the baby would inevitably be as well; and community members were skeptical that drugs could prevent transmission of HIV from mother to child due to their misunderstandings about pregnancy and fetal blood supply. Such misunderstandings could result in decisionmaking that does not optimize the survival chances of an infant born to an HIV-positive mother.

HIV/AIDS-related stigma and discrimination

Reducing stigma surrounding HIV/AIDS and the resulting discrimination against those with the disease is a community-wide effort. A key finding of the Botswana and Zambia studies was that HIV-related stigma and discrimination is a major barrier to voluntary counseling and testing, and that pregnant women typically resist being tested for fear that, if they were found to have HIV, they would be subject to stigma and discrimination.

If HIV/AIDS is destigmatized and women are confident that they will not be discriminated against if they are known to be HIV-positive, they might be more likely to seek out treatment and take preventative measures to avoid passing the disease on to their child, and also to take measures to enhance the quality of their own lives.

Five Steps to Creating an Effective Program to Prevent MTCT

1. Survey the community to design effective and appropriate services and messages for the prevention of MTCT of HIV

Qualitative research (such as through focus group discussions) is a recommended approach to gauge community knowledge of and attitudes on HIV/AIDS, and how these affect behavior; to assess community perceptions of the need for information and services; and to expose knowledge gaps and misinformation about HIV/AIDS and how it is transmitted.

Programs that involve community members in developing, implementing, and monitoring activities are more likely to be acceptable to the community and to have more effective outcomes.

Since the beginning of the epidemic, an estimated 5.1 million children worldwide have been infected with HIV

2. Introduce interventions to reduce stigma

Stigma has a significant influence on an individual's willingness to undergo HIV testing or to participate in other components of prevention programs. Program messages should address knowledge gaps and misconceptions about the prevalence of HIV infection, promote hope and compassion, and offer advice about and examples of positive living with HIV/AIDS.

3. Foster social support for women

Programs should support the ability of women to make independent decisions. Women should have full control over who knows about their HIV status and over information regarding their health that they share with others. Also, counseling and support should be available on a continuous basis, not just when first tested.

4. Ensure ongoing dialogue between health service providers and the community

Health service providers should keep community members informed about the purpose and availability of program services and also monitor the acceptability and impact of the program within the community.

5. Establish a mechanism for evaluation

Programs must determine who is being reached by their messages and services, assess their acceptability in the community, and then act on this information. The feasibility of each of the program elements for clients, their families, providers and the community should be continually monitored. Mechanisms need to be established to respond to problems and changes in community perceptions, knowledge, and understanding.

Community advisory committees are a useful means to offer program managers and service providers feedback on how the program is being received and how it can be improved. In addition to providing guidance and feedback, advisory committees can be actively involved in all phases of program evaluation, including formative research to design services and messages, development of program indicators, analysis of the information collected, and dissemination of information to program staff and the community.

For more information

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