



What is the impact of HIV on families?

December 2005

ABSTRACT

This Health Evidence Network (HEN) evidence report examines how HIV influences family lives and how families deal with the disease. In the context of an increasing number of HIV positive people in Europe, the report highlights several policy considerations such as:

- promotion of primary and secondary HIV prevention with specific efforts directed at the group of people below 30 years of age;
- environmental changes likely to reduce the risk of HIV, such as policy changes and the reduction of poverty; and
- establishment of family-based services, possibly integrated into family planning, antenatal care and obstetric and child health services, aimed at the specific needs of living with HIV and HAART.

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Summary

The issue

In Europe, the number of people infected with human immunodeficiency virus (HIV) is increasing. More infections of heterosexuals are appearing, and young people and women are becoming more vulnerable. For these people, the introduction of highly active antiretroviral therapy (HAART) now allows them to live longer with HIV. Also, since antiretroviral therapy has reduced the risk of mother-to-child transmission of the virus, infected men and women can consider parenting, and HIV-infected children are living into adolescence. This synthesis examines how HIV influences family lives and how families deal with the disease.

Findings

Human immunodeficiency virus has a large psychological, physical and social impact on infected individuals and their families. Stigmatization worsens this impact: it hinders the prevention and treatment of HIV and hampers social support and HIV disclosure. The families most affected by HIV are characterized by low socioeconomic status, which includes such groups as drug users, migrants and asylum seekers.

The risk of transmitting HIV, which includes that of mother-to-child transmission, increases when people are unaware of their HIV infection, when they do not disclose their HIV status, when they do not have access to effective treatment and HIV care, and when they do not have access to family planning advice that addresses the issue of HIV.

The long-term aspects of living with HIV in the era of HAART need to be considered. New possibilities, such as parenting and care of children, need to be considered, and the difficulties in managing HAART (such as adhering to treatment, side-effects and optimal treatment regimen) need to be investigated further. Also, the inequalities faced by those living with HIV, such as obtaining or maintaining employment and life assurance, need to be addressed.

The psychological, physical and social needs of HIV-infected children and their parents need to be considered, especially the needs of HIV-infected children growing into adolescence and adulthood. Also, parents find it difficult to disclose the child's HIV status. Moreover, promoting HIV prevention among HIV-infected young people is important. For children orphaned by HIV, special care is needed to equip them for the future.

Policy considerations

Primary and secondary HIV prevention needs to be promoted, which means educating people about HIV, providing materials for its prevention, providing access to treatment and providing programmes that reduce both the short and long term physical, psychological and social harm it causes in adults and children. Specific prevention efforts should be directed at the group of people below 30 years of age.

Environmental changes likely to reduce the risk of HIV, such as policy changes and the reduction of poverty, should be encouraged. Policy changes should be directed at ensuring laws that protect the human rights of people infected with HIV, regardless of their cultural background or lifestyle, and at ensuring the institution of an active testing policy for HIV.

Family-based services, possibly integrated into family planning, antenatal care and obstetric and child health services, need to be established, to provide assistance to couples affected by HIV and to address the specific needs of parents and their children – all aimed at the specific needs of living with HIV and HAART.

More research should be directed at the better understanding of the long-term side-effects of HAART, at ways to improve adherence, and at ways to improve treatment safety, such as drug treatment interruptions.

Type of evidence

This synthesis presents evidence based on a systematic review of (social) scientific and grey literature and uses all forms of studies, but mainly observational series.

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Introduction

Studies on the impact of human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) have focused mainly on the individual, especially on preventing HIV/AIDS, and on strategies for individuals infected with HIV to cope with the disease. Infection with HIV, however, also has an impact on the individual's family (1). This impact depends on the way in which HIV spreads among communities (and who it infects), the prognosis of infection, and the social setting in which the individual and family live.

Pattern of HIV infection across Europe

The onset and spread of HIV/AIDS varies across Europe. For two decades, western Europe has been confronted with HIV/AIDS. For eastern Europe, the spread of HIV is quite recent. These two European regions also differ in terms of size and type of populations affected by HIV/AIDS. The number of people with HIV/AIDS (PWA) in western Europe is 610 000, compared with 1.4 million PWA in central and eastern Europe (CEE), including central Asia (2,3). The rate of HIV prevalence among adults is 0.3% in western Europe and 0.8% in eastern Europe and central Asia (4). In the latest edition of the European Centre for the Epidemiological Monitoring of AIDS (EuroHIV) report on the prevalence of HIV/AIDS in Europe, a total of 71 755 new HIV diagnoses were reported, the majority being in eastern Europe (70%), compared with 2% in central Europe and 28% in western Europe (5).

The first people to be infected with HIV/AIDS in western Europe were intravenous drug users and men who had sex with men (MSM). Now, the majority (58%) of newly diagnosed HIV infections in western Europe are related to heterosexual contact (2). This increase in heterosexual HIV infections is due mainly to the influx of migrants¹ from regions where HIV is endemic, with over 90% of newly diagnosed cases involving people from sub-Saharan Africa and other areas with a high prevalence, such as eastern Europe (7). Also, behaviour that increases the risk of transmitting HIV has been reported among MSM, which may be explained partly by the optimism related to HAART and by "an AIDS prevention fatigue" (8).

The proportion of women with an HIV infection in western Europe is increasing (4). In western Europe, for example, the percentage of women among people diagnosed with HIV grew from 25% in 1997 to 38% in 2002 (8). The European Collaborative Study (ECS) was set up in 1986 to study issues related to mother-to-child transmission (MTCT) of HIV across 10 centres in seven European countries: Belgium, Germany, Italy, the Netherlands, Spain, Sweden, and the United Kingdom (9). Evidence from 2000 to 2004 shows that 75% of the women studied in western Europe acquired HIV through heterosexual contact and that the vast majority were African women or women with African partners (10).

In eastern Europe, the number of HIV infections reported in the past was attributed mainly to injecting drug use (Poland) or to nosocomial transmission (such as blood transfusion (Romania (2, 11))). Recently, the number of HIV infections in eastern Europe and central Asia has increased sharply, arising mainly from injecting drug users, increased mobility and commercial sex (12). Although the number of HIV cases reported in parts of CEE (such as the Baltic states) has been relatively small (4), the number is increasing rapidly and further increases are expected. For example, during the past few years, in Bucharest, the number of injecting drug users rose rapidly. The majority of those injecting drugs are less than 30 years of age and use non-sterile syringes; over 70% are unemployed and about 50% are infected with hepatitis C (4). Also, a United Nations Children's Fund (UNICEF) report shows that in eastern Europe and central Asia vulnerable young mothers who are HIV positive and inject drugs are more likely to abandon their children (13). The number of people infected sexually with HIV is also increasing (14), with more women being infected and more children being born to HIV-positive

¹ This synthesis uses the term migrants to include refugees and immigrants. There are differences between these two groups in terms of their reasons for movement and handling according to international laws (6), but these differences have little impact on this synthesis.

mothers (4). Moreover, increasing prostitution, with an east to west migration, has been reported in CEE (15, 16). Thus, in the future, it is likely that HIV/AIDS will become more pronounced in countries with a low prevalence of HIV.

HIV and families

Traditionally, families were thought of as being genetically related. Nowadays, however, families are defined more broadly. In the present synthesis, family is defined as “a social network of biologically related members and socially (chosen) relationships” (17–19). For example, partners, close friends and close external family may support gay men.

In the first 15 years of the AIDS epidemic, families had to deal with death and the loss of family members. Since the introduction of HAART in 1996, however, their widespread use has reduced the number of AIDS-related deaths in Australia, Europe and the United States (20). Now, families must deal with HIV infection as a chronic disease to be managed for the lifetime of the infected members.

Within families, several routes of HIV infection need to be taken into account: first, sex partners within the family may be at risk from their partner; and second, newborns may be at risk of HIV infection by vertical transmission – in utero and during labour and breastfeeding.

Children infected with HIV and those whose parents have HIV need special attention. The EUROSUPPORT IV study in western Europe found that 27% of the more than 3000 HIV-infected people surveyed had caregiving responsibilities and lived with at least one child under 18 years of age (21).

Family members may also become burdened by caregiving as the disease progresses, and they may be affected by the stigma often attached to HIV infection.

This synthesis seeks to determine the impact HIV/AIDS has on the different aspects of family relationships.

Sources for this review

This synthesis is based on a systematic review of scientific and social science publications, AIDS journals, and electronic reports and publications that address issues that relate to the impact of HIV on families, with a particular focus on Europe. The research was undertaken between January 1997 and August 2005, using the process outlined in Annex 2, to identify studies that relate to the period after the introduction of HAART.

All types of studies were included. They ranged from qualitative studies to longitudinal studies and narrative reviews, and covered theoretical and practical perspectives that could elucidate causal relationships, general issues and processes.

Findings

There were no recent systematic reviews on the subject of families and HIV. Two reviews were published before the introduction HAART (17, 18). Another review, which focused on the impact of HAART on the needs of HIV-positive people in the United Kingdom, also referred to the issue of HIV and families (20). And still another review, which was in a special issue of the *Journal of Family Psychology*, focused on HIV disclosure in families (19), but it was not related specifically to Europe. Consequently, the present synthesis has had to focus on individual studies. Given the nature of the policy question, the main sources of evidence are qualitative reports and commentaries, with a limited number of observational studies of patients.

Several major issues, identified from the literature search, form the framework for this synthesis:

- the physical, psychological, and social impact of HIV on individuals and their family;
- HIV disclosure;
- the role of caregivers and social support;
- parenthood; and
- HIV-positive children and adolescents.

Stigmatization is also an important issue, but it is discussed within the context of each of the major issues identified above.

The physical, psychological and social impact of HIV

This section considers first the physical, psychological and social issues that affect HIV-infected individuals (because they can impact on his/her relation with the family) and then considers issues that affect the family directly.

Individuals

Timing of diagnosis

In western Europe, a recent study in the United Kingdom showed that 31% of HIV infections were undiagnosed and that HIV testing was most common in high-risk groups (22). A systematic review showed that mass media campaigns may promote short-term HIV testing, but they do not produce sustained changes in the uptake of HIV testing (23).

A study that looked at the effect of HIV infection on parenting and family relationships in families from sub-Saharan Africa, situated both in the United Kingdom and in the country of origin, showed that parents and children were diagnosed late in the course of infection because they did not consider they were at risk and because symptoms were missed (24). The emotional impact of HIV testing and counselling was reported to be high, particularly among women tested during the antenatal period who may not have considered the possibility of an HIV infection (25).

Physical impact of HAART

Western Europe generally has good access to HAART and, consequently, the death rate among HIV/AIDS patients has dropped (4). In eastern Europe, however, access to HAART appears to be limited, and only 11% of the people who need antiretroviral drugs are being treated (4). For HIV-positive drug users, access to treatment is poor to non-existent in the countries worst affected (4). The exceptions are the Republic of Moldova and Romania, where most people in need are reported to be receiving treatment (4).

People with HIV need to incorporate HAART into their lives. One of the stressors HIV-infected people need to address is the decision about when to begin combination therapy for HIV. Although combination therapies can produce sustained suppression of viral replication and can reduce viral load to a level where viral particles are undetectable, concerns about the long-term detrimental effects of HAART on the patient's health and daily functioning may postpone the decision to start combination therapy (26, 27).

The need to adhere to a complex regimen of several drugs is a major burden for the person infected with HIV (28). For many people, the need to constantly adhere is associated with anxiety and frustration. Also, not all people infected with HIV respond well or consistently to new combination therapies. There is evidence of antiretroviral-drug resistance among some people newly infected with HIV (29), and Bogart et al. (30) describe striking mental health needs, such as strong feelings of depression and hopelessness among HIV-infected men and women who do not achieve or maintain the

benefits they expect from the treatment regimens. Even when the therapies are effective, people experience uncertainty and other forms of distress (31).

Stress associated with the response to treatment interacts with other potential stressors, such as concerns about employment, the future of relationships, sexuality and the social reactions of others (30, 31). Also, HAART has several side-effects, some of which have psychosocial consequences, such as lipodystrophy (32). Furthermore, long-term physical side-effects, such as cardiovascular diseases, have become more evident during recent years (33).

Psychosocial issues

After being diagnosed, people confronted with their HIV-positive status are highly stressed and uncertain, despite the availability of HAART (34, 35), and their lives may be devastated by the need to deal with the new medical, personal and social situation (20). Research on the psychosocial aspects of HIV-positive status show that living with HIV is associated with a large measure of stress and depression (36, 37). People with HIV/AIDS must also manage the stigma associated with HIV/AIDS. Moreover, they must tolerate treatment with adverse side-effects, deal with rejection and social discrimination, and confront the deaths of others in their social networks (38). Being HIV positive generally makes HIV part of a person's identity.

In terms of social stigma and discrimination towards people with HIV/AIDS, differences exist between European regions. In the Netherlands, for example, the public reaction to people with HIV/AIDS was shown to be moderately positive (39); knowledge about HAART was associated with a perception of lower risk, and there was a positive attitude towards homosexuals, less fear, and a greater willingness to have personal contact with people with HIV/AIDS. In eastern Europe, however, stigmatization may be more intense, especially of specific groups, such as homosexuals (11).

Finances too can be adversely affected by HIV status. Even in the post-HAART era, HIV-positive people still find it difficult to obtain life insurance or a mortgage (40). Because illness often leads to loss of productivity and income, infection with HIV may also have adverse financial repercussions on the individual infected and on their family (18); also, the unemployment rate is higher in those infected with HIV (41). Although people infected with HIV consider returning to work, several barriers prevent them from doing so. Among these barriers are fear of the repercussions of poor health, medication management and disclosure, fear of discrimination, and fear of problems related to long-term unemployment (20).

Families

The social stigma that surrounds HIV may have adverse repercussions not only for the individual, but also for their family (18,42,43).

HIV has an impact on partners and on the dyadic relationship. Caregiving is associated with stress and AIDS-related stigma (44). A qualitative study in the United States of HIV-discordant couples (44) showed they had difficulty communicating about HIV. Also, the risk of HIV infection has an adverse affect on people's sex lives, leading to feelings of discomfort between sex partners. Moreover, couples may be in denial and, consequently, may engage in unprotected sex. Similar findings have been reported in a qualitative study of HIV-positive gay Dutch men (35). European studies have also shown high rates of sexual dysfunction in men and women (20).

The impact of HIV on the family depends on which family member is infected. Depending on whether the person infected is a heterosexual man, gay man, drug user, women or infant, they face different challenges (19). Also, for some families, knowledge about the HIV infection introduces new information, such as sexual behaviour or drug use, about the HIV-infected family member (44). Individuals infected with HIV, and members of their family, may be stigmatized socially, by overt or

covert behaviour (such as rejection by friends), or by subtle gestures (such as reduced visits from neighbours and children not being invited to parties) (18).

Children may also experience emotional distress due to the HIV infection of a parent. A study in the United States (45) showed that HIV-negative children experienced stress related to the HIV-associated stress experienced by the mother. This impact was reduced, however, when the child received social support from others, such as parents and teachers. The disclosure of HIV by parents living with the infection may, by itself, engender a large measure of emotional distress in their children (46). Other psychological stress arises when adolescents take responsibility for caring for their parents (47) and when children have to cope with the loss of a parent and with the situation of foster care (9).

Disclosure

Why disclosure is important

When living with HIV, people may face a dilemma in disclosing their HIV status to others, because it may lead to stigmatization and exclusion. For various reasons, however, disclosing one's HIV status is important and has its benefits (48).

- It avoids the enhanced risk of HIV transmission among sex partners due to concealment.
- It helps gain additional support, including access to treatment and help adhering to it, pregnancy planning, replacement feeding for infants, future care and custody planning.
- It influences others who fear disclosure and improves the existing knowledge about HIV and its transmission.

Issues influencing (non-)disclosure among family members

People may choose not to disclose their HIV status to their partner or family because the HIV status may be associated with revelations of sexuality, infidelity or drug use. Social unacceptability may also play an important role (18). Also, parents may be reluctant to disclose their HIV status due to concerns about the emotional well-being of their children (49). Thus, people are in a constant dilemma about disclosure: on the one hand, they may find enhanced social support; but on the other hand, they run the risk of being stigmatized.

Unlike other diseases, such as cancer, HIV is less likely to be disclosed, probably because of fear of the associated stigma, discrimination, and isolation (24,49,50). Also, prior to disclosing their status to their children, parents may first have to deal with the anger, fear and depression related to their own HIV diagnosis (46,51).

European studies show that the rates of parents disclosing their status to their children are low (10–11%) (49,52,53) and are generally lower than in the United States (40–72%, depending on age) (46). A possible factor that accounts for this difference is the presence of migrants. Most migrants in Europe come from African countries. Strong barriers to HIV prevention and care, including cultural, socioeconomic, linguistic, administrative and legal barriers, frequently affect them. In general, they may face stigmatization and social hostility (8,54). Moreover, many migrants are isolated and may not have family members nearby to support them (9).

The stigma associated with HIV/AIDS is likely to have less of an impact in western Europe (39), whereas it is much more intense in African countries and in eastern Europe (55). In such contexts, people may be more reluctant to disclose their HIV status to others. In a Belgian study, for example, migrant parents were found to be less likely to disclose their HIV status to their children than non-migrant parents (5% versus 20.5%) (53). Another possible reason for non-disclosure may relate to the fear of being deported from a specific country. In France, another study (56) showed several possible

differences between HIV-positive women with roots in Europe or in Africa (24). Among these differences, women raised in Europe were more likely to disclose their HIV-positive status to family and friends.

Reports from eastern Europe and central Asia state that people with HIV/AIDS are discriminated against, by denying them health care, by employment redundancies, and by being excluded from their own family (57). This affects the psychological and physical health of HIV-infected people; moreover, it is likely to encourage non-disclosure of HIV status due to fear of stigmatization, discrimination and exclusion.

Disclosure of a child's HIV infection is controversial, emotionally laden (58) and occurs selectively (10). For example, in a study of 34 HIV-infected children, the school was informed about 58% of the cases, but the degree of disclosure varied: in some cases only the school doctor or head teacher was told, whereas in other cases the class teachers were told (59).

EUROSUPPORT, a study carried out in 10 western European countries, showed that the overall rate of parental disclosure of HIV status to children was 20.5%. If, however, their children were also infected with HIV, 55% of the parents informed the children about the child's HIV status (21). It has been stated that parents are more likely to disclose parental status to their children when the children are older (46,49). In the EUROSUPPORT study, 24.5% of those 10–15 years of age were told about parental HIV infection, compared with 47% of those between 15 and 17 years of age.

The American Association of Pediatrics (60) advises that parents or caregivers be counselled by health care professionals about disclosure to the child, which should be tailored to the specific situation of the child, taking into account the child's cognitive ability, stage of development, clinical status and social circumstances.

The impact of disclosure on the family

Disclosure to family members has its pros and cons (51). It may increase closeness, but it may also increase stress (20).

A review of the evidence in the early 1990s showed that when people disclosed their HIV status, family members experienced a range of emotions, including feelings of helplessness, fear of the loved one dying, concern about care and fear of becoming infected (18). A recent qualitative study, with mainly European participants, showed that even in the post-HAART era disclosure of an HIV infection may have an emotional impact on family members: they may be surprised and saddened by the disclosure (1). The potential for terminal illness – as well as the impact of medical treatments, and constant adjustment of hopes and fears – can affect both the individuals infected with HIV and their families.

In the context of being a parent, it is not only important to anticipate children's negative reactions when disclosing the infection to them, but it is also important to actually look out on a short-term basis for the children's emotional and behavioral reactions and problems, such as depression, anxiety, and acting overly mature (21).

Researchers recommend that disclosure be integrated into the overall counselling and psychosocial support of parents living with HIV, to avoid giving parents the message that HIV is a topic to be kept silent in families, thus implicitly contributing further to the stigma that surrounds HIV (46,53).

The role of the family as caregivers

Caregivers providing social support

Families are important caregivers, providing social (emotional and instrumental) support for members infected with HIV, with mothers and close friends being the most important caregivers (18). The benefits of emotional support are that it buffers stress (61), improves adherence to HIV treatment (62), results in fewer symptoms of depression (63) and improves the quality of life (64). Meanwhile, emotional support may also help the family member infected with HIV to restore their reason for being and increase their self-esteem. Another aspect of social support, instrumental social support, involves practical help, such as shopping, housekeeping and transportation (65).

In western Europe, especially southern Europe, the extended family is the most important source of care for children with an HIV-infected parent (49). In CEE, however, many such children receive institutional care (66). In CEE, 1.5 million children live among others under public care, with a proportion of those children receiving public care, as they are affected by HIV – that is, being infected themselves or having (had) HIV-infected parents.

Impact on the carer

Caregiving may engender many stressors (1). One study showed that AIDS caregivers were more likely to report emotional distress when overloaded by the demands of giving care, when experiencing high levels of alienation/stigmatization and when concerned about financial matters (61).

The process by which caregivers and people infected with HIV influence each other is a reciprocal one. Unpublished research has shown that caregivers are more capable of coping with an HIV-infected person who is actively coping with the disease – for example, talking openly about it and its implications – rather than one that presents only suffering (67). People infected with HIV may also be taught strategies to influence the emotional and behavioural reactions of others (67).

Family members who are caregivers may experience the need to talk with others about the HIV status of their infected family member, because keeping the HIV status a secret may be a burden (1). Disclosure, however, may lead to stigmatization by association. A study of the impact of AIDS-related stigmatization among caregiving volunteers (43) showed that AIDS-related stigma had an impact on those who did not expect any stigmatization, resulting in less satisfaction and higher burnout than in those who expected the stigma.

Family members may also express the need for social support: initially, to increase their own understanding of the disease; and later, if the condition of the HIV-infected family member worsens (18).

The impact of HIV on parenthood

Positive parenthood: planning pregnancy and care

Highly active antiretroviral therapies have had an impact on pregnancy planning. Before the era of HAART, HIV-positive women were confronted with their HIV status and the likely bleak outcome of death. The number of deaths, however, has decreased among HIV-positive women receiving HAART, and women now live longer and healthier lives. As most HIV-positive women are of reproductive age and see a future for themselves, deciding about pregnancy has become an important topic.

Before the introduction of antiretroviral therapy (ART), about 15–20% of the children born to HIV-infected mothers became HIV positive, due to vertical transmission (9). With the introduction of ART, the risk of MTCT has been reduced to about 2–5% (53). This reduced risk may make pregnancy a

more favourable option and, indeed, the number of pregnancies among HIV-positive women has increased in the HAART era (68).

A qualitative study by Kirshenbaum et al. in four cities in the United States (69) showed that considerations that might play a role in decisions about parenting include: the desire for motherhood, already having children, the opinions of partners and health care providers, religious values, and perceived partner capacity to parent successfully. The study concluded that decision-making about pregnancy is not always clear-cut and that women with a large desire to become pregnant considered their chances of vertical transmission to be lower than those whose desire to become pregnant was smaller. Another study, based on 56 patients (70), showed that motherhood has its contradictions, in that it may both intensify and buffer against the adverse physical and social effects of being infected with HIV.

In the EUROSUPPORT study, 68.5% of all parents living with HIV considered their family planning to be finished, because they did not want to have more children, 16% were undecided, and 15.5% expressed a definite desire to have more children (21). Another study, conducted in France (58), showed possible differences between HIV-positive women originating from Europe and Africa, with African women more likely to want children, despite already having several children.

Less is known about the role of fathers, but it is important to include them when discussing positive parenting and interactions with children. The EUROSUPPORT study, for example, showed that 11% of all fathers were self-identified gay men who lived together with at least one child under 18 years of age (21). Furthermore, a study in the United Kingdom of 32 HIV-positive heterosexual men (71) found that, while children were considered to give meaning to their life and represented a reason to live, fathers were not provided with information about reproduction and parenting (72). This study suggested that men would value the possibility to discuss fathering and fatherhood.

Vertical transmission

A study of HIV-infected children in Denmark (73), which focused on demographic associations, showed that the majority of the children infected (76%) were infected perinatally. A systematic review has demonstrated that ART, in the form of zidovudine (ZDV) and nevirapine (NVP), or delivery by elective caesarean section were effective in reducing the risk of MTCT (74). Conversely, a recent systematic review of the merits of supplementation with vitamin A reducing MTCT found two trials involving 1813 HIV-infected women, but there was no indication of an impact on reducing MTCT (75).

The optimal therapy recommended is a combination therapy (76). Women who need antiretroviral (ARV) regimens should receive it, as it benefits their health and decreases the risk of HIV transmission to the child. For women who do not have indications for ARV or do not have access to ARV, it is advised that ARV prophylaxis (ZDV and a single dose of NVP, plus ZDV for the infant) be offered to prevent MTCT transmission.

A recent publication based on the ECS cohort (77) showed that, in a study among 1167 mother-child dyads, 42% of the HIV-positive mothers took ART during pregnancy to delay their disease progression or to reduce the risk of vertical transmission, or both. The majority of women (83%) who delivered after 1994 received ART.

A recent study based on the ECS study (10), but with the inclusion of eastern European regions, demonstrated differences between western and eastern Europe. In western Europe, HIV MTCT transmission was low, with an MTCT rate of 1.5% among women receiving HAART, whereas in eastern Europe, in the last 5 years, the MTCT rate was 6.7%. In recent years (2000–2004), 72% of HIV-positive women in western Europe and central Europe received optimal ART therapy during pregnancy and 50% were on treatment before the current pregnancy. In eastern Europe, the situation

was different, with a large proportion (80%) of women receiving no ART during pregnancy and the use of single-dose NVP or short courses of ZDV therapy being highly prevalent. Furthermore, in western Europe, caesarian section rates were much higher (66%) than in other regions.

To effectively reduce vertical transmission by the use of ART, it is essential that mothers-to-be know their HIV status; it has been shown, however, that pregnant women may be unaware of their HIV status (20). In the EUROSUPPORT study, 39% of all women delivered at least once since their HIV diagnosis. Of these, 35% planned the pregnancy, 38% learned about their HIV diagnosis during pregnancy and the remaining 27% received their diagnosis before their most recent pregnancy and became pregnant accidentally (21). These figures suggest there is an unmet need for family planning among women and couples living with HIV.

The ECS study showed that only 20% of the women surveyed in eastern Europe were aware of their HIV status before pregnancy, compared with the majority (66%) of women in other parts of Europe. In the Ukraine, 61% of the women surveyed learned their HIV status during pregnancy, and 19% were only diagnosed at the time of labour and delivery (10). Testing policies for HIV have changed in countries such as the Netherlands (78) and the United Kingdom (20), with these countries taking an active testing stand, but this is not the case in all European countries. An active testing policy for HIV should encompass a policy aimed at earlier detection and treatment of HIV. This is realized by ensuring enough test facilities and by educating people about the importance of early detection and HIV-testing possibilities. Testing for HIV is more routinely offered in clinical situations (such as to pregnant women) and to high-risk populations (such as to people with an HIV-positive partner and to intravenous drug users with a history of sharing needles).

Consequently, issues relating to the prevention of HIV among children need to be integrated into family planning, antenatal care, and obstetric and child health services (79).

Assisted reproduction

For heterosexual couples where the male partner is HIV positive, assisted reproduction is possible by means of sperm washing, which reduces the risk of horizontal transmission. Sperm washing has existed for nearly 10 years (80) and is used in several centres in Europe. Preliminary reports from various European centres that have incorporated washed sperm with intrauterine insemination or in vitro fertilization have demonstrated the safety of the procedure, with no seroconversions occurring in women or their offspring (81). It is difficult, however, to ensure that all CD4-positive cells are washed away in any of the sperm-preparation techniques. Since HIV could, theoretically, remain undetected, sperm washing is currently regarded as an effective risk reduction, but not a risk-free, method (82). There are ethical concerns about the potential risk of transmitting the virus to the embryo, fetus or mother, as well as concerns about the socioeconomic impact of raising a child by a parent with a potentially fatal disease, but this concern applies to all positive parenting techniques. Legislation may also be a barrier, if inseminating a woman with sperm from an HIV-positive male is seen as a criminal act. On the other hand, this method is safer than the risk of sexual intercourse between serodiscordant couples.

The impact of HIV on children

HIV-infected children

Most of the information available about the effects of HIV infection on children comes from the United States. Because of the cultural differences in child-rearing practices, parenting roles and the understanding of the illness that may exist between Europe and the United States, transferring the conclusions derived from those studies may not be appropriate. Nevertheless, as children grow older in the post-HAART era, the quality of their life deserves attention (83).

In some European countries, the majority of vertically infected children are born to parents that inject drugs intravenously, whereas in other European countries vertical transmission arises predominantly in parents who migrated from sub-Saharan Africa (68). A literature review that examined the psychological effects of vertically acquired HIV infection in infants and children (68) suggested that the risk of premature delivery was higher among HIV-positive women. Children that are HIV positive also have a higher risk of mortality – for example, from haemophilia and cancer. Moreover, HIV may affect the neurological system of children and lead to impairment of the central nervous system (CNS). Consequently, HIV-positive children may have lower cognitive abilities or higher cognitive deficits, have behavioural problems, and have a lower quality of life. Children infected with HIV may also have difficulties in living a normal life because of the medical treatments they must take and because of problems that stem from disclosure (20).

Most HIV-infected children receive HAART (59). The effectiveness of HAART was shown in a study of children in Ireland and the United Kingdom who were infected with HIV (71). The study demonstrated substantial reductions in mortality, AIDS, and hospital admission rates. Consequently, children are living longer, and there is an increasing need to address their medical, social and psychological needs as they enter adolescence and adult life (71).

In the United States, guidelines advocate therapy for all children less than 1 year of age with HIV, whereas in Europe “consideration” of treatment was recommended (84). In Europe, evidence of disease progression, adherence problems and side-effects are reasons to modify treatment. The latest recommendations (PENTA guidelines) and United States guidelines are quite similar (85). A meta-analysis (86) also suggested that neither CD4% nor viral load could identify young children at low risk of disease progression, thus lending some support to a universal treatment policy for infants, or at least to the need for close observation to promptly detect clinical signs or symptoms preceding AIDS.

Specific attention should be paid to the possible long-term adverse effects of HAART, as vertically HIV-infected children in developed countries are likely to experience these effects during or before adulthood. Hypercholesterolaemia is more prevalent among HIV-infected children, and one study showed that the strongest predictor for hypercholesterolaemia was the current use of a HIV protease inhibitor in the antiretroviral regimen (87). It is important therefore to examine ways of reducing possible side-effects – for example, by planned treatment interruptions. A European study (88) of the immunologic response in HIV-infected children showed that after stopping HAART, CD4% declined on average, but the response was largely variable. This suggested designing paediatric trials of planned treatment interruptions, where interruption length could be determined by time taken for CD4 to decline below a threshold, rather than by imposing interruptions of fixed duration. More research is needed to find ways to enhance the safety of long-term HAART use, including optimal provision of treatment interruptions.

Coping styles of families with HIV-infected children

Coping styles may have an impact on the way HIV affects the lives of children and their families. In general, problem-based coping is more effective than emotion-based coping. Families of children with HIV-related CNS impairment may experience a greater degree of inability to deal with the situation than families in which the child is not significantly impaired. It has, for example, been shown that families of children with HIV-related CNS impairment report more passive coping strategies. This passive response may prevent parents from stimulating their child's development or from advocating appropriate care (89).

In addition, family members may play a prominent role in the child's adherence to treatment. A study in the United States (90) showed that such caregiver/family factors as poor parent-child communication, higher caregiver stress and less HIV disclosure to the child were most strongly associated with non-adherence. Also, a qualitative study carried out in Belgium highlighted the family dynamic that evolves around adherence to treatment in families living with HIV and highlighted the

importance of the parents' positive coping style in supporting HIV-positive children's adherence to treatment (91).

Children of HIV-infected parents

The ECS study showed that 53% of the mothers acquired HIV through intravenous drug use, that 26% of them were from a country with a high prevalence of the disease (77), and that their children were affected regardless of their own HIV status (9, 77). No differences were found in the child's health status due to the clinical status of the mother.

More children may need social care, however, when their mothers are in the symptomatic stage of the disease and may leave them motherless (77). Although most children in the ECS study were cared for by their mother or father (or both) in their early life, by the age of four, 30% of the children had experienced alternative care (such as foster care or care by an extended family) (9). Children of mothers who used drugs were in special need of alternative care, whereas children from African families were less likely to need alternative care. These findings, however, do not seem specific to children affected by HIV, with drug use often the main reason for mothers and their children being separated. With the number of injecting female drug users increasing, particular efforts should be made to strengthen comprehensive HIV/AIDS prevention and care services for injecting drug users and their partners, to reduce MTCT and to provide further care for those children infected with HIV or affected by related drug use (79).

Also, HIV may have a different impact on migrant families in European countries (particularly those from sub-Saharan Africa) compared with European families – for example, from the United Kingdom (24). This may be the case, for example, when dealing with the HIV diagnosis and with the organization of parenthood and parent–child relations. Another longitudinal study in the United States showed that children with HIV-infected mothers reported more symptoms of depression than children with non-infected mothers (92). Still another study in the United States (93) showed that the number of orphans was diminishing, but that even in the HAART era children may be orphaned. The loss of parents entails social, psychological, and physical needs that demand immediate attention. And a third study in the United States showed that in most cases the extended family (grandparents) provided care (9), but nearly a quarter of the children had lived under institutional care or under other care arrangements, such as foster homes.

In the southern part of Europe, the family plays a more central role in the social care of children born to HIV-infected mothers, whereas foster care is a much more important care setting in the northern part (9). These results suggest that the demand for alternative care may increase as a consequence of an increase in the number of HIV-infected parents, but they may underestimate the effect of HAART and its potential to reduce the need for additional care. In regions where HAART is less likely to be available, the finding still has important implications.

A study of children left motherless by AIDS in the United States (93) showed that when long-term care becomes the task of grandparents, support may be needed with many aspects of care. Such support would include transportation for their own and their grandchild's medical appointments, stress reduction and anxiety management for dealing with their own serious illnesses, respite care, and psychological support. Also, family members may need additional financial support, as income declines in the senior years.

Planning children's future

In general, long-term care for children lacks planning, with custody planning being one of the important issues with which parents have to deal. Lack of planning may be enhanced by fear, as a result of social stigma (94), or may result from denial of the possible consequences of HIV. Lack of custody planning may affect children adversely if they are not placed with the desired guardians; also,

unexpected loss versus prepared loss by children may increase the adversity of the outcome, and legal consequences may be more complicated. A study in the United States among parents living with AIDS in New York City showed that parents were more likely to make custody plans when using adaptive coping strategies, such as problem solving and positive action, and when receiving social support (94). Moreover, parents who were aware of their HIV status for a long time were more likely to plan for the future care of their children. Another study showed that European parents were more likely to have planned for their child's future than were migrant parents (49).

Long-term perspective with a specific focus on HIV-infected adolescents

With HAART, HIV-positive children live longer and reach adolescence (59, 77). Growing more independent, adolescents need to manage their illness and possible consequences (such as treatment medication and future planning), and deal with disclosure and sexuality.

Safe sex among HIV-infected adolescents needs to be promoted. A study in the United States (95) showed that at least a quarter of adolescents with vertically acquired HIV infection were sexually active and that condom use was generally inconsistent. Inconsistent condom use is reported among HIV-positive adolescents – especially where two contraceptive methods are available, condom use is less likely (96).

In a study of 575 sexually active HIV-infected women in France (96), condom use was higher in serodiscordant than in seroconcordant couples. In serodiscordant couples, oral contraceptive use diminished after the introduction of HAART, but it was higher among people with inconsistent condom use. This means that the risk exists for both horizontal and vertical HIV transmission.

Preventing HIV infection in adolescents

Prevention efforts need to continue to seek to protect HIV-negative young people from becoming infected with HIV. This means both education and facilitating ways to ensure they can protect themselves. Families may play a role in reducing possible risk-taking behaviour. A review in the United States (97) showed that when parents and adolescents specifically communicate about sexual behaviour the result is fewer sexual risks, in terms of delayed and safer sexual behaviour. At the same time, it has been recognized that parents do not talk sufficiently with their children about sex. Discussions are more effective when both the quality and the timing of the communication is appropriate, meaning that parents need to be skilled and discussions need to take place before the onset of sexual activity. Parental monitoring (knowing what the child does) has also been shown to be an important factor in protecting children from unsafe sexual behaviour.

In eastern Europe, the number of young women and girls infected with HIV is growing. Eighty percent of HIV infections are found in people below 30 years of age (4). Specific prevention efforts should be directed at this group, to prevent the further spread of HIV. In addition to more educational efforts directed at young people, young people need access to prevention measures, such as condoms, and to treatment facilities (4, 98). In particular, women are much more likely than men to contract HIV from a single act of unprotected sex with an HIV-infected partner. Whether women have sex and whether that sex is protected often depends on the decisions and behaviour of their male partners. Unfortunately, a female-controlled prevention method is not widely available yet. Female condoms do protect women, but they require some degree of negotiation and male cooperation. They are also more expensive than male condoms and, despite indications of increased uptake, they remain neither widely available nor socially accepted, but they remain an important additional method (99).

A number of areas need attention. Specific attention should be given to migrants coming from high prevalence areas. Also, more education about sexual health and HIV is needed to increase awareness of the risk of HIV infection and the availability of HIV testing and treatment. Moreover, access to

health and social care is needed. In particular, HIV-positive asylum seekers need access to HIV specialist health care (20).

Current debate

The current debate on the impact of HIV on the family covers several questions and issues, such as:

- whether the focus should be on individuals or on families;
- the desirability of HIV prevention among HIV-positive people (100). The debate focuses on the responsibility of HIV-positive and -negative people and on the possible adverse consequences versus the new needs of HIV-positive people;
- the need to reduce poverty;
- the need to involve men in protecting women and the need to empower women;
- when, where and how to disclose HIV status;
- what to do in the case of low HIV treatment adherence rates. In addition, there is a debate on how to specify a norm on what adherence or the lack of adherence is;
- whether the focus should be on people or on environmental changes (101);
- to what extent laws and prevention conflict. On the one hand, it is essential that people know their HIV status. On the other hand, what is the proper response to people who infect other people, despite knowing their HIV status; and
- whether HAART increases risk behaviour.

Discussion

Like people living with other chronic illnesses, PWHAs are challenged to take care of their own health and to integrate the management of the infection into their daily life. Thus there is an indirect effect on uninfected family members. In contrast to other chronic diseases, however, several family members may be infected with HIV, and improper behaviour in the family can have an impact on HIV transmission, the effectiveness of treatment and the psychological well-being of family members. This synthesis has sought to identify the various impacts of HIV on families.

Strength of evidence

The impact of HIV on families cannot be determined simply by traditional clinical trials; instead, evidence from qualitative evaluations, surveys and reviews must be included. These provide interesting insights into issues faced by families living with HIV. From a traditional evidence-based perspective, however, these sources are generally of low quality. Consequently, policy recommendations based on them can only be tentative and should be considered in conjunction with other HIV/AIDS initiatives and evaluated as they are implemented.

The scope of this synthesis has not permitted evaluation of cost implications that relate to the impact of HIV on families or of the cost effectiveness of strategies that might improve the well-being of families with HIV. Human immunodeficiency virus can affect different forms of family units in many different ways, and any economic model would be complex and require a societal perspective. This synthesis has considered instead the social, legal and ethical issues that are paramount in any AIDS policy development: these have been presented as an integral part of the findings and will affect policy considerations.

Policy considerations

Reduce the stigma of HIV

Empirical evidence indicates that some of the most effective responses to the HIV/AIDS epidemic have involved affected communities mobilizing themselves to fight stigmatization, discrimination, and

oppression (102). Brown et al. (103) conclude that contact with people with HIV/AIDS seems the most promising approach, in combination with information about reducing stigmatization. Policy-making should be directed at laws that protect the human rights of HIV-infected people, regardless of their behavior (such as drug use) or place of origin, so that acceptance, care and support increase for people and families affected by HIV.

Primary and secondary prevention of HIV

Several targets are needed in any strategy to prevent HIV infection. Preventing new infections should aim at primarily preventing risk taking behaviour – for example, drug use and high-risk sex.

Secondary prevention can reduce the number of horizontal infections between partners and reduce the chance of MTCT. For this, early diagnosis and treatment of HIV, and encouragement of HIV status disclosure, are necessary.

Prevention measures aimed at HIV-positive people should receive attention. For example, given the role of intravenous drug use in the spread of HIV and its association with suboptimal access to care, HIV-positive drug users should be targeted. Also, a policy acknowledging the need to treat both diseases should promote patient well-being, reduce stigmatization and promote the delivery of comprehensive, ethical medical care.

Environmental and policy changes

Prevention should not only be directed at individuals, but should also be directed at the environmental conditions that need to be improved to reduce the possibilities of HIV transmission. Policies need to consider reducing poverty, distributing condoms among specific risk populations and settings (such as prisons), as well as making needle exchange programs and drug replacement therapy available (101). The distribution of syringes and promotion of safe sex should be encouraged. Also, HIV treatment facilities should be of good quality, and everyone should have equal access to treatment.

Testing people for HIV is important for improving HIV disclosure, accessing treatment, and preventing infection in family members and others. An active testing policy should be considered to reduce the number of undiagnosed HIV-positive people, so that HIV testing is normalized – that is, becomes common place and without stigma – and a wider uptake of testing is promoted.

To improve the uptake of active HIV testing, it is also vital that HIV-positive people are not criminalized. Recent data show that prosecution rates related to HIV transmission are increasing (104). UNAIDS (105) and other parties (106) have warned against the negative consequences of specifically prosecuting cases related to HIV transmission. From a public health perspective, it is desirable that HIV infections are identified as early as possible and that the treatment of HIV infections prevents new infections. Also, early treatment is desirable to improve the quality of life of people infected with HIV. Moreover, prosecution may lead to a reduction in the number of people tested for HIV, and HIV-positive people are likely to become stigmatized and discriminated against. Thus, in line with the views of UNAIDS and, for example, STI AIDS Netherlands, it is desirable that HIV/AIDS is not criminalized unless there are other relevant legal issues, such as power injustice, force or deliberate deceit, which should not include the non-disclosure of one's HIV status. In general, the development of a legal and policy framework that protects the human rights of PWHA and those affected by the epidemic should be given priority.

The families most affected by AIDS are often characterized by poverty, homelessness, substance abuse, belonging to minority cultural and ethnic groups, and the practice of alternative lifestyles (19). Also, the beneficial effect of HAART therapy is less pronounced among ethnic minorities and poorer populations in high-income countries (107). Thus, HIV-positive people and their social environment need support not only psychologically, but also materially, to foster change (101). Moreover, migrants

in Europe may face barriers to HIV prevention and care that arise from cultural, socioeconomic, linguistic, administrative and legal issues. And furthermore, they may be more prone to stigmatization and social hostility (8, 54).

Supporting couples and parents

Couples positive for HIV should be informed and supported, to make informed decisions about sexuality and positive parenting. Unintended pregnancy should be prevented and ART treatment provided for pregnant women. When HIV-positive women make an informed decision to give birth, they need to receive appropriate treatment to reduce MTCT. For HIV-positive men, sperm washing has been used over the last 10 years and has been shown to be relatively safe, but not risk free. Further research on its safety is about to be published (108). Research that examines the role of fathers in positive parenting and pregnancy decision-making is lacking, and so more information is needed about their role.

Studies in the United States (109, 110) showed that a family-centred intervention that focuses on disclosure, coping and future planning could improve the lives of family members. Also, health care professionals should counsel parents or caregivers about disclosure to a child. This is best tailored to the specific situation of the child, taking into account the child's cognitive ability, stage of development, clinical status, and social circumstances. It should include education about coping skills and be integrated into paediatric care.

Family-based alternatives to institutional care should be promoted through appropriate policies. Care should be offered beyond the traditional family framework and be tailored to the specific needs and concerns of subpopulations identified, such as migrants. Children without primary caregivers will need to be equipped with life skills, knowledge and opportunities to participate. Also, caregivers may require ongoing support and training in coping skills, particularly as a child grows into adolescence or as AIDS progresses.

Improve social and health care for HIV-positive people, with a specific reference to adolescents

A long-term view of people living with HIV is needed, and it should entail care for the needs of adolescents and adults who live with HIV as a chronic illness. Policy changes need to be made to promote equal rights, such as life assurance (recent changes have been reported in the Netherlands (111)). HIV-infected people should be supported in reintegrating into every day life – for example, by returning to work and coping with disclosure. Policies should also ensure a supported transition from child or family care to adult care. Also, more research should be directed at the long-term side-effects of ART, at ways to improve adherence, and at ways to improve treatment safety, such as drug treatment interruptions.

Conclusions

Every year across Europe, thousands of people become infected with HIV, and large numbers of HIV-infected people are unaware of their HIV status. The main challenges are to promote HIV testing of those at risk, to encourage disclosure, to provide early and effective treatment and care to all HIV-infected people, to continue developing prevention efforts that are adapted to the changing patterns of the epidemic, and to reduce the psychosocial, economic and physical repercussions of HIV infection. Policies should be tailored to consider the needs of families – as a whole unit, as couples considering becoming parents, and as HIV-infected mothers and HIV-infected children and adolescents.

Annex 1: Abbreviations

AIDS	acquired immunodeficiency syndrome
ART	antiretroviral therapies
ARV	antiretroviral
CEE	central and eastern Europe
CNS	central nervous system
ECS	European Collaborative Study
HAART	highly active antiretroviral therapies
HIV	human immunodeficiency virus
MSM	men who have sex with men
MTCT	mother-to-child transmission
NVT	nevirapine
PWHA	people with HIV/AIDS
ZDV	zidovudine

Annex 2: Evidence search methods

A systematic search was undertaken to find evidence that relates to the impact of HIV on families. The search encompassed:

- literature databases (Cochrane, Pubmed, PsycINFO, Online Contents);
- Web of Science (Social Science Citation Index, Science Citation Index Expanded, Arts & Humanities Citation Index);
- specific journals (*AIDS*, *AIDS Care*, *AIDS and Behaviour* and *AIDS Patient Care and STDs*);
- databases and websites of UNAIDS, Health Evidence Network (WHO/HEN), WHO and EUROHIV;
- Internet search engines Google (Scholar); and
- International AIDS Society (IAS) abstracts.

Key words used different combinations of “HIV”, “AIDS”, “impact”, “famil*”, “Europ*”, (not “America*”, not “Africa*”).

The search was undertaken on 15 March 2005 and updated 29 September 2005. Only studies after 1996 were included, to cover the era after the introduction of HAART. (Some studies after 1996 included data from before the introduction of HAART: where applicable, this is mentioned.)

After initial selection from abstracts, full text papers were reviewed to select specific members of the family and specific issues using the keywords of “child or children”, “parents”, “couples”, “adherence”, “stigma”, “disclosure”, “assisted reproduction” and “pregnancy”. The main focus was on identifying European-related studies, but some non-European studies were examined if they were thought relevant to the European context.

Given the nature of the question, no grading system was used to appraise the evidence, as it is generally of low quality in strict evidential terms. The basis of any statement (such as survey and longitudinal study) is presented, however.

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