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HIV-infected women and their families: psychosocial support and related issues

A literature review



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Abbreviations

3TC	Lamuvudine
AIDS	Acquired immunodeficiency syndrome
ANC	Antenatal care
ART	Antiretroviral treatment
ARV	Antiretroviral
AZT	Zidovudine (also ZDV)
HIV	Human immunodeficiency virus
MTCT	Mother-to-child transmission
NGO	Nongovernmental organization
PETRA	Perinatal transmission study
PLHAs	People living with HIV/AIDS
PMTCT	Prevention of mother-to-child transmission
RTI	Reproductive tract infection
STD	Sexually transmitted disease
STI	Sexually transmitted infection
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
VCT	Voluntary counselling and testing
WHO	World Health Organization
ZDV	Zidovudine

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Background

In April 2000, the Department of Reproductive Health and Research of the World Health Organization (WHO) commissioned a global review of the literature (emanating from academic institutions and United Nations agencies) on psychosocial support and counselling to HIV-infected pregnant women and their families. This review also collected information about practices and projects that care for HIV-infected women and their families throughout the world. The purpose of this review was: (i) to find out what literature was available on psychosocial support and counselling to HIV-infected women and their families (from preconception until the child is two years old); and (ii) to learn what methods were being employed in existing projects to support and care for HIV-infected women and their families in relation to mother-to-child transmission (MTCT) of HIV during the perinatal period.

The specific terms of reference were:

- to review the literature on psychosocial support to women with a special focus on pregnant women with STIs/HIV/AIDS and summarize the lessons learnt;
- to examine the structure and efficacy of programmes for the support of HIV-infected women and their families, and issues related to discrimination, abuse, exploitation and social injustice to pregnant women/mothers and their families;
- to collect, review and assess any work that is being undertaken by different United Nations agencies, donors, international/national nongovernmental organizations (NGOs) and professional groups such as psychologists, nurses/midwives, physicians, etc.;
- to synthesize and derive recommendations from the lessons learnt that would be useful for health care workers and community groups to support HIV-infected women and their families, not only during pregnancy and delivery but over the long term.

This review is divided into three sections. Section one provides a synthesis of the reviewed literature on prevention of mother-to-child transmission (PMTCT) of HIV, voluntary HIV testing and counselling (VCT), and other issues that impact on the care, psychosocial support and counselling needs of HIV-infected women and their families in the perinatal period. Section two provides examples from around the world of projects that focus on the care and support of women and families, with a focus on MTCT. The final section contains recommendations on psychosocial support and counselling for HIV-infected women and families.

Section One

Review of the Literature

Review of the Literature

Introduction

The acquired immunodeficiency syndrome (AIDS) is a profound human tragedy and has been referred to as the “world’s most deadly undeclared war” (1). The human immunodeficiency virus (HIV) and AIDS continue their devastating spread, affecting the lives of 16 000 people each day with women, babies and young people being increasingly targeted. According to the latest data from the Joint United Nations Programme on HIV/AIDS (UNAIDS) (2), there are now approximately 40 million people living with HIV/AIDS (PLHAs) worldwide, of whom 17.6 million are women and 2.7 million are children under the age of 15 years. This report also states that there is now compelling evidence that the trend in HIV infection will have a profound impact on future rates of infant, child and maternal mortality (2). In fact, MTCT of HIV is by far the largest source of HIV infection in children below the age of 15 years. In countries where blood products are regularly screened and clean syringes and needles are widely available, MTCT (also known as vertical transmission or perinatal transmission) is virtually the only source of HIV transmission in young people (3). A cumulative total of over 13 million children under the age of 15 years have lost their mother or both parents to AIDS (1). Though Africa accounts for only 10% of the world’s population, about 90% of all HIV-infected babies are born here, largely as a consequence of high fertility rates, combined with very high infection rates (3). However, the virus is now spreading fast in other regions of the world, and everywhere the proportion of women among those infected is growing.

AIDS threatens to reverse years of steady progress in child survival. In Harare, Zimbabwe, for example, between 1990 and 1996, AIDS caused infant mortality to double from 30 per 1000 to 60 per 1000; it is likely that this is also the case in other most affected regions of the world. Also, deaths among one-to-five-year-olds, the age group in which the bulk of child AIDS deaths are concentrated, rose from 8 per 1000 to 20 per 1000 in the same period (4).

These devastating statistics point to the need for therapeutic interventions for PLHAs including infected mothers and their infants. Considerable advances have been made in discovering new and varied types of short-course antiretroviral therapies (ART) and other medical interventions that have considerably reduced the transmission of HIV from mother to child (5). In various parts of the world, new and advanced antiretroviral (ARV) regimens and other forms of treatment, combined with no breastfeeding are reversing MTCT trends (4). However, these therapies are not available globally. Lack of an adequate health care infrastructure and financial resources are the primary reasons why these therapies are not available to all those who need them (4).

Voluntary HIV testing and counselling (VCT) plays a vital role in preventing MTCT. The primary focus of VCT is on knowledge development and risk assessment in order to promote HIV testing. If a person tests positive for HIV, then counselling focuses on behavioural change and supportive adherence counselling with therapeutic regimens. As one group of researchers states, VCT is “a tool in controlling the spread and effects of this disease” (6).

Although VCT is vital in preventing MTCT, what about the psychosocial and emotional needs of women and families who test HIV positive? There is considerable evidence to suggest that people can only absorb and understand new and important health information through effective interpersonal communication (7–10). This communication goes beyond the simple provision of information; it addresses the emotional, psychological and personal/social/legal needs of the persons being counselled. Issues of family violence, abuse, legal inequity, discrimination, stigma, poverty and others lead to vulnerability and oppression for HIV-infected women and their families. In addition, the emotional reaction to an HIV-positive diagnosis can be profound (11). New and important

information related to the prevention and care of HIV/AIDS is difficult to absorb through a filter of emotional distress (12). Therefore, people need more than the provision of information to promote HIV testing, behavioural change and adherence; they also need considerable psychosocial support and emotional counselling in order to live effectively, adhere to therapeutic interventions and enhance their quality of life.

How the literature was searched

The keywords used to access literature included: HIV, AIDS, mother-to-child transmission, HIV pregnancy, HIV newborn/paediatrics, HIV counselling, HIV psychosocial support, HIV disclosure, HIV vertical transmission, perinatal HIV, HIV voluntary counselling and testing, HIV diagnosis, HIV interventions, HIV and violence, and HIV and women. The search engines used were psych info, CINHALL, Medline, Grateful med, Health star, Healthlink.org.UK, pubmed, dogpile and google. In addition, literature was accessed from the WHO, UNAIDS, United Nations Children's Fund (UNICEF), *African Journal of Health*, *International Journal of STD and AIDS*, and approximately 15 different HIV/AIDS internet web sites. Over 200 pieces of literature were accessed via these means and 151 are referred to in this report. Following the literature review, people and projects throughout the world were accessed via email, telephone and facsimile to learn about the various practices and services provided for HIV-infected women and their families related to the prevention of MTCT. There was correspondence with over 150 people for this purpose. Finally, people attending the 13th International AIDS Conference in Durban, South Africa, in July 2000 provided further details on services and projects related to psychosocial support and counselling.

Readers wishing to have more information on VCT, MTCT, orphans and recent reports on the global HIV/AIDS epidemic are referred to the following publications:

- *Voluntary counselling and testing for HIV infection in antenatal care: practical considerations for implementation* (13)
- *Counselling and voluntary HIV testing for pregnant women in high HIV prevalence countries: elements and issues* (14)
- *Report on the global HIV/AIDS epidemic 2001* (2)
- *Children orphaned by AIDS: frontline responses from eastern and southern Africa* (1)
- *HIV/AIDS: emerging issues and challenges for women, young people, and infants, 2nd ed.* (3)
- *Prevention of HIV transmission from mother to child: strategic options* (4)
- *Fact sheets on HIV/AIDS for nurses and midwives* (15)
- *Source book on HIV counselling training* (16)
- *Counselling for HIV/AIDS: a key to caring* (17)
- *HIV and infant feeding: guidelines for decision-makers* (18)
- *The impact of voluntary counselling and testing: a global review of the benefits and challenges* (19)
- *New data on the prevention of mother-to-child transmission of HIV and their policy implications: conclusions and recommendations* (20)
- *Discussion paper on models for VCT for MTCT interventions in Eastern Europe* (21)

Women and vulnerability

The effect of the AIDS epidemic on women has changed considerably over the past decade (22). Currently, women are at the centre of concern. WHO estimates that women account for almost half of all newly infected adults and, worldwide, there are 15.7 million women living with the HIV infection. Girls become infected at an earlier age than boys due to biological, sociocultural and economic factors. This rise in female infection rates also affects MTCT. Studies of women attending antenatal clinics find that many women are monogamous and have been infected by their one partner, usually their husband (16). Sexual coercion of women, or the act of forcing or attempting to force another individual through violence, threats and verbal insistence is found worldwide (23). Violence against women is often socially tolerated and, in some contexts, forced sex with a spouse and wife beating are accepted or even expected expressions of masculinity (24,25). The most common form of violence against women is abuse by a male partner (26).

Migration as a result of war, famine, political oppression or poverty can increase a woman's vulnerability to HIV infection if she is isolated from community structures and support, and does not speak or read the local language. Female migrant workers, refugees or returnees are often more vulnerable than other women to some kind of sexual barter as they try to negotiate employment, necessary documentation or a place to live (22). In times of war, rape of women is widespread (27). Furthermore, according to UNAIDS (3), there are women from traditional families who are caught in a terrible bind of pressure to produce children while being unable to admit that they have contracted HIV from a husband who is unfaithful. There are teenage girls from very poor homes whose only way of staying at school is to barter sex with teachers or "sugar daddies" to pay for books, school uniforms and fees. Research confirms that nonconsensual sex is pervasive in the lives of girls and women (3).

Infants born to HIV-infected mothers acquire the infection either through pregnancy, delivery or breastfeeding. Most of these mothers have no real choice because ARVs and other prophylactic measures are either unavailable to them, or they are unaware of their availability. Also, they are unaware of, or have no real choice about, safe and affordable replacement feeding alternatives for their babies. In addition, many women are afraid of drawing attention to their HIV status by not breastfeeding, and suffer in silence while putting their babies at risk because of the cruel stigma attached to AIDS.

Cultural practices such as female genital mutilation may also increase the risk of HIV transmission through tearing and other trauma during sexual intercourse. According to WHO, 130 million women worldwide are living with the consequences of this practice and an estimated two million young girls each year are at risk of being subjected to it. In addition, a large number of studies conducted in many countries and in all continents of the world, suggest that between one-third to one-half of all married women have been beaten or otherwise physically assaulted by their partners (13). In this sense, women are at high risk of suffering verbal, physical or sexual abuse (28). The most powerless and vulnerable are children and women coerced into the sex trade by traffickers. An estimated two million girls 5–15 years of age are coerced into the trade each year. Unfortunately, prostitution is often the only means of financial security for women, but they rarely have the power to negotiate condom use.

Many women live in poverty, lack education and economic opportunities, and suffer subordination to men (3,29). In recent US studies, HIV-infected women were noted to be predominantly single parents, belonging to a racial minority group, and living in poverty in marginalized communities with poor access to health care and other social, financial and legal services (28,30). In many cultures there are social and cultural taboos about discussing sexuality. Consequently, women have inhibitions about seeking information on HIV or procuring condoms. Many women remain powerless and are afraid to request condom use with their partner as they fear a violent reaction or aban-

donment by the man on whom they are entirely dependent for survival (16,19,31,32). In addition, women often have no right to inherit land and property, they have limited opportunities to run a business of their own and have limited access to health care. Thus, in some of the worst-affected countries, HIV-infected women outnumber infected men by as much as 16 to one in the younger age groups (3). This disproportionate risk for women has enormous social implications since they are the principal guardians of future generations and the caregivers and nurturers of society. Yet, women's health and well-being have always received a low priority (3).

Some national laws reinforce women's economic dependence on men, such as those restricting property ownership and inheritance. Also, in some cases, laws limit women's ability to enter into independent contracts or obtain credit under their own names and impede their ability to control income and property. These practices reinforce women's economic dependence on male relatives. Laws regarding marriage, divorce and child custody can prevent women from leaving relationships in which they or their children are physically or sexually abused, or exposed to the risk of HIV infection (16). Succession rights need to be protected or revised in order to enable women to exercise their rights and control their property, and children to inherit from their parents.

Women and young girls also suffer from biological vulnerability. Research shows that the risk of becoming infected with HIV during unprotected vaginal intercourse is as much as 2–4 times higher for women than men (15). Male-to-female transmission during vaginal intercourse is more efficient as women have a larger mucosal surface area exposed to their partner's semen, which has a higher concentration of HIV than a woman's vaginal secretions. In addition, women are also more vulnerable to other sexually transmitted infections (STIs) that multiply the risk of contracting HIV tenfold. Younger women are even more at risk as their immature cervix and scant vaginal secretions make them prone to vaginal mucosal lacerations. There is also evidence that women become more vulnerable to HIV infection again after the menopause. In addition, tearing and bleeding during intercourse, whether from rough sex, rape, or prior genital mutilation increase the risk of HIV infection, as does anal intercourse. [Anal intercourse is sometimes preferred to vaginal intercourse by those who want to preserve virginity and avoid the risk of pregnancy. However, anal intercourse often tears the delicate anal tissues and provides easy access to the virus (15).]

People's experiences of HIV/AIDS in developed and developing countries

The main modes of HIV transmission for people living in developed countries are from the male to male unprotected sexual intercourse and sharing HIV-contaminated needles and syringes during injecting drug use (31). However, the incidence of AIDS in women in these countries is increasing steadily through heterosexual exposure, i.e. from male partners. Most people living in developed countries have access to affordable or free health care, including various ARTs and treatments for opportunistic infections.

In contrast, in the developing world, 40% of women lack access to adequate antenatal care (ANC). In sub-Saharan Africa, less than half of all births are attended by a professional health care provider, with even lower levels being reported from individual African countries and some parts of Asia. Moreover, the proportion of people without access to any health care ranges from over 40% in some parts of Latin America and Asia to nearly 80% in the poorest parts of Africa (3).

Reports from studies in Africa and the developed world indicate that even before the introduction of ART, the rates of MTCT in the European Collaborative study were lower than those of cohort studies in Africa (33,34). Variations in infection rates may be due to differences in viral strains or to other characteristics such as nutritional factors, types of prenatal care received, or the prevalence of other STIs (35).

In less developed countries ANC is limited, testing programmes for HIV are almost nonexistent, effective interventions for PMTCT remain unimplemented, and prevention of postnatal transmission of HIV through breast milk, without compromising infant nutrition, is a major dilemma (36).

HIV/AIDS also has a disastrous effect on family economics. For example, in Côte d'Ivoire, when a family member has AIDS, the average income may fall by as much as 52–67%, while expenditure on health care can quadruple. In addition, food consumption has been found to drop by 41% (1).

Stigma and discrimination

In reviewing the literature on stigma, Alonzo and Reynolds (37) contend that stigma represents a construction of deviation from some ideal or expectation. Stigma is a powerfully discrediting and tainting social label that radically changes the way individuals view themselves, or how they are viewed by others. When individuals fail to meet societal expectations they become discredited and are rejected, which isolates them from themselves and others. These authors have developed a stigma scale that moves from considering oneself at risk of contracting HIV infection, to being diagnosed as positive for HIV, to the asymptomatic or latent period of living with the virus undetected, to the manifest stage of symptomatic infection.

Most people living with HIV and AIDS suffer or fear stigmatization (21,31, 44). Studies from Africa (38–42) suggest that AIDS stigma is linked to people's sense of sexual morality and their fear of breaking taboos (43). It is thought that the fear of stigma adversely influences women's health-seeking practices (45–47). A "conspiracy of silence" (13) exists in which HIV/AIDS is seldom openly discussed, even in heavily affected areas. People do not want to admit that a fatal disease spread by behaviour branded as "immoral" could be rampaging through their community or their country (13). Unfortunately, in places where denial flourishes, people are most vulnerable to the silent spread of HIV. Discussions of sexual practices or use of illicit drugs are often taboo and associated with embarrassment, shame, guilt and rejection.

Cultural norms of silence regarding sexual practices, preferences and desires can be problematic (15). Rarely are people open about their HIV status and many people go untested for fear of the result. It is still common for women to be blamed for spreading STDs, including HIV, despite the fact that women are often infected by their husbands or partners, to whom they are entirely faithful. Interventions to reduce HIV infection in MTCT, particularly the administration of ARV prophylaxis and avoidance of breastfeeding, make it virtually impossible for HIV-infected women to keep their infection a secret from their families and people in the wider community. Many women fear discrimination, violence and even murder if they are identified as HIV infected, and thus are reluctant or completely unable to take advantage of interventions offered to protect their infants from infection (13).

The consequences of stigma and discrimination for HIV-infected people are profound. It is common for stigmatized people to repress their anger at being discriminated against, which often manifests as self-hatred and shame (37,48–50). In addition, stigma and discrimination can lead to compromised care (15). Fear of contagion, victim-blaming, lack of confidentiality, and misinformation and negative attitudes about HIV significantly limit a caregiver's ability to provide effective, respectful and dignified care to PLHAs and their families (28,51–54). Some documented negative behaviours by health care workers include:

- condemning a PLHAs as a "bad person";
- considering women to be irresponsible for exposing their vulnerable fetuses to HIV;
- isolating or avoiding PLHAs because of embarrassment or not knowing how to deal with such people;
- refusing to treat or care for PLHAs;
- ignoring or refusing to discuss risky behaviours and HIV prevention; and
- inability or unwillingness to care for PLHAs and their families in a nonjudgemental, caring and supportive manner (13,15,21,55).

It has been suggested that people are more concerned about the social consequences of HIV—including issues of death, sex, misbehaviour (sin), blame, shame, rejection and stigma—than with the technical facts about HIV/AIDS (56).

Benefits and risks of disclosure

The benefits of disclosure of HIV status include: (i) increased knowledge about HIV/AIDS and its transmission (21,57); (ii) greater likelihood of adopting preventive measures and changing behaviour (using condoms, avoiding injecting drug abuse) (21,58); (iii) greater access to social, medical, psychological, financial and legal support for PLHAs (13,21); (iv) increased provision of psychosocial support to PLHAs on the part of family and community members (15,21,59); and (v) positive influence by PLHAs on others who might fear disclosure (60).

The benefits of shared confidentiality, i.e. disclosing one's HIV-positive status to a strictly limited number of persons, such as care providers or partners include: (i) expanding and sharing the burden of helping PLHAs beyond professional care providers; (ii) providing care and support that is sensitive to the person's cultural, traditional and social milieu; (iii) planning for future care including orphan care; (iv) enhancing the quality of life of PLHAs and their partners; and (v) enhancing the knowledge of HIV transmission and prevention (56). In relation to PMTCT, shared confidentiality is considered beneficial in order to prevent unwanted pregnancies and prevent the spread of HIV infection to uninfected partners. An additional benefit is in assisting the HIV-infected woman to plan for her future and that of her partner and children (59), and to access and adhere to therapeutic regimens such as ART and replacement feeding for the infant. However, in most VCT services associated with MTCT interventions, the pregnant woman is seen alone. Even when the involvement of partners is encouraged, male attendance at ANC clinics and their willingness to be tested is very low (21).

The major problems associated with disclosure of HIV status are the fear of experiencing stigma and discrimination, and the associated problems of rejection, abandonment, violence, abuse, loss of custody of children and property, and ostracism (see the chapter on "Women and vulnerability").

Over the past 15 years, notification of partners' HIV status has been a major public health strategy in HIV/AIDS prevention (61). There is wide consensus that partner notification and contact tracing could be used under certain conditions to protect people at risk of HIV infection (62,63). People living with HIV are encouraged and supported to inform their sexual partners of their status. A difficulty arises when the HIV-infected person is a woman who fears domestic violence and the partner to be notified is the man she fears (58). Hence, the problems of violence, abuse, discrimination and abandonment against women following disclosure have broad policy, legal and ethical implications that require re-examination of current public health requirements of disclosure and partner notification (21).

In a study in Baltimore, MD, USA (58), researchers interviewed care providers who counselled HIV-infected women. Forty-five per cent of the providers reported having had female patients express fear of physical violence as a result of disclosure to their partners, while 56% had had patients express fear of emotional abuse, and 66% had had patients who feared abandonment.

While talking to women about disclosure, Moneyham et al. (64) found that women did not tell their children or anyone else about being HIV positive because they feared that their children would be stigmatized and isolated by their classmates and neighbours. Roberts' (65) research arrived at similar conclusions.

In a study conducted in Nairobi, Kenya, Temmerman et al. (50) found that less than one-third of women living with HIV had informed their partners of their HIV status, and violence against HIV-positive women was common. Such violence included being chased away from their homes or being replaced by another wife and beatings; one woman was driven to suicide. In a similar study in Rwanda, Van der Straten et al. (23) found that women had suffered beatings and break-up of relationships. In contrast, in a West African study (66), more than half of the women undergoing

HIV testing stated that they wished to receive their test result in the presence of another person, namely their regular partner. A study in Zimbabwe (67) found that with enhanced counselling, 75% were able to disclose their HIV status to their partner/spouse. A Thai study found that 84% of the study participants had disclosed their HIV status to their partner while only 34% had disclosed it to family or friends (59). The reason for not disclosing to family or friends was reportedly a feeling of shame and fear of rejection and discrimination.

Sowell et al. (49) studied women's disclosure patterns in Georgia, USA and found that 90% of women disclosed their HIV status to health care providers, while only 69% reported disclosing it to their sexual partners. According to Seigel and Krauss (68), deciding whom to tell about one's HIV status entails trying to protect oneself from discrimination, assessing one's fear of rejection, and avoiding people who might inflict pain or pity. In an evaluation study in Uganda, Kaleeba et al. (69), found that 90% of people sampled—a rare high figure—had revealed their HIV status. However, this study also reported that only 36% of the sample revealed their serostatus to a spouse or sexual partner. It should also be noted that in this evaluation study, 41% of the respondents had been widowed. A Tanzanian study (56) reported that people often chose to postpone the disclosure of their HIV status because they felt they did not deserve the blame associated with the disease, or that the family burden of the stigma should be avoided. This study also found that people mostly chose a confidant of the same gender and generation. Reasons for these decisions included the desire to reduce the impact of moral judgement, and the near-prohibition of discussing sexuality across generations. In a Thai study (48), it was found that women who did not disclose their HIV status had higher levels of worry and feared family shame.

Although the emotional and physical ramifications of disclosure can be profound, Gielen et al. (57) found that women's fears of disclosure did not necessarily reflect their experiences when disclosure was made. The women in this study feared rejection, discrimination, public ignorance and violence, but reported somewhat different experiences when disclosure was made, i.e. emotional upset, acceptance and support, rejection and violence. Therefore, some of the women's fears were actualized in this study while others were not. All the women in this study felt that it was better to limit the number of people who knew their status in order to protect their own privacy and that of the family.

Despite the considerable barriers to shared confidentiality, one author raises the question of involving couples in PMTCT all the way from VCT through decisions on treatment and care (70), noting that "all arguments have been about mother-child transmission and not parent-child ... we have ignored the role of the father" (p. 8-10). In fact, studies have shown that providing HIV counselling and testing to both partners together can lead to greater acceptance and less abuse and abandonment of HIV-infected women. Thus, involving the fathers and couple counselling, or shared confidentiality, could promote the reduction of MTCT (5,21,70). However, questions must be raised about who should be responsible for partner notification—the counsellor or the woman. Such questions are very complex and no clear guidelines can be laid down. Therefore, each circumstance must be assessed individually, and decisions made by both the counsellor and the HIV-infected woman, about whether disclosure should be made and, if so, by whom. Such negotiations will be complex and might require repeated counselling before the best solution is found.

In conclusion, although public health mandates, and many AIDS organizations support, the need for shared confidentiality, decisions to disclose HIV status must be considered in light of the personal, social, psychological, financial and legal ramifications of doing so. However, it should also be stressed that shared confidentiality leads to better strategies for prevention, increased support from health and social service providers, and enhanced care and support from family and community members. It should also be noted that people's fears of disclosure might not fully represent their experiences of sharing their HIV status with designated others. Further information on issues related to the benefits of disclosure, ethical partner counselling and issues of case reporting can be found in a document prepared by UNAIDS (71).

Mother-to-child transmission of HIV and its prevention

Mother-to-child transmission (MTCT) of HIV, also known as vertical transmission and perinatal transmission, is responsible for about 1500 new HIV infections in infants daily. Transmission mainly occurs around the time of delivery, rarely during early pregnancy, with breastfeeding contributing substantially to the overall risk. The other risk factors for transmission include high maternal viral load, advanced maternal immune deficiency, prolonged rupture of membranes and vaginal delivery (5).

In the absence of specific interventions the rate of MTCT varies from 15–20% in Europe and the USA to 25–40% in sub-Saharan Africa. The difference in MTCT rates is largely associated with the additional risk posed by infant feeding practices. In developing countries, breastfeeding is more common and usually practised for longer periods of time than in the industrialized world (4).

United Nations agencies recommend a four-pronged strategy to prevent MTCT of HIV. This includes: (i) the primary prevention of HIV infection among parents to be; (ii) the prevention of unwanted pregnancies (including safe abortion where permitted by law) in HIV-infected women; and (iii) the prevention of HIV transmission from infected women to their infants and (iv) the treatment, care and support of infected and affected women, their infants and young children, partners and families. The best ways to prevent HIV infection in infants remain primary prevention of HIV infection and reduction of unwanted pregnancies among infected women.

The third prong of the strategy is based on the use of ARV prophylaxis, promotion of good obstetrical practices and safe infant feeding practices. In October 2000, WHO recommended: “*The prevention of mother-to-child HIV transmission should be part of the minimum standard package of care for women who are known to be HIV-infected and their infants*” (20).

A brief overview of interventions to reduce the risk of MTCT of HIV is given below. In addition, a comprehensive overview of evidence and policy implications of interventions to reduce the risk of MTCT of HIV was prepared for a Technical Consultation convened by WHO in October 2000 (available online at: http://www.who.int/reproductive-health/RTIs/MTCT/mtct_consultation_october_2000/index.htm).

ARVs in preventing MTCT of HIV

Several ARV regimens have been evaluated in randomized controlled clinical trials and shown to be effective, as determined by infant infection status. The effective ARV prophylaxis regimens included zidovudine (ZDV) alone, ZDV + lamivudine (3TC), and nevirapine. All regimens include an intrapartum component, with varying durations of antepartum and/or postpartum treatment. The most complex and expensive regimen includes antepartum/intrapartum/postpartum ZDV, while the simplest and cheapest includes single-dose intrapartum and postpartum nevirapine.

The efficacy of short-course ZDV, ZDV + 3TC and nevirapine has been demonstrated even in breastfeeding populations. Long-term efficacy as measured by infant infection status through 12–24 months has been demonstrated for short-course ZDV and nevirapine regimens, showing that the early reduction in HIV transmission is maintained despite continued exposure to HIV during breastfeeding.

Short-term safety and tolerance of the effective ARV prophylactic regimens have been demonstrated in all the randomized trials, while collection of long-term safety data is ongoing. Selection for pre-existing resistant viral populations or development of new mutations may occur with all ARV drugs or drug regimens that do not fully suppress viral replication. However, this is more likely to

occur rapidly with drugs for which a single mutation is associated with the development of drug resistance; such drugs include 3TC (with and without concomitant ZDV treatment) and nevirapine. Virus containing drug-resistant mutations decreases once ARV drug prophylaxis is discontinued and wild-type virus dominates.

In October 2000, the WHO Technical Consultation concluded that the benefit of these drugs in reducing MTCT of HIV greatly outweighs any potential adverse effects of drug exposure and concerns related to development of drug resistance. Thus, the implementation of any of the ARV prophylaxis regimens shown to be effective in randomized clinical trials (ZDV, ZDV + 3TC, or nevirapine regimens) can be recommended for general implementation.

WHO (20) recommends:

The local choice for the antiretroviral prophylactic regimen to include in the standard package of care should be determined by issues of feasibility, efficacy and cost. Considerations that contribute to decisions regarding the composition of the standard prophylactic package include: proportion of women attending antenatal care; time of initiation of antenatal care; frequency of antenatal visits; type of voluntary HIV testing and counselling available; logistics and acceptability of antiretroviral prophylaxis administration; and cost of drugs.

Safer obstetrical practice interventions

Vaginal delivery, compared with elective Caesarean section, presents a higher risk of transmission. Elective Caesarean section can reduce the rate of MTCT by up to 50%; however, its potential benefit has to be balanced against the risks to the mother, for example, anaesthetic complications, postoperative infection and risk of obstetrical complication during a subsequent pregnancy. In most developing countries where resources are scarce, elective Caesarean section cannot be recommended as a routine intervention.

Rupture of membranes for over four hours is associated with an increased risk of MTCT. Therefore, avoidance of routine artificial rupture of membranes is an intervention to prevent MTCT. Vaginal cleansing with chlorhexidine 0.25% is also an intervention that may reduce the risk of MTCT where membranes are ruptured for longer than four hours. As with all women in labour, the use of the partogram (72) will improve the management of labour and reduce the risk of its prolongation.

Being newly infected has been associated with an increased risk of MTCT. Therefore, during antenatal follow-up, all the interventions that reduce the risk of new infection could be beneficial in preventing MTCT: promoting safer sex, providing early detection and appropriate treatment of STIs.

Although the evidence (for increasing the risk of MTCT) is limited, invasive obstetrical procedures such as chorionic villus sampling, amniocentesis or cordocentesis, and routine episiotomy should be avoided in HIV-infected women.

Low vitamin A levels have been associated with higher rates of MTCT and with higher levels of virus in breast milk (73). However, there is no evidence that vitamin A supplementation reduces the risk of transmission, but supplementation may provide other health benefits to the mother and baby.

The dilemma of infant feeding

Breastfeeding increases the overall risk of MTCT of HIV and in 1992, it was estimated that if a woman with established HIV infection breastfed, the additional risk of vertical transmission was between 7% and 21%. For women becoming infected during lactation, the risk was estimated to be between 16% and 42%. This highlights the importance of primary prevention of HIV acquisition in

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lactating women. Transmission of HIV through breast milk can take place at any time during lactation; however, the risk appears to be greatest during the first months of infant life and persists as long as breastfeeding continues. The high viral load of early HIV infection has been associated with increased risk of MTCT through breast milk. The risk depends also on clinical factors (mastitis and nipple pathology), and may vary according to the pattern and duration of breastfeeding. There is evidence from one study that exclusive breastfeeding in the first three months of life may carry a lower risk of HIV transmission than mixed feeding but this remains unconfirmed by other studies (20).

In developed countries, replacement feeding has been integrated with few problems into interventions to reduce MTCT. In developing countries, there are two main considerations: (i) exclusive breastfeeding is the best form of feeding for the infant during the first six months of life and helps protect the mother against another pregnancy; and (ii) replacement feeding carries an increased risk of infant morbidity and mortality associated with malnutrition and infections other than HIV. In addition, replacement feeding in areas where breastfeeding is the norm gives a very public display of the woman's HIV status to the community (4).

In most developing countries, policy-makers are facing a dilemma. WHO (20) recommends:

(i) When replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of all breastfeeding by HIV-infected mothers is recommended; otherwise, exclusive breastfeeding is recommended during the first months of life. (ii) To minimize HIV transmission risk, breastfeeding should be discontinued as soon as feasible, taking into account local circumstances, the individual woman's situation and the risks of replacement feeding (including infections other than HIV and malnutrition). (iii) When HIV-infected mothers choose not to breastfeed from birth or 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. Programmes should strive to improve conditions that will make replacement feeding safer for HIV-infected mothers and families.

There are concerns about the cessation of breastfeeding; indirect evidence of the risk of HIV transmission through mixed feeding suggests that keeping the period of transition as short as possible may reduce the risk. WHO (20) recommends:

HIV-infected mothers who breastfeed should be provided with specific guidance and support when they cease breastfeeding to avoid harmful nutritional and psychological consequences and to maintain breast health.

For mothers not infected with HIV or of unknown HIV-infection status, WHO recommends exclusive breastfeeding for the first six months of life.

Implementing programmes to prevent MTCT is a complex issue. Considerable experience has been obtained in launching pilot programmes with the support of governments, UN agencies (UNICEF, UNFPA, WHO and UNAIDS Secretariat), bilateral cooperations and NGOs. Scaling up these interventions to cover a wider segment of the population and ensuring their sustainability present formidable challenges. The experiences of Brazil and Thailand, which have been implementing national MTCT-prevention programmes, are important examples for other countries.

Voluntary HIV testing and counselling

In order to incorporate PMTCT into existing health care services, it is essential to know the HIV status of the woman (and preferably her partner). The overall goals of VCT are: (i) to prevent HIV transmission; (ii) to prevent HIV acquisition; (iii) to provide early and appropriate uptake of services for people testing positive; (iv) to provide emotional care, family planning advice and enhanced coping strategies for those testing seropositive; (v) to provide social benefits; and (vi) to counsel PLHA to support adherence to treatment and prevention therapies and to cope with any adverse effects (19).

Potential benefits of VCT for different populations in reproductive health

(i) Potential benefits for women and men

Voluntary HIV testing and counselling can help women and men who may be considering forming 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.

(ii) Potential benefits for pregnant women

Counselling a woman after a *negative test* can help her:

- understand and maintain safe behaviour to avoid future infection;
- understand the window period and undertake a second test while preventing future HIV infection;
- breastfeed for optimum health of the infant.

Counselling a woman following a *positive test* result can help her:

- decide whether to share her HIV status with anyone and, if so, with whom;
- choose to continue or terminate the pregnancy, where it is safe and legal;
- learn more about HIV infection and its implications for her health;
- seek early appropriate medical care for HIV-related conditions, e.g. tuberculosis;
- choose ARV therapy where it is available and affordable;
- join the continuum of care such as referral for specialist medical help, or to NGOs for ongoing HIV care and emotional and social support;
- access support groups and health services that promote positive living;
- make choices about sexual behaviour and future fertility;
- understand infant feeding options, and choose what is best in her circumstances;
- seek diagnosis, treatment and follow-up for her infant.

(iii) Potential benefits for 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.

(iv) Potential benefits for the wider community

Widespread availability and use of VCT 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;
- encourage breastfeeding (and reduce the spill-over of artificial feeding) for HIV-negative mothers.

Thus, VCT addresses three key issues:

- preventing transmission through the provision of information, and engaging in a shared problem-solving approach on the constraints people face in practising safe behaviours;
- improving clients' quality of life through exploration of their psychosocial and mental health issues;
- sustaining treatment adherence through shared problem-solving on constraints to treatment maintenance.

Treatment adherence includes medication compliance, follow-up attendance, referral to other agencies and acting on specific counselling issues and advice. As a result, VCT is seen as a tool for the prevention of HIV transmission by increasing knowledge, promoting behavioural change and reducing risk behaviours (6).

The minimal requirements for VCT associated with MTCT interventions (21) are: (i) informed consent including the right to opt out or refuse testing; (ii) confidentiality, with special consideration being given to issues of partner notification (see the chapter on "Benefits and problems of disclosure") and shared confidentiality with health care staff (see the chapter on "Stigma and discrimination"); (iii) legislation to prevent discrimination; and (iv) quality control. As the primary purpose of VCT is to encourage informed decision-making and behavioural change, it is important that individuals (and couples, if appropriate) have ready access to the relevant services, including: family planning for those women and couples wishing to avoid or postpone pregnancy, or practice safe sex during pregnancy and lactation; abortion services, if legal, for those who choose to terminate a pregnancy; mother and child health and other health care and support services for HIV-infected people (3,21). These services are more widely available in specialized HIV/AIDS centres and antenatal, maternity and health care settings in the industrialized world (74). However, currently VCT and PMTCT services and facilities are scarce in developing countries, where 95% of MTCT infections occur (3,14). As a result, UNAIDS suggests that it is not necessary to wait until the full range of services is available 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 exposure to HIV infection for themselves and their partners, and avoiding unwanted pregnancies. Health professionals can also ensure services and practices before and during delivery that minimize the child's exposure to HIV infection. Pre-test information and counselling and post-test counselling related to PMTCT will differ according to the needs of the client.

Pre- and post-test counselling*(i) Pre-test counselling*

The primary purposes of pre-test counselling for pregnant women are: (i) to provide information about sexual transmission of HIV and how to prevent it; (ii) to discuss issues related to HIV transmission from mother to child and possible interventions; (iii) to provide information about the HIV-testing process; (iv) to discuss confidentiality, and the possibility of shared confidentiality

and couple counselling; (v) to discuss the implications of a negative test, including promotion of breastfeeding; (vi) to discuss the implications of a positive test, including the costs and benefits of available interventions, issues related to the woman and the child's survival; (vii) to consider possible exposure to stigma; and (viii) to undertake risk assessment. Many women and their partners will never have considered testing, and some will have very limited knowledge or misinformation about HIV/AIDS. In these situations, it is likely that the quality of the information and counselling provided to women (and their partners) will have a bearing on whether they choose to be tested.

Much of the information in pre-test counselling is straightforward and can be given in groups (14,60,66). Individual counselling is then important to help women (and partners) assess their own level of risk and consider the implications of a positive or negative result before deciding whether to be tested or not.

(ii) Post-test counselling

Post-test information and counselling is very different, depending on the HIV test result. For non-infected women (and possibly their partners), post-test counselling provides information on prevention of future infections; the potential risk of the window period, during which the woman is infected but the test is not yet positive; the high risk of HIV transmission from a newly HIV-infected woman to an infant during pregnancy and breastfeeding (due to high viral load); and the importance of sustained and exclusive breastfeeding for infant health. It should not be assumed that a negative test will be devoid of emotional reactions; further counselling could well be required.

Post-test counselling should include information about: (i) the PMTCT package, access to care and related costs; (ii) infant feeding options, including the health benefits and risks of breastfeeding, costs of replacement feeding, exposure to stigma, and the need for contraception; (iii) future pregnancies; (iv) the prevention of HIV transmission to uninfected sexual partners; (v) shared confidentiality; and (vi) referral for support, additional services and positive living. Unlike pre-test counselling, post-test counselling must be done in private with the concerned individuals or couples.

For readers who would like additional information on VCT, the documents *Counselling and voluntary HIV testing for pregnant women in high HIV prevalence countries: elements and issues* (14), *Voluntary counselling and testing for HIV infection in antenatal care: practical considerations for implementation* (13), *Discussion paper on models for VCT for MTCT interventions in Eastern Europe* (21) and *Tools for evaluating HIV voluntary counselling and testing* (75) provide excellent overviews of the important elements to consider in pre- and post-test counselling.

Four models for VCT are presented here followed by a summary of the benefits of information, counselling and voluntary testing for different clients in reproductive health settings. This is followed by the potential downside of HIV testing. Finally, the minimum conditions for providing VCT in antenatal settings are addressed.

Models of VCT

There are several models of VCT in operation in various parts of the world (21), of which six are described below.

(i) Individual pre- and post-test counselling

This is known as the classic model of pre-and post-test counselling with follow-up counselling for those requiring further support. This classic model has been adopted by the majority of free-standing VCT sites and is known as the "gold standard". This model includes individual counselling for personal risk assessment in order to make an informed decision regarding testing and consider a

risk reduction plan. Ongoing individual counselling, preferably with the same counsellor, provides coping support following testing and help in exploring options for follow-up care and support, sexual behaviour change and involvement of the partner or family. However, this model is very time-consuming and therefore unrealistic in many MTCT settings where health workers are expected to include VCT in routine antenatal care.

(ii) Group information, opt-in individual pre-test counselling, individual post-test counselling

This VCT model has been widely used in MTCT projects. Group information is provided in pre-test counselling. Such information can be given in ANC waiting rooms where health educators and counsellors share information on HIV and MTCT. Women are encouraged to ask questions and to explore issues related to VCT and MTCT. Following group pre-test information/education, women can choose to “opt in” for a shortened version of individual pre-test counselling. Individual post-test counselling is then provided to all women who chose to be tested.

Although this model has been acceptable in many ANC settings, particularly where there is some prior knowledge and understanding of HIV/AIDS and MTCT, in areas where there is less knowledge, the uptake of this “opt in” option has been reported to be low. In addition, it has been noted in some settings that the views of particularly vocal members can persuade the group to either choose testing or refuse it. It is therefore important that the counsellor or educator be trained in group facilitation and in managing group dynamics.

It is also important to ensure that post-test counselling and continued support be available for those who test both seropositive and seronegative. Such support should be provided by referral to counselling services and/or post-test support or peer support groups.

This “opt in” model focuses on counselling and testing of pregnant women only. Involving partners in VCT/MTCT has been shown to be difficult, often resulting in low levels of disclosure. However, involving men in MTCT decision-making could be beneficial in promoting sexual behaviour change and reducing HIV transmission (76).

(iii) Group information, opt-out individual testing, individual post-test counselling for HIV-infected women, women tested seronegative are informed of their negative status

This model has been used in many low-prevalence countries. Women are usually given a leaflet explaining the benefits and rationale for HIV testing and that they will be tested as part of routine antenatal screening. This leaflet also explains that women can opt out of testing, should they so wish. Women who test seronegative are informed of their result, while those who test seropositive are provided with post-test counselling and ongoing support and referral to other counselling services. This ongoing support includes offering ARV treatment, information on infant feeding options, education on other preventive measures and follow-up support, and treatment for the mother and infant, and testing for the infant.

The advantages of this model are that in low-prevalence countries, counselling can be focused solely on the women who test seropositive. Therefore, the number of health care workers who are trained in HIV/MTCT counselling need be fewer. However, this model depends on the availability of treatment and support for all HIV-infected women and their infants. If these services are unavailable or inadequate, then women and their infants will be at a disadvantage by this model. In addition, this model provides little opportunity for partner involvement in testing, treatment and ongoing management and support. Finally, women with limited levels of literacy, those with language barriers or poor understanding of HIV may not understand about the opting-out process or feel intimidated about doing so.

(iv) Shared confidentiality model: group information, opt-in couple/family pre-test counselling and individual/couple/family post-test counselling

This model is an enhanced version of model (ii) where women are encouraged to attend ANC with their husband/partner, a supportive friend, or trusted family member. This model has considerable benefits as it has been shown that HIV-infected people cope better, are in a better financial position to access proper nutrition and treatment, and are better supported if they share their diagnosis with a trusted person. In addition, blame can be avoided and sexual behavioural change can be promoted if the couple is tested together. However, this shared confidentiality must always be voluntary and women must be provided with the opportunity to be tested individually and have post-test individual counselling, should they so wish (see the chapter on “Benefits and risks of disclosure”).

Models of support, training and evaluation in resource-poor settings

There are a few examples of models for support and training in resource-poor, high-demand rural settings. These examples include: *Taso Uganda: the inside story*; *Knowledge is power: voluntary HIV counselling and testing in Uganda UNAIDS Case study (60)*; *The evaluation of HIV/AIDS training program (77)*; *Counselling pregnant women and new mothers about HIV (78)*, *Tools for evaluating HIV voluntary counselling and testing (75)*.

Challenges in HIV testing

Where interventions for PMTCT are unavailable or too expensive, women (and possibly their partners) may decide that there are limited benefits to testing. Where breastfeeding is universal and privacy is limited, it may be impossible for the HIV-infected woman to choose alternatives to breastfeeding without publicly displaying her HIV status to her family and the community. The woman might risk ostracism, abandonment, divorce or abuse as a result of her public disclosure of her HIV status. In addition, it is possible that breast-milk substitutes are too expensive for the family to afford (14). Sherr (79) also noted that the psychological impact of a positive test result might be so severe as to be harmful to the woman and her family. Therefore, it is possible that people might consider the psychological impact of a positive test result, the risk of disclosure and the costs of interventions to outweigh the benefits of knowing their HIV status. It is therefore important that counsellors provide adequate and accurate information to their clients about both the benefits and downside of HIV testing in PMTCT.

Minimum conditions for providing VCT in antenatal settings

(i) Acceptable, accessible and affordable services

For VCT services to be acceptable to women there must be clearly defined protocols in confidentiality and information management. In addition, the woman (and her partner) must feel that they have made their own decision about testing without coercion or even well-meaning pressure. Therefore, informed consent must form the basis for the woman’s individual decision. VCT should be integrated into ANC services so that it is indistinguishable from attendance at ANC. The staff should be friendly and nonjudgemental, and the woman should be assured that continuing counselling would be available to her. The distance from home to the VCT/ANC services should not be too great, and transportation should be assured. Opening hours need to correspond with women’s many other tasks and duties. Services should also provide for the inclusion of partners, family members and/or friends attending VCT with the pregnant woman, where appropriate. Finally, services should be affordable and should be provided free or at low cost.

(ii) Adequate numbers of qualified, nonjudgemental staff

Health care workers in ANC where VCT and PMTCT interventions are offered will need training in basic skills for pre- and post-test counselling, including HIV/AIDS information, the window period, risk factors, transmission routes, and possible and available PMTCT interventions. In addition, issues related to disclosure will also require sensitivity and education. It has been noted that the attitudes of some health care workers can be judgemental and unsupportive (21). Therefore, beyond providing general information on HIV, VCT and MTCT, it is important to help health workers come to terms with their fear of HIV and to dispel unfounded fears about nosocomial infection.

For HIV-infected women and families to absorb new information and make behavioural changes, their psychological status must be assessed. Such psychological assessment requires effective counsellor education. Counsellors also need to be educated on problem-solving interventions, identification and management of mood disorders including postpartum depression, and on how to detect HIV neuropsychiatric disorders.

Additional staff may need to be recruited, especially when initiating PMTCT interventions or current services may need to be reorganized to make more efficient use of staff time. That is, effective treatment, counselling and psychosocial support should be available, but this complex work must be undertaken by well-trained staff. This training should begin in professional training curricula and be supported by periodic training and support sessions within the workplace (21).

Lay or peer counsellors and volunteers may also be recruited to help augment the work of regular staff. However, it is important to note that volunteer peer and lay counsellors will need support for their work, and these workers cannot take the place of more qualified staff. Lay counsellors will need training, support and supervision in order to perform their work effectively. Moreover, PLHA are often recruited as lay counsellors. Although these volunteers provide an important contribution to counselling, they may become sick and require care themselves. Therefore, although the use of lay counsellors can be useful and effective, thought must be given to the extent of their role, the type of supervision required, and the training and support that should be provided for these volunteer workers.

If health workers are to be given additional work counselling for HIV and MTCT interventions as well as supervising lay/volunteer counsellors, this role must be recognized and appreciated and sufficient time must be provided for them to carry out this work effectively. In addition, health care workers will require periodic training sessions to keep them updated on treatment and support issues. Finally, support sessions must be provided to prevent or alleviate some of the problems of counsellor and caregiver burnout (80).

(iii) Additional space to ensure privacy

In order to undertake VCT and discussions about PMTCT, there must be a quiet, private room. Issues related to risk factors and sexual relationships must be discussed privately. This can be difficult in a busy antenatal clinic where women often need to bring their children. Therefore, a space for children to play is also important. Finally, a well-ventilated area is important as HIV-infected women can be vulnerable to nosocomial TB.

(iv) Inclusion of parallel community-based programmes

VCT cannot be expected to meet all the psychosocial needs of HIV-infected women and families. Therefore, it is important that community-based programmes and services are available that address stigma, violence, sexual coercion, abuse, HIV risk behaviours and other issues related to prevention, transmission and behaviour change. That is, a multisectoral approach is necessary to attend to the needs of HIV-infected women and families related to PMTCT.

(v) Knowledge of referral

In high-prevalence areas where PMTCT interventions are planned, a wide range of care and support activities may already be in place in the community. These services might include HIV clinical and medical services, PLHA support groups, community groups and NGOs. Health workers need to be aware of these resources and refer women and families as necessary. TB treatment should be available and home care services available for women and families who need care.

(vi) Support for counsellors

Learning about HIV/AIDS and, in particular, VCT and PMTCT is often new to health care workers and they need adequate training before they begin to counsel women and families. Counselling is also known to be very stressful, therefore regular support and supervision should be provided. This strategy has been found to be effective and feasible even in busy hospitals. Another strategy is for health care staff to alternate counselling with other duties.

Reported experience of VCT

Much of the literature reporting experiences of VCT providers attends to the following issues: the uptake of testing; why people refuse to be tested; why people do not return for test results; whether VCT should be conducted in groups or individually; and whether VCT for PMTCT should be integrated into existing services, or considered a new and specialized service. Each of these considerations is addressed in some detail below.

(i) Uptake of testing

Recent research studies on vertical transmission of HIV have determined that a majority of women are not willing to be tested. Fear of knowing the test result accounted for test refusal in a study in Côte d'Ivoire (81). Similarly, Sherr (82) found that women who did not endorse testing were more anxious than those who agreed to be tested. In another study in Côte d'Ivoire and Burkina Faso, Cartoux et al. (83) found that, although there was a high uptake of testing, several factors accounted for an unwillingness to be tested, including wanting to seek a partner's agreement before undertaking the test and wanting more time to consider whether to be tested or not.

Other factors leading to test refusal included high educational level and last trimester gestation. In this study (83), refusal for testing increased with age and almost doubled for women over 35 years of age. Ignorance about sexual HIV transmission and condom use was another factor for test refusal. In addition, women who perceived themselves to be at risk of infection were better able to analyse potential adverse consequences of testing and more likely to decline the test.

Finally, some counsellors in this study appeared to have a negative impact on women's willingness to accept counselling, possibly due to their limited professional skills and empathy (83). A similar finding was reported by Meadows et al. (84) from a study in which testing uptake varied from 3% to 82%, depending on the midwife offering the test. Sherr et al. (85), in a study in the United Kingdom, found that the quality of information and its mode of presentation had an impact on a woman's willingness to be tested. Similarly, Boyd et al. (86) found that the personal qualities of the midwife, including a positive attitude toward testing with no doubts of its benefit, and a conviction that her role was to increase uptake and that testing should be offered at the ANC, accounted for the highest uptake.

In a Scottish study (87), women stated they were in favour of testing although not necessarily for themselves. In a study in the United Kingdom, Sherr et al. (85) found similar results. Temmerman et al. (50) stated that women in their study mostly agreed to be tested because they trusted

and believed that the health care provider knows best about whether they should take an HIV test. These women returned to the clinic for their test results because they were told to do so. It should be noted that many of the international agencies and various research reports stressed the right of women to refuse to be tested.

Some of the barriers to VCT uptake have been summarized in a review of VCT outcomes (19). These barriers include: (i) problems with the methods of reporting and issues of confidentiality; (ii) availability of treatment including ART; (iii) the type of HIV test being used; (iv) community mobilization, including information, education and counselling; and (v) poor quality services.

(ii) Failure to return for test results

The simple/rapid HIV tests can give final results within a few minutes. Therefore, women can wait for their HIV test result at one visit. However, these women will not be afforded the time to consider whether they want to know their test results or not. That is, pregnant women may not have the opportunity to be appropriately counselled, or be given enough time to reflect upon the advantages and disadvantages of knowing their status and make an informed decision when rapid tests are used. The WHO *Clinical guides for the management of pregnant women with HIV infection* (88) series emphasizes the importance of providing women with the choice of whether they receive their results immediately or at a subsequent antenatal visit. In cases where the woman does not choose to wait for her test result, it is important to give her a date on which she can return for the results. In contrast to the simple/rapid HIV tests, the slower tests can take up to two weeks for the results to be known. In this case, women can fully consider the impact of an HIV test result, and might choose not to be informed (13).

In many VCT sites in developing countries, up to 50% of people do not collect their results. In a study in West Africa, Cartoux et al. (89) found that infected women were three times less likely to return for test results than uninfected women, and that the return rates were independent of the pre-test counselling technique. In an international study (83), fear of disclosure of HIV status and the risk associated with an unfaithful regular partner caused women to fail to return for their test results. The type of test requiring a two-week waiting period for results negatively affected women's return rates. Women who had to travel long distances or delivered in the meantime or those who had second thoughts about knowing their test results failed to return to the clinic. Therefore, the type of test used can have a significant bearing on whether the woman accesses her test results or not.

(iii) Group pre-test versus individual counselling

Several studies have suggested that group pre-test counselling is effective for test uptake (14,36,66,83,89). Cartoux et al. (66) reported that, on the whole, knowledge about HIV/AIDS was better after group than after individual counselling. In addition, this report stated that individual pre-test counselling resulted in higher uptake of testing, but both group and individual counselling accounted for a high degree of test acceptability. It should be noted, however, that all research reports and papers written by UN agencies related to VCT reviewed for this report suggest that post-test counselling should be done individually, or with couples. The supporting person need not necessarily be the father of the child, but might be another trusted member of the family or a friend.

(iv) Separate or integrated VCT services

Access to women who may benefit from VCT for PMTCT is most likely to be found in antenatal clinics (15). In the developing world where 95% of MTCT occurs, many pregnant women know little about HIV/AIDS and would consider themselves at low or no risk for infection. In addition, where there is a high degree of awareness about HIV/AIDS, the risk of vertical transmission is not

as well known or understood. Therefore, successful VCT and PMTCT services would most likely be found as an extension of ANC. However, the costs of recruiting and training new, committed staff and the added strain on already busy antenatal clinics must be taken into account (13). In addition, special projects and initiatives to prevent MTCT might require additional space and funding (13).

An integrated PMTCT service within ANC also helps prevent stigma and discrimination about a woman's HIV status. It is often the case that the wider community holds misconceptions about HIV resulting in stigma and denial. These community attitudes may affect women's willingness to participate in PMTCT. In a recent study in Botswana and Zambia (90), it was found that the men and elders had a considerable influence on the decisions women made about participating in PMTCT or on the difficulty women experienced during their participation (90). Taking these issues into account, UNAIDS suggests (13) that strengthening reproductive health services is essential so that they can integrate HIV/AIDS into regular activities. Women should be given an active role in planning and running services to ensure that they are truly relevant to their needs and female-friendly. In order to be successful, these services should be integrated with other services and be decentralized as much as possible, and shared with a wide range of partners in the field.

It has also been noted that specialized services for VCT and PMTCT are also effective. Specialized services that have HIV/AIDS prevention and care as their mandate can provide more focused care. Counsellors can be specially trained and supported in VCT and PMTCT practices. Referral services can be coordinated and the specialized treatment for PMTCT can be monitored and evaluated. Moreover, most ANC services are not considered to be inviting or supportive to men. This is problematic when women are encouraged to bring their partners along for testing. In addition, Cartoux et al. (66) found that more than half of the women in their study stated that they wished to receive their test result in the presence of another person, and their regular partner was the first choice. Thus, free-standing clinics might provide a more conducive environment for couple testing, or act as a referral unit for partners to access VCT.

Whether the services are integrated or specialized, the primary focus should be on supporting the HIV-infected woman and her family in order to enable her to make the best decisions regarding PMTCT. WHO (13) suggests that there is no preferred model or site and the choice should depend on existing VCT resources. Logistical (structural and staff) considerations such as available financing, seroprevalence of HIV in the community, community attitudes toward HIV, commitment to VCT, the maturity of the epidemic and the stage of development of associated support services will all have to be taken into account when this decision is made. In addition, it should be noted that PMTCT research or pilot projects might not be well integrated into the infrastructure of the community and may be difficult to sustain after the research is completed (13).

The need for psychosocial support and counselling for HIV-infected women and their families

In the chapter on VCT various models and issues have been explored. The overall purposes of VCT included: (i) preventing transmission through education, shared problem-solving and promoting safe behaviours; (ii) improving the client's quality of life through exploration of psychosocial and mental health issues; and (iii) sustaining treatment adherence. However, the literature on VCT also acknowledges that exploration of mental health issues often requires ongoing counselling and psychosocial support. Therefore, this chapter attends to ongoing psychosocial support and counselling for HIV-infected women and families with respect to PMTCT. To that end, this chapter will be divided into three components. First, the need for psychosocial support and counselling for HIV-infected women and families is presented. This is followed by an examination of the interpersonal communication strategies and types of counselling required for effective counselling and support. Finally, the systems and processes necessary to support, care for and educate people to be effective counsellors in psychosocial care are examined.

The need for psychosocial support and counselling

A person diagnosed as HIV-infected will undergo considerable psychological distress. The main concerns for those who test seropositive include the need for social, peer and psychological support, access to medical care and treatment, disclosure and planning for the future, and access to PMTCT and family planning services (19). Anger, fear, depression and denial are common initial reactions to an HIV-positive result. Women who are tested during the antenatal period usually have more profound psychological distress (19). First, they probably have not considered the possibility that they may be HIV-infected until they consent to testing as part of VCT in ANC. Not only do they have to adjust to being pregnant, they also have worries about the pregnancy, and often have to make decisions about whether to terminate it, or to agree to interventions such as ART and replacement infant feeding. In addition, the future health and well-being—including succession rights—of the unborn and her other children, who probably will outlive her, will be of central concern (13). Added to these stressors is the knowledge that the woman has been diagnosed with a disease that carries stigma, fear and discrimination. In countries where breastfeeding is the norm, this will lead to an added strain, as decisions have to be made about whether to breastfeed or artificially feed her infant. All these stressors are combined with the desire of women to have children (55,109), and the strong social pressures for them to do so (50). For these reasons, *The report on the global HIV/AIDS epidemic 2000* (2) has included psychosocial support for PLHA and their families on its list of essential services.

Temmerman et al. (50) consider the aim of counselling HIV-infected women to be to help them cope with the disease and prepare for the future, reduce the sexual risk behaviours and enable them (and possibly partners) to make informed choices about reproductive health. However, the vast majority of the literature on counselling and HIV focuses almost exclusively on VCT. This literature primarily focuses on the information a woman and couple need in order to consider testing, and to promote decision-making in relation to safer sex practices and behavioural change. The mother-to-child HIV transmission literature, although focusing on the special needs and risks for HIV-infected women and infants, still considers the primary focus to be on information sharing, preparation for testing, and uncoerced, informed decision-making (3,4,13,14). Within these publications, reference is made to the need for ongoing psychosocial support and counselling; however, very little literature addresses this specific issue.

In a review of the literature on prevention of MTCT, Vials (110) acknowledges that counselling and support are very important, but provides little indication of what these counselling and support needs might be, other than counselling for pregnancy termination and bereavement. In a review

of the literature of HIV interventions for at-risk women (including at-risk sexual behaviours and injecting drug use) (31), a five-component interpersonal intervention model is provided. These five components include information-only; condom skills; relational skills; HIV counselling and testing; and an individual risk counselling focus. Information-only interventions consider facts about HIV transmission and prevention strategies, while condom skills involve teaching proper use of condoms. Relational skills include sexual negotiation, assertiveness and problem-solving, and HIV counselling and testing involve information-giving and promotion of safer sexual practices. Finally, the review addresses individual risk counselling in “purely informational interventions to incorporate personal issues or concerns regarding HIV prevention” (31). Thus, in reviews reported in the literature, little is mentioned about the psychosocial support needs of HIV-infected pregnant women and their families.

Counselling has also been considered as discussion (96), highlighting the need for dialogue between the counsellor and the client, focusing on the needs of the latter. Similarly, Norton et al. (74) suggest counselling should be more of a two-way conversation instead of a passive transmission of information to the client. Andrews (111) recommends that women be encouraged to tell their story, rather than only being given information and advice. Furthermore, DiScenza et al. (6) caution that counselling should not be a lecture, but should target motivational strategies to promote behavioural change.

Sherr (82) provides a review of papers presented at the 11th International HIV/AIDS Conference in Vancouver, Canada in 1996 on the psychosocial aspects of pregnancy and childbirth. Despite this focus, Sherr reports that the major thrust of papers was directly associated with perinatal transmission (or the prevention thereof). She went on to state, “there were 165 presentations covering pregnancy—149 on mothers, 11 mentioning fathers, and 9 mentioning siblings” (p. 69). Sherr also reported that there were no papers addressing evaluation of interventions from a qualitative or psychosocial perspective. Finally, this report addresses the fact that counselling was not put forward directly as an intervention, “despite the need for it to underpin HIV testing and the contribution of therapeutic counselling to HIV adjustment” (p. 72).

From this review of the literature, it is evident that the psychosocial needs of the woman and her family are given very little consideration. However, many authors note this omission and the need to support psychosocial and emotional counselling. Bennetts et al. (48) report that, “although HIV-infected mothers have been studied extensively, these studies have focused on risk behaviour and vertical transmission. Social and psychological studies of mothers with HIV are rare” (p. 738). This report goes on to suggest that more research is needed on the social and psychological impact on HIV-infected mothers. MacNeil (112) also suggests that there is very little known about the psychological and sociological impact of the choices HIV-infected women must make, and Ingram and Hutchinson (55) report that there is little research about the psychosocial aspects of mothering when HIV-infected. De Cock et al. (5), Cartoux et al. (83), UNAIDS (4), Lie and Biswalo (56) and Sherr (79) also suggest that further research is needed to assess the psychological stress experienced by HIV-infected women related to HIV testing and decision-making. Furthermore, Mofenson and McIntyre (36) recommend that further studies be carried out to assess the psychological stress and acceptability of testing and prevention interventions. These authors also recommend that new models of counselling are needed to encompass the wider community, maintain sustainability, support HIV-infected women and reduce discrimination. Finally, UNAIDS has published two documents that attend to a review of the outcomes of VCT (19) and tools for evaluating VCT (75).

The diagnosis of HIV infection for women contemplating pregnancy, or presenting at the antenatal clinic already pregnant, is associated with considerable psychosocial distress. Emotions such as worry (48), anxiety and despair (32), shame (49), fear, grief, worry and depression (12,19,30,59), distress (11), anger, guilt, self pity, confusion (113), fear of death, loneliness and worry about health (114) are reported in the literature. These emotions have been summed up in a source book for

HIV/AIDS counsellor training to include: shock, denial, anger, suicidal thoughts and actions, fear, isolation, loss, grief, guilt, depression, anxiety, loss of self-esteem, and spiritual concerns (16).

These emotions are associated with all people who test HIV positive. The HIV-infected woman will also have concerns about shame, fear of disclosure, and anxiety about her family and the future of her children. She may have experienced considerable guilt as she watched another child die, grief at witnessing the death of her partner, or the anxiety of wondering if her unborn child will be infected (113). Manopaiboon et al. (59) found that these emotional reactions got worse over time as the women witnessed family disintegration, financial decline and loss of a spouse. These emotions will be present at a time when many HIV-infected women and their families have to make important decisions about possible pregnancy termination, consenting to ART and methods of feeding the newborn. However, as Norton et al. (74) contend, such emotions will make it difficult for the woman to understand fully the consequences of the diagnosis and treatment options and make fully informed choices. Asera et al. (12) also make a similar point that HIV education will be interpreted through an emotional filter of fear and vulnerability, resulting in misunderstanding and poorer comprehension. Lindberg (35) also suggests that counselling, as information-giving in order to make informed choices, is counterproductive at the time of diagnosis.

As Asera et al. (12) contend, health education needs to start with people's concerns, rather than facts and information. People's emotions must be acknowledged and addressed before information can be absorbed (14). Similarly, Norton et al. (74) suggest that anxiety makes it difficult for people to concentrate on future HIV prevention at a pre-test session. Therefore, emotional counselling is critically important (114). A study conducted in the United States of America by Bunting et al. (30) support this contention. Women were asked to identify and rank their needs related to living with HIV/AIDS. The highest ranking need was for psychosocial support and the need for information was third. Similarly, Sara et al. (116), studying quality of life in women with symptomatic HIV/AIDS, found that these women experienced the most stress in the psychosocial domain.

Another cause of distress for HIV-infected women and their families is their long-term uncertainty and need for ongoing care (117). In many parts of the world, the HIV status of the child might not be known until the child is 18–24 months. This period can be very stressful on the family as they wait to see if the child becomes sick, or if the diagnosis is HIV infection. In industrialized countries, this diagnosis can be available within days of the child's birth.

Over the long term, the child or mother may become sick, require treatment and even hospitalization. In addition, the effects of the illness on the extended family have to be taken into account. Discussions with the extended family can often be clouded in a desire for secrecy that greatly compounds the problem. Finally, planning for the future care of children after the parent's death has to be considered. All these considerations have to be attended to at a time of stressful emotions, possibly multiple losses and bereavement.

Bendell (11) adapted the grieving process developed by Kübler Ross to the process of grief experienced by HIV-infected women. The first stage is shock and denial at the time of diagnosis. This is a time of disorientation where normal coping mechanisms may not work. Crisis intervention including identifying the woman's previous coping mechanisms and mobilizing psychosocial resources and support could help the woman through the shock and crisis of this initial stage. The anger stage is usually directed to feelings of anger over how she contracted the disease. However, this anger may be directed to the counsellor. At this stage, people sometimes contemplate or attempt suicide, and specialized counselling and referrals may be necessary. The third stage is bargaining, where the woman might try to bargain for survival with God or others. Prevention counselling is effective at such times. This stage is often followed by depression when the woman starts to come to terms with the full impact of her diagnosis and its ramifications. The final stage is one of acceptance, whereby the woman accepts her diagnosis and her eventual death. She is able to consider options for treatment for herself and her child, and to consider important preventive actions. At this time,

the woman might be able to plan for the family after her death and to settle her affairs. It should be noted that movement through these stages is not necessarily sequential, and that considerable time might be necessary before acceptance is attained. Therefore, it is obvious that psychosocial support will be needed through each of these stages and over a considerable period of time.

Similarly, Nichols (118) developed a model of the psychosocial reactions of AIDS patients. The first state is one of crisis characterized by denial, alternating with periods of intense anxiety. In this state the woman might have difficulty retaining information or might distort it. Support systems should be identified and accessed as soon as possible. The transitional state is one where emotions alternate between anger, self-pity and guilt—a time of self-devaluation, distress, confusion and sometimes disruptiveness. It is also a time when fear, depression and suicide ideation may be experienced. Psychosocial support and counselling are critical during this period. The deficiency state follows, where people make a conscious effort to live each day to the fullest, and they often become involved in volunteer and community work. The final state is preparation for death. At this time, the woman may become totally dependent on help from others. It is also a time when the woman may settle her affairs and consider the needs of family and friends following her death.

There is considerable interest in how people cope with HIV and AIDS (48). The importance of coping as a buffer to stressful life-events is well recognized. Lazarus and Folkman (119) contend that stress consists of three processes: *primary appraisal* attends to how the threat is appraised by the person, *secondary appraisal* involves bringing to mind a potential response and decisions about how to cope with the threat, and *coping* is the process of responding to the threat. In a review of the coping literature (48), it appears that people generally choose two different types of coping: active (problem-focused) or passive (emotion-focused). The former is aimed at problem-solving or doing something to alter the stressful situation or the stress itself, while the latter is aimed at managing the emotional distress caused by the situation. It is generally believed that each type of coping is helpful, and that neither is considered superior to the other. Judgement lies in how well the type of coping used helps with a specific situation (64).

Little is known about the specific coping strategies used by HIV-infected women, or the relationship between these strategies and their psychological well-being. In a study in the United States of America, Moneyham et al. (64) found that the emotion-focused coping strategy of avoidance was associated with emotional distress and physical symptoms. In contrast, Rose and Clarke-Alexander (120) found emotion-focused coping to be associated with increased psychological well-being and improved quality of life. Studies have also found problem-focused coping to be positively associated with the psychological well-being of HIV-infected women (64,120). In an evaluation study, Kaleeba et al. (69) found that counselling had a positive effect on people's ability to cope. From these findings, it would appear that further studies should be undertaken to investigate how women cope with the diagnosis and consequences of HIV, and to promote effective coping strategies during counselling sessions. However, Bennetts et al. (48) caution that such investigations should be culturally specific, as one group of women might cope quite differently with a stressor than another. This observation was borne out in their Thai study's findings that emotional "venting" was associated with a reduced ability to cope and higher levels of depression. However, in many other parts of the world it is generally recognized that emotional venting often helps women adjust and cope with stressful situations.

It is obvious from this overview of the psychological impact of being diagnosed with HIV, and the stages and states that a person might experience following diagnosis, that considerably more care, psychosocial support and counselling is required than just the information-sharing and support for decision-making, behavioural change or compliance with treatment regimens that is most evident in the literature. Yet, in an extensive review of the literature, there is very little mention of *how* women and their families come to make the decision to be tested, come to terms with their HIV infection diagnosis, or make informed choices about their future. It is critically important that the practices and processes of VCT are undertaken; however, is this enough to support the woman and

her family through some difficult decisions and life-altering experiences? Issues of death and mortality, stigma and discrimination, multiple bereavements, and planning for the future will all require ongoing, effective psychosocial support and counselling. Much of the literature suggests that referrals for such care should be made to other services (13,21). However, in resource-poor settings, the VCT/PMTCT/ANC centre might be the only resource available. Therefore, it might be necessary to expand such resources to include adequate psychosocial support and counselling within the existing framework. Later in this review, an overview of different projects and initiatives throughout the world is provided as examples of how different groups have expanded their services to include psychosocial support and counselling to women and their families.

Interpersonal communication strategies and types of counselling required

Issues that need to be addressed in counselling sessions include emotional and crisis counselling, problem-solving, decision-making, promoting behavioural change and enhancing the quality of life (17). In addition, it is important to assess and address the risk of domestic or community violence and abuse, conflict resolution (23,28,58,61,121), at-risk sexual and injecting drug-use practices (31,56,78,122–124), and anticipatory guidance and succession rights, bereavement and death (69,122). This section is divided into a discussion about the meaning and importance of counselling, a review of the literature on individual, couple, family and community counselling, and a discussion of the need for adequate time and continuity to make counselling effective.

(i) What is counselling?

HIV counselling is a confidential dialogue between a person and a care provider, aimed at enabling the person to cope with stress and make personal decisions related to HIV/AIDS. Voluntary and confidential HIV counselling and testing is an important component of HIV prevention and care.

In order for people to counsel effectively, they have to become skilled in methods of effective interpersonal communication. Considerable research and theory development have been undertaken over the past century to understand better the processes and practices of counselling that most effectively help people cope with difficult decision-making, severe distress, anxiety and crises. Despite many differences in these theoretical perspectives it is generally agreed that effective interpersonal communication and counselling should be person-centred (125–129) and contain several essential elements. Counsellors must be respectful, nonjudgemental, knowledgeable about the issue at hand, supportive, empathetic, and able to generate feelings of trust and establish good rapport with their clients (7,8,10,17,130,131). However, the type of counselling undertaken will depend on the situation at hand, the availability of resources and the needs of the people, including their sociocultural circumstances. That is, there is no “one way” to counsel or any way that is deemed better than another. Each is situation-dependent and should be responsive to individual, group and community needs. In addition, HIV/AIDS counselling has some special challenges. People with HIV sometimes have psychiatric disorders that influence how they comprehend information, enact necessary behavioural change and adhere to treatment regimens including follow-up visits, referrals and medication compliance. That is, counselling HIV/AIDS-infected individuals might include some additional complex challenges for the counsellor.

(ii) Individual, couple, family, group and community counselling

Counselling women and families with respect to PMTCT and perinatal care should be considered in the light of its relative effectiveness in caring for individuals, families, groups and communities.

Individual counselling is necessary for topics that might engender embarrassment, fear, stigma, disapproval, high anxiety or make privacy a central concern. Some elements of pre- and post-test HIV counselling would fall into this category. Ongoing counselling for sensitive topics or issues that

generate a considerable amount of emotion might also be better conducted in one-on-one sessions.

Group counselling has been found to be effective in pre-test counselling (see the chapter on “Voluntary HIV testing and counselling”) and for some post-test counselling intended to increase people’s knowledge about HIV/AIDS and treatment options and to promote necessary behavioural change. Peer group sessions, often facilitated by another PLHA, have been found to be very effective in helping women cope with their HIV status, with the decisions they have to make, and with enacting necessary behavioural changes, in particular, condom negotiation (60,69). Such strategies lead to individual and community empowerment (132).

Throughout the literature, many references are made to the need for couple or family counselling in PMTCT (13,19,48,50,65,69,84,133,134) and in respect for the effectiveness of family counselling to promote safer sexual practices and other risk-reduction activities (17,19). However, Kaleeba et al. (69) noted that counsellors had difficulty counselling discordant couples, particularly in relation to condom use. Furthermore, counselling on risk assessment can be problematic when one partner is reluctant to disclose risk behaviours to the other. In this case, accurate risk assessment will be compromised and subsequent counselling will be inaccurate and problematic. For example, one partner may wish to avoid disclosing a specific risk behaviour and therefore the counsellor’s feedback on the level of risk may be inaccurate and impact on the couple’s decision to test or not. Although suggestions were made throughout the review to incorporate couple and family counselling, there are few examples of provision of this type of counselling in the literature. In family counselling, it is also important to consider the needs and emotional impact on children (135). Children might benefit from family or group counselling, or they might require individual sessions. Similarly, although family counselling is promoted in the literature, there may be times when women (and men) need individual or peer group sessions.

Finally, community counselling has been found to be effective in reducing stigma and enhancing collective problem-solving and behavioural change. Downing et al. (143) presented a paper at the 13th International AIDS Conference in Durban, South Africa in July 2000 providing an overview of community counselling and reporting on its success in Uganda and Zambia. Community counselling is a process for helping a community acknowledge its own issues, losses and feelings. The overall purpose is to support the emotional dimension of relationships, intimacy, family life and future, and to acknowledge and respect people’s collective rights and responsibilities. Community counselling is an ongoing series of facilitated community discussions, in which feelings and issues are explored and acknowledged, norms and actions are assessed, choices are considered, and decisions and commitments are made about the life of the community. This process addresses community-level attitudes, behaviours and norms. It is a facilitated process through which community members work together to name problems and explore solutions, to share implementation strategies and to develop indicators that show that effective implementation has taken place. The function of the community facilitator is to help the community identify its issues and to sustain motivation over time. For this reason, the facilitators are sometimes called community motivators.

(iii) Counselling takes time and continuity

Another important strategy in effective counselling is to allow enough time for people to come to terms with their own issues and to seek their own solution (17,69,136,137). Counselling sessions can often be rushed, with little privacy. People need time to accept and cope with their diagnosis and its consequences. Therefore, privacy, confidentiality and adequate time should be assured (17). Furthermore, many of the problems identified in this report will require ongoing counselling and psychosocial support (4,13,15).

It is important to emphasize that although psychosocial support and counselling services that go beyond VCT are essential in the provision of adequate care for HIV-infected women and their families, these services must be developed and run by people in their own communities in order to

meet their particular sociocultural needs. It has also been noted in the literature that, on the whole, women are more comfortable being counselled by women, and men counselled by men (4, 13, 15).

Support, care and education for counsellors

Certain important issues must be considered in identifying, educating, supporting and providing adequate provisions and infrastructure for counsellors to do their work effectively. Therefore, this chapter has been divided into six sections: (i) the personal qualities of counsellors; (ii) training and educational support; (iii) stress and burnout among counsellors; (iv) the status afforded to counsellors; (v) necessary health and social service infrastructure; and (vi) whether psychosocial support and counselling for HIV-infected women and their families should be integrated into the existing health care system or should be a specialized service.

(i) The personal qualities of counsellors

There is considerable evidence in the academic literature that the personal qualities of the caregiver have a considerable effect, both negative and positive, on the client (51, 138, 139). Some counsellors in a study conducted by Cartoux et al. (89) appeared to have had a negative impact on women's willingness to accept counselling, possibly due to their limited professional skills and unempathetic attitude. Uptake of HIV testing was also noted to vary considerably, depending on the skills and personal qualities of the counsellor (50, 79, 84, 86, 87). It is therefore important that counsellors are well trained and committed to counselling, and that their personal beliefs, values and assumptions are explored.

(ii) Counsellor training and educational support

Counsellor training has been cited as an important aspect of HIV/AIDS counselling (14, 15, 117). Counsellors need to understand and be knowledgeable about HIV/AIDS and its transmission. They should also be educated in the specific purposes and practices of voluntary HIV testing and counselling. Additionally, counsellors should learn about effective interpersonal communication and counselling skills (15, 60). These educational sessions should also include a practical component so that students can learn not only the theory of counselling but also practise the necessary skills. The counsellor should be able to assess—and help the client work through—emotional reactions, vulnerability to abuse and violence, sexual practices, issues of loss, bereavement, grieving and anticipatory guidance. Counsellors should also be knowledgeable about, and make referrals to, other resources for comprehensive client care such as medical care, financial, legal and social services and community support groups (13, 60).

Counsellor education can be conducted via lecture format, practice demonstrations, role modelling and peer education. However, such extensive education cannot be completely covered in short sessions, but should be approached over time. Educational courses over the short term have been found to be effective (3, 48, 79, 117); however, they are not sufficient for all the information and practical experience required for effective counselling. These authors suggest that continued counsellor education be part of the counselling service. Counsellors should also be trained in group facilitation and peer support-group counselling. It has been noted that volunteers and PLHA can be trained to be effective individual and group counsellors (60). Such strategies lead to individual and community empowerment (3).

A note of caution concerning health worker education was raised in a study from Lusaka, Zambia, (123) which reported that although counsellors were well trained, they did not always follow their own advice. Although these counsellors were knowledgeable about the benefits of providing HIV/AIDS information for the purpose of promoting HIV testing, they were reluctant to be tested. Of the counsellors interviewed, 40% of the men and 64% of the women stated that they did not

want to have an HIV test. In addition, some counsellors expressed difficulty in counselling because of personal unresolved issues. Counsellors who did not know their HIV status found it difficult to counsel people to take the HIV test. Nearly half the women interviewed expressed fear about their partners' sexual practices; however, they often felt unable to discuss issues of sexuality, even within their relationship. The result was that some counsellors found it difficult to discuss issues related to sexuality in the counselling session. In addition, although counsellors had been educated about the benefit of condom use in the prevention of HIV transmission, only 27% of the respondents admitted to ever using one. This study highlights the need for education to address not only the facts and skills required for effective counselling, but to explore the personal beliefs, values, experiences and assumptions of the counsellors. It is difficult for people to counsel effectively if counselling is inconsistent with their personal experiences.

(iii) Counselling is a stressful occupation

People who devote their time to HIV/AIDS counselling find it extremely stressful (13,123,140,141). In many parts of the world these counsellors face the death of friends, relatives, partners and even their own mortality (123). They are required to discuss issues they often find difficult and stressful, such as violence and abuse, sexuality and discrimination. In addition, despite their best efforts, they see mothers, fathers and children dying of AIDS, being discriminated against, abandoned and abused. Counsellors in the developing world know that HIV/AIDS treatments are available, but beyond the reach of most of their clients. In this sense, counsellors often feel frustrated and impotent to help people cope with the disease. Therefore, counsellors require regular supervision, care and support (13). Peer support groups are considered important (60,69), as well as individual counselling and support. It has been noted that only people who wish to be counsellors should be educated and hired for this work. People who are not motivated or committed to taking on these difficult tasks are unlikely to be effective counsellors. It has also been suggested that rotating counsellors to work that is less stressful may be another strategy to avoid burnout (4,13).

(iv) The status afforded to counsellors

There has been concern raised about the status afforded to counsellors within the health and social welfare system. In many places, counselling is not seen as a profession to be respected (13). This is due to the fact that counselling is often an "add-on" to an already busy workload, and therefore often gets very little attention. If a health worker is busy performing other required tasks, counselling is often ignored. Where VCT is established, counsellors have a designated role, but where psychosocial support and counselling is considered part of a busy workload, it is often considered a low priority in the overall care of the client, and tasks, treatments and other health care activities take precedence (13,15). If health workers are to be given additional duties in counselling for HIV and MTCT interventions, this role must be recognized and appreciated and they must be allowed sufficient time to carry out their counselling duties.

(v) Health and social service infrastructure

In order for counsellors and other health workers to be able to do their jobs effectively, there has to be an adequate health and social welfare infrastructure in place. VCT, ART, replacement feeding and the provision of adequate and effective psychosocial support and counselling require that certain key services be in place (4). There have to be widely available and acceptable antenatal, delivery and postnatal services. Counselling services, family planning and medical care for HIV-infected women and their children should also be part of basic health care provision, including, when feasible, ARVs. In particular, there should be easy access to and privacy for clients attending services, continuity of care and a good flow of information between the various units involved in the management and care of the HIV-infected woman and her family, technical supervision of services to ensure quality, and opportunities for clients to express their own needs and be involved in the

setting-up and maintenance of these services. In addition, there must be an adequate, uninterrupted supply of medicines, treatments, salaries and, where appropriate, breast-milk substitutes (15).

(vi) Counselling as an integrated or specialized service

There is considerable debate as to whether treatment for HIV-infected women should be part of existing services such as ANC or offered through a separate PMTCT service. In an evaluation report, Kaleeba et al.(69) described how the TASO project started as a specialized service within the hospital to attend to the growing, yet unmet needs of PLHA. Later, it was thought that the services could be provided in complementary settings. Russell and Smith (142) address the need for comprehensive services in one location. Women in this study found it difficult, costly and tiring to travel long distances for care. The authors also noted that services should be open during times that women can access care. Finally, the authors addressed the need for services that focus specifically on the care of women and children. They suggest women often avoid services that care for both men and women. Therefore, they suggest that there be a full complement of services within one setting focusing on the care and support of HIV-infected women and their children. In contrast, authors who wish to promote couple counselling believe that services should be welcoming to both men and women. There is also the fear that specialized HIV/AIDS services may be stigmatized.

From this brief review of the literature, it is evident that there is no consensus about whether PMTCT and psychosocial support and care services should be integrated into the existing health service, or should be a separate, but complementary service. It would appear that the quality of the services is more important than their location (13). Each country, district and/or community will have to decide whether to integrate or segregate PMTCT services and psychosocial support and counselling. This decision will be based on many considerations such as cost, resource availability, location, staffing, sources of supply, sustainability, travel, HIV/AIDS stigma, community acceptance, availability of supervision and accessibility. Community resources, NGOs, and other private and public organizations, including traditional healers and spiritual leaders, should also be brought into this decision-making process, as they are essential in the continuum of care. A WHO publication on VCT and ANC (13) provides a list of advantages of free-standing sites, including community support, ownership and participation, links with PLHA groups, support services, skills training, legal advice, ongoing counselling, social support, post-test clubs, and accessibility to both men and women. Disadvantages to free-standing sites might include HIV/AIDS stigma, distance and access to medical care (13). It is clear from this discussion that a continuum of care for the HIV-infected woman and her family will require a multidisciplinary approach (4,35,48). Whether services are segregated or integrated is not as important as the coordination, flow of information and services, and cooperation of all people and services involved in psychosocial support and counselling for mothers and families in PMTCT and perinatal care.

Section Two

**Examples of Projects from
Around the World**

Examples of Projects from Around the World

This section provides a brief description of projects in different parts of the world that provide care, psychosocial support and counselling to HIV-infected women and their families. In addition, some useful references and web sites are provided. These case examples were collected through email to various organizations throughout the world who either provided a case study or referred the author to other organizations. In addition, some case studies were taken from poster presentations at the 13th International AIDS Conference, Durban, South Africa. It is fully acknowledged that these projects provide only a few examples of various programmes. There are undoubtedly considerably more MTCT programmes and services available worldwide.

The AIDS Information Centre (AIC), Uganda

The AIDS Information Centre (AIC) was established in 1990 to provide anonymous, voluntary and confidential HIV testing and counselling services to the people of Uganda. The Centre operates with the understanding that knowledge of one's own infectious status is an important intervention in controlling HIV infection. As the HIV/AIDS epidemic spread in Uganda and its existence became public knowledge, people began to donate blood in order to learn their HIV serostatus. Only a few private laboratories offered HIV testing, but did not provide any counselling services. The establishment of AIC was a response to the growing community need for knowledge of HIV serostatus. AIC now has branches in Jinja, Mbarara and Mbale. Their services include: same-day HIV testing and counselling, ongoing psychosocial and medical support through the Post Test Club (PTC), counselling and treatment for STIs and other medical problems, TB information and referral, training of peer educators, family planning services, condom distribution and community outreach programmes.

Some of the major findings of the project are that:

- VCT should be part of a comprehensive HIV-prevention programme.
- Anonymity and protection of confidentiality are critical to ensure public trust in, and demand for, VCT.
- Integrated services for family planning, detection and treatment of STIs, education and referral for TB diagnosis and treatment are feasible and well-received.

In addition, effective counselling requires a client-centred approach based on trust with good rapport between the client and counsellor, and good counsellors need basic training in one of the helping professions. Ongoing support from the PTC helps HIV-infected members cope with the infection and maintain effective prevention behaviour; PTC members can also contribute to overall HIV prevention as community educators and condom distributors.

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Reference

Knowledge is power: Voluntary HIV counselling and testing in Uganda. Geneva, UNAIDS, 1999 (UNAIDS Best Practice Collection; UNAIDS/99.8E).

The AIDS Support Organization (TASO), Uganda

TASO is a voluntary organization, created in 1987 by Ugandans to provide psychosocial support to people living with HIV/AIDS. TASO was founded to contribute to a process of restoring hope and improving the quality of life of people and communities affected by HIV. By the end of 1993, TASO had expanded into seven districts in Uganda, and was providing counselling, medical care and social support to a cumulative number of over 22 500 PLHA and their families. In addition to providing care, TASO offers training in counselling, provides material support to clients and their families, and supports community efforts to respond to the AIDS epidemic. Counselling is usually on one-on-one basis; however, family counselling to the extended family is also undertaken. This extended family counselling is only done with the consent of the infected person. TASO also offers special HIV services in hospital settings, although it is now realized that much care can be provided in complementary settings.

TASO defines counselling as “a dialogue between a counsellor and a client during which issues are discussed, options are examined and possible plans for coping are made” (69). The relationship between a client (and family) and a counsellor is continuous and, on average, a client receives one counselling session per month. This organization underwent an evaluation between 1993–94. Overall, the evaluation was in favour of the organization. In particular, TASO demonstrated a strong capacity to overcome four problems that haunt AIDS care in most places: revealing the person’s HIV status, accepting PLHA in the family and community, seeking early treatment, and combining prevention with care.

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Malaysian AIDS Council: Treatment Information Project (TIP)

The overall aim of this project is to provide accurate and accessible information on the treatment and management of HIV/AIDS. According to the Treatment Officer, psychosocial support forms the basis for all information, treatment and counselling sessions. TIP provides toll-free telephone, email and face-to-face counselling. The project does not target a specific group; however, some of their clients are pregnant and nonpregnant women. Pregnant women often first find out their HIV serostatus during routine antenatal blood testing at the government-run hospital. These women can refuse to have the HIV test, but most women are not informed in detail of the various tests being conducted, and are not aware that the HIV test is being performed. Therefore, the women that contact this service have usually just been informed of their HIV-positive serostatus, and are shocked and confused.

The Malaysian Government provides ZDV to all pregnant women, and free combination therapy to children under 13 years of age. Therefore, the focus of the initial counselling session is on treatment options. Other psychosocial support includes counselling discordant couples and providing follow-up HIV tests, counselling about condom use, and issues of trust and support within the relationship. TIP also counsels about disclosure to extended families and others who can provide support and care to the family. During these counselling sessions, the health of the mother and the infant are also discussed. TIP does not provide treatment or monitoring of treatment, and the HIV-infected woman and her family are referred to treatment centres. However, if required, TIP

provides ongoing counselling and support. In addition, the Malaysian Paediatric AIDS Fund (PAF) provides financial assistance to those families who need it.

Contact

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**Family Social Department at Huddinge University Hospital,
 Stockholm, Sweden**

The antenatal clinic at the Huddinge University Hospital has a social worker and a midwife who work part-time as counsellors to HIV-infected pregnant women. They meet with the women twice a week for pregnancy check-ups and for psychosocial support and counselling. These practitioners also follow up on the newborn child and the family in the children's health clinic. This is known as the "Children's HIV Team", consisting of two paediatricians, one medical social worker and a child psychologist. They also have an "HIV School Camp" to support HIV-infected children. Many of the families are from other parts of the world, mostly refugees from various African countries. In Sweden, there are about 50 HIV-infected children, 16 of whom are treated at the Huddinge University Hospital.

Contact

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Twin State Women's Network, United States of America

This organization is based in the states of New Hampshire and Vermont in the USA, and its purpose is to connect with the community to care for women, children, youth and families affected by HIV. The Dartmouth-Hitchcock Family HIV Program (DHMC), established in 1995 serves women, children, youth and families infected with, affected by, or at risk for, HIV in Vermont and New Hampshire. Their goal is to provide "state-of-the-art" care through primary care in the community. They are committed to supporting local providers so that clients and families receive comprehensive and coordinated care at DHMC and in the community. The services provided include telephone support groups, retreats, peer counselling and sexuality training.

Contact

HIVNet at: <http://dartmouth.edu/~hivnet/>

**The Chennai Integrated HIV/AIDS Care (CIHAC) Project,
 Chennai, India**

The CIHAC Project is run by World Vision, India. The goal is to improve the quality of life of poor and marginalized HIV-infected women and children facing destitution. The project started in 1999, and operates as a drop-in centre in Chennai (previously Madras). Some of the services offered by the project include:

- Psychosocial counselling
- Health education related to STIs, RTIs and HIV/AIDS
- Treatment advice and management of opportunistic infections
- Support groups for HIV-infected women
- Support groups for commercial sex workers
- A short-stay facility for HIV-infected women and their children.

HIV-infected women are provided with ART in the last trimester of pregnancy to reduce MTCT. These women are encouraged to breastfeed their infants due to their social and financial conditions. Psychosocial support forms part of the perinatal care.

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National Community of Women Living with HIV/AIDS in Uganda (NACWOLA)

The NACWOLA project in Kampala, Uganda, provides VCT, PMTCT and psychosocial support activities for women and families. In particular, the services include:

- Pre- and post-test counselling
- Ongoing support
- Peer support
- Initiation of support groups
- Information sharing related to VCT and PMTCT
- Information, education and communication through drama and plays
- Referrals to other centres
- Research on positive living, long-term survival and psychosocial issues
- Empowerment of HIV-infected women through information-gathering activities, and information sharing
- Disclosure and communication to children and other affected family members
- The Memory Project

The Memory Project aims to help parents open up dialogue with their children about their serostatus. The primary objectives of this project are: to help children cope with the effect of HIV/AIDS in the family; to help parents make future plans for their children; and to help parents talk about their family history and important childhood memories with the children. HIV-infected mothers are encouraged to share their diagnosis, and allow their children to be involved in the family's problems to enable them to face their future loss. Developing a relationship with their future caregivers is encouraged. In this way, children can become familiar with their new community and be reassured

about schooling arrangements. If these arrangements are not suitable, there is time to look for other suitable arrangements. The memory books include saving the family history and important childhood memories. The purpose of these books is to provide the children with a clear sense of their identity and the values to live by. These books have been translated into two local languages, and translation into a third local language is under way.

Contact

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The Mildmay Centre, Uganda

The Mildmay Centre has been providing palliative care and training for men, women and children living with HIV/AIDS since September 1998. This service provides medical, palliative and psychological care and support by a multidisciplinary team including nurses, physicians and counsellors. The services include psychosocial support and counselling, spiritual counselling, occupational therapy, physiotherapy and nutritional advice. An additional programme is under way to support HIV-affected and -infected families in helping plan for the children's future ("succession planning"), and to support disclosure within the family.

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The ZVITAMBO Project, Harare, Zimbabwe

This project is currently undertaking a large clinical trial of providing vitamin A supplements to mothers and babies in Harare. It also provides antenatal education, education to men, and outreach programmes including HIV counselling and support to postnatal women and their families. The ZVITAMBO counselling programme includes HIV pre- and post-test counselling, emotional support, bereavement counselling and referral to other services in the community. The project also provides education and counselling about MTCT, particularly HIV transmission through breastfeeding. This counselling aims to fully inform women about MTCT issues, and to help HIV-infected women and families make informed decisions about how to feed safely their babies. The options include both breastfeeding and replacement feeding. ZVITAMBO routinely monitors their counselling services and an evaluation of the impact of counselling on MTCT knowledge and practices (particularly infant feeding) is planned.

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Wola Nani: Self-Help, Greater Cape Town, Western Cape, South Africa

Wola Nani has been in existence since 1994 to respond to the growing AIDS crisis and to offer help and support to those most in need. Wola Nani focuses on women with dependent children in poor communities who are historically disadvantaged and economically marginalized. At this time, about 85% of the women accessing services are referred from antenatal clinics. From the first project in Khayelitsha, Wola Nani has developed self-help programmes in Nyanga and Philippi, Soweto and Potchefstroom for people with HIV/AIDS to reclaim their dignity and become self-empowered.

Wola Nani is Xhosa for “we embrace and develop each other” and facilitates client-driven income generation, individual and peer group counselling, family care education, child care, and home care visits. In addition, Wola Nani is initiating a pilot model of orphan care that will be evaluated within 15 months. If successful, this model will be replicated in other parts of South Africa.

At Wola Nani, women and their families are helped with the critical psychosocial aspects of care such as acceptance, learning to live positively, caring for HIV-infected children, dealing with prejudice, discrimination, grief and bereavement. Since its beginning, thousands of HIV-infected individuals and families have benefited from Wola Nani’s work in the field, with the larger community being reached through innovative media and education initiatives. They offer a multifocused range of services to people living with HIV, including psychological, emotional and welfare needs. The counselling services include individual and family counselling, bereavement counselling, peer support, HIV education, primary health care training, home visits and health monitoring. Their outreach programme includes HIV education, promotion of safe sex, condom distribution and public speaking in schools, clinics and community organizations, etc. Wola Nani is also involved in media campaigns, promoting a positive nation, and the red ribbon campaign. Every six months, the project organizers undertake an internal evaluation of their programmes. Based on the results of these evaluations, modifications, if necessary, to the strategic plans are made.

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Wadia Woman’s Hospital, Mumbai, India

The People’s Health Organization initiated “Safe Motherhood” interventions for HIV-infected women and children in 1992 in collaboration with the Wadia hospital. This service provides information, education as well as counselling services including pre- and post-test HIV counselling, and group counselling. They perform HIV tests on approximately 12 000 pregnant women each year. HIV-infected women below 20 weeks’ gestation are offered pregnancy termination or ART. Women over 20 weeks’ gestation are offered ART, elective Caesarean section and modified breastfeeding. The children are followed quarterly until 18 months and tested for HIV at 9 and 18 months. This service stresses the importance of pre- and post-test counselling. However, they note that an integrated form of care is needed whereby the counsellors, physicians, nurses, social workers and other hospital personnel are trained in HIV counselling which becomes part of antenatal care. This service also stresses prevention counselling of couples. A challenge they face is how to prevent a breach of confidentiality of HIV-infected women and their families.

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Positive Women Voices and Choices: Thailand and Zimbabwe

Voices and Choices is a participatory research and advocacy project of the International Community of Women living with HIV/AIDS, concerning the sexual and reproductive health experiences of HIV-infected women in Thailand and Zimbabwe. It is a collaborative venture between HIV-infected women, women's activists and researchers. The objectives of the project are:

- to document HIV-infected women's experiences of, and concerns with, sexual and reproductive health including sexual relationships, contraception, pregnancy, childbirth, abortion and infertility;
- to describe reproductive health provision and policy for HIV-infected women in each country;
- to improve awareness among HIV-infected women, their partners and caregivers, to enable them to make informed choices concerning reproduction;
- to increase awareness among policy-makers and service providers and advocate for changes in legislation and service provision which will support the reproductive rights of HIV-infected women.

The Zimbabwe project is based with the Women and AIDS Support Network in Harare. This project began in 1998 and is carried out in four districts. As a result of their investigations, they noted challenges in reproductive health and health services, including: discrimination in antenatal and maternity care, lack of information about the health needs of infected women, fear of discrimination that may deter HIV-infected women from using family planning clinics, frequent ill-health in pregnancy and poor pregnancy outcomes. However, this project has led to free medical care for HIV support group members in two areas, the appointment of a team leader to the local hospital advisory board to represent the community and infected women, and one hospital outpatient department issuing letters to women with STIs to call their male partners in for treatment.

The Thailand project began in 1999 and is taking place in the north, north-east and central provinces. It is based at the Institute for Population and Social Research at Mahidol University. Women's teams from the three regions were trained in gender and reproductive health issues and fieldwork. Counsellor training was also introduced in response to the emotional distress women experienced during interview training. Some of the study issues explored include women's experiences of reproductive health services, feelings about having children, sex and sexual relationships, and involvement in clinical trials.

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Positively Women: London, United Kingdom

“Positively Women” is the only national charity in the United Kingdom offering peer support for African women living with HIV by African women living with HIV. The main purpose of this organization is to empower women living with HIV to make informed choices and to ensure that their voice is heard. The programme offers creche facilities and therapeutic services for children affected by HIV, peer support, advocacy, information, advice, training and volunteering opportunities. This project started as a seminar for African women living with HIV in the United Kingdom to promote peer support, share personal experiences, and explore sexual health and treatments in the light of religious and cultural norms and practices. The seminar also focused on building skills and confidence for the women, many of whom were meeting other HIV-infected women for the first time. The seminar’s results include the formation of a disclosure group, training women to become public speakers, volunteer work with Positively Women, and agreement about the potential benefits of complementing physical health with complementary healing modalities.

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Contacts, projects and resources throughout the world

This chapter provides a brief overview of other PMTCT projects under way in various parts of the world. More information on these projects can be found at: http://www.comminit.com/drum_beat_43.html.

Short-course ZDV: Thailand

The Royal Thai Ministry of Public Health established this drug regime and interpersonal counselling programme in 1996 as a means to prevent MTCT of HIV in the Phayao district of Thailand, thereby decreasing infant mortality.

Contact

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Communication intervention of the MTCT initiative: Zambia

An effective programme on MTCT of HIV was developed to create a supportive environment to facilitate attitudinal and behavioural change among mothers and the general public. Information,

education and communication in partnership with advocacy were used to create awareness, increase knowledge, develop partnerships, reduce stigma and discrimination, and ensure public support for PMTCT interventions.

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076 Program: Brazil

Training and supervision at the Dr Cesar Cals Hospital in northern Brazil gave medical professionals the required knowledge and skills to plan and implement a comprehensive programme to reduce MTCT. This will be the first hospital to introduce such training into the workplace in Brazil.

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Community participation: Botswana and Zambia

The International Council for Research on Women (ICRW) is implementing an operational research project that aims to identify ways and means of seeking community participation and involvement in MTCT programmes. This project has conducted several focus group discussions in the two countries. The initial findings (draft) are now available.

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Counselling pregnant women and new mothers about HIV: Thailand

This is a comprehensive booklet compiled by The Bangkok Collaborative Perinatal HIV Transmission Study Group in December 1999, outlining the counselling practices at Siriraj and Rajavithi hospitals and Queen Sirikit National Institute for Children and Health, Bangkok. The book's preface states:

Our experience has taught us that counselling HIV-infected pregnant women and new mothers differs in many important ways from counselling other persons, because it involves families, relationships between husbands and wives, and bonding between parents and children. As a result, our counselling program has many different components, as reflected in the organization of this booklet.

The booklet provides some valuable information and practices in psychosocial support and counselling to HIV-infected pregnant women and families. It is a practical guide and teaching tool for counselling and psychosocial support. Although the context for the booklet is Thailand, much of the information and practice skills are transferable to other populations.

Contact

<http://www.cdc.gov/hiv/pubs/HACPerinatalCounsellingGuide.pdf>

AIDS organizations worldwide, 1999/2000. National AIDS Manual (NAM)

This directory lists contact details and service profiles of key organizations throughout the world working in the field of AIDS and HIV. Information is presented in English, French, Spanish and Portuguese.

By promoting effective international communication, it aims to foster the sharing of skills, information and expertise around the globe. International, national and major regional organizations are listed, as well as international networks, key specialist agencies and research units linked to community-based projects. Only organizations meeting these criteria, and able to deal with enquiries and give referrals for their own country have been included. Inclusion in the directory does not equal recommendation, but is provided as a resource for others to follow and investigate for themselves. The organizations are listed by their name and by category of work. NAM is a United Kingdom-based charity that produces a wide range of publications on HIV/AIDS.

Contact

web site: <http://www.aidsmap.com>

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Tel: +44 207 627 3200

Advice and information about HIV/AIDS-related electronic networking and Internet resources

A fund of information and coordinates on issues related to HIV/AIDS can be found from the following source:

Foundation du Present, PO Box 1493, 1211 Geneva 1, Switzerland

Tel: +41 22 788 27 33; Fax: +41 22 788 1375

web site: <http://www.fdp.org>; email: info@hivnet.fdp.org

O c c a s i o n a l P a p e r 7

Section Three

**Recommendations for
Psychosocial Support and
Counselling**

Recommendations for Psychosocial Support and Counselling with respect to PMTCT

Based on an extensive review of the academic literature and UN publications related to psychosocial support and counselling for HIV-infected women and families during the perinatal period, including the examples of projects and programmes from around the world, the following recommendations are made:

Raising awareness of the need for psychosocial support and counselling

- UN agencies should collaborate on the development of practical guidelines for health and social service workers and others on how best to provide psychosocial support and counselling to HIV-infected women and their families, and how to provide assistance via linkages with support services/resource networks within the health sector and the wider community.
- UN agencies should collaborate in the development of a guide for HIV-infected mothers and families for accessing support resources within their community.
- There needs to be a concerted effort by UN agencies and others to raise awareness regarding the need for psychosocial support and counselling for HIV-infected women and their families in relation to PMTCT. Although many publications refer to this need, there is very little evidence in the current literature of what these needs are.
- There needs to be succinct marketing of the advantages of VCT that draws upon research findings and showcases best practice examples.
- When initiating PMTCT projects, psychosocial support and counselling should be considered a priority and an integral component of the service.
- National and local governments, NGOs, and other agencies should promote and support community-driven initiatives that provide psychosocial support and counselling to HIV-infected women and their families.

Education

- Counsellor education should be provided in core professional training programmes. Nurses, physicians, social workers and other allied health and social service providers should receive basic counsellor training in their core programme of studies. Midwifery and relevant post-graduate medical training programmes should incorporate VCT training and the promotion of VCT.
- Counsellor education should be given priority. This education should include issues related to HIV/AIDS, VCT, MTCT, as well as psychosocial support, confidentiality, and skills for counselling individuals, couples, families and communities. Specific introductory modules on PMTCT counselling, couple and group counselling should be integrated into the basic VCT training. Current publications attend to the knowledge development of counsellors more than to the effective practice of interpersonal communication. More attention must be given to the acquisition of counselling skills. This can be achieved through simulation, role-playing, supervised practice experiences, etc.
- Counsellor education should include issues related to emotional support, crisis management, pregnancy termination (where legal), suicide ideation, bereavement counselling, future planning, and stigma and discrimination.

- Attention should be paid to how personal beliefs, values, assumptions and attitudes of health and social service workers, as well as others caring and supporting PLHA and their families are addressed in counselling education. Evidence from the literature suggests that the attitudes of these workers can have a beneficial or detrimental effect on people accessing HIV testing and other services. Therefore, workshops on values clarification should be conducted by trained educators to help participants become self-aware, and to move beyond self-awareness toward attitudinal change.
- Counsellors should be educated to perform effective couple-counselling.
- Counsellors should be educated in group facilitation skills and peer group formation.
- Counsellors should be educated in training volunteers and PLHA in peer support.
- Counsellors should be educated about the full complement of resources within their community and feel confident to make referrals.
- Where appropriate, traditional healers could be involved in perinatal care and support of HIV-infected women and their families. To that end, traditional medical healers should be included as part of the educational strategies developed for other health and social service workers.
- In the context of counsellor education, instruction in the aims of counselling and systems of service delivery should be provided to policy and health planners. Educating these people helps to enlighten them about the need for effective counselling for HIV-infected families in PMTCT.

Counsellor support

- Counselling is a very stressful profession. Therefore, counsellors should be provided with adequate psychosocial support and counselling as well as peer supervision and support. They should also have access to additional training.
- Counselling should be given a high profile in community initiatives. Psychosocial support and counselling is often seen as an “add-on” and very little time is provided for this invaluable service. Therefore, the professional status of counsellors is not high. Campaigns and programmes should be initiated to increase the profile of counselling as a respected profession. Increasing the salary of counsellors (where possible) would add to this heightened profile.
- Only motivated people who are committed to counselling HIV-infected people should be chosen for this work. There is considerable evidence that people who are required to perform counselling without the necessary commitment or motivation provide a poor quality of service. As a result, they arouse fear, stigma and discrimination and deter people from accessing testing and other necessary services.

Infrastructure of counselling services

- Many forms of psychosocial support and counselling should be initiated through community mobilization. These should be community based and managed. This will contribute to the relevance of the programmes and to their sustainability.
- Organizations and communities should consider the provision of psychosocial support and counselling to individuals, couples, groups, families and communities. Family and couple counselling is recommended for PMTCT.
- PLHA should play a central role in setting up psychosocial support and counselling initiatives.
- VCT should be addressed at the community level. Existing health sector providers need to have their capacity strengthened to enable them both to provide VCT and to integrate success-

fully with community-level service providers.

- Counselling centres must be assured of an adequate and reliable supply of provisions. Such supplies might include testing kits, ART and replacement infant feeding supplies.
- These VCT and PMTCT supplies must be affordable and accessible to the general population.
- There should be coordination between counselling services and other referral agencies. There should be no duplication of services.
- Additional resources for HIV-infected women and families should include legal services, advocacy, child custody and succession rights. Financial aid, including the promotion and support of income-generation projects, should also be included.
- Communities should consider the costs of counselling and education. These costs can be reduced with the training and supervision of volunteer counsellors and community educators.
- Decisions should be made at the local level regarding whether psychosocial support and counselling should be integrated into the existing services or be considered a specialized service.
- In small rural communities, it is essential that community organizations are strengthened to provide VCT service, possibly in partnership with limited health services.
- On the whole, it is considered beneficial for women to counsel women and for men to counsel men. Decisions to the contrary should be considered with care.

Ethical considerations

- Questions must continue to be raised about the ethical considerations of PMTCT.
- Issues related to women's vulnerability must be highlighted so that HIV-infected women and families feel able and willing to access VCT and PMTCT initiatives.
- Issues of shared confidentiality must be assessed in the light of potential violence and abuse.
- Issues related to stigma and discrimination of HIV-infected women and families must be addressed at the local level. Community counselling is an effective strategy to help confront and alleviate this stigma.

Research

- Research is needed to better understand the psychosocial support and counselling needs of HIV-infected women and their families during the childbearing years, from preconception through pregnancy, labour and delivery, and postnatal care. The scope of this research should be from preconception until the child is 24 months old. This research should be culturally specific and should be conducted in those areas of the world that are most affected by HIV.
- Considerably more needs to be known about issues related to disclosure and couple counselling. That is, research into effective forms of disclosure and couple counselling should be undertaken immediately. The reason for this urgency is that current research is inconclusive about how to promote safe and supportive disclosure and couple counselling.
- Research should be undertaken to gain an understanding of the efficacy of one counselling approach over another (i.e. individual, couple, family or group counselling) in providing effective and responsive psychosocial support and counselling. From a review of the literature, it appears that counsellors are more comfortable with individual and group counselling, whereas there is a lack of education and experience in the more complex and difficult couple and family counselling.
- Evaluation of successful projects and programmes in the field attending to the psychosocial and counselling needs of HIV-infected women and their families during the perinatal period should be undertaken. Data from these evaluation projects should be pooled to form a data-

base of “best practices” that can be shared globally. This outcome research should ideally be linked to the three principal aims of VCT as well as to the individual programme objectives. This database can then become a template for other programmes and organizations to follow as they initiate and modify their programmes of care.

- Research should be conducted on gender issues that affect counselling. For example, female counsellors might not be able to effectively counsel male clients when sexual behaviour and other risk behaviours need exploration. Thus, culture- and location-specific research should be conducted on issues related to gender that might affect the type and quality of counselling services.

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and their families, and issues related to discrimination, abuse, exploitation and social injustice to pregnant women/mothers and their families; to collect, review and assess any work that is being undertaken by different United Nations agencies, donors, international/national nongovernmental organizations (NGOs) and professional groups such as psychologists, nurses/midwives, physicians, etc.; to synthesize and derive recommendations from the lessons learnt that would be useful for. The final section contains recommendations on psychosocial support and counselling for HIV-infected women and families. Paper. 7.