Families Living with HIV Disease

Scope of the problem
It is now more than 25 years since AIDS as a distinct syndrome was first formally reported in the medical literature following the presentation of rare clinical symptoms in three previously healthy gay men in the U.S. Looking back, we now know that these first cases that affected gay men and intravenous drug users in several Western countries gave the appearance of HIV infection (human immunodeficiency virus) being a limited epidemic confined to so-called risk groups. The epidemic rapidly spread beyond these groups and into the general population in many different communities and countries. Because of the long latency between infection and the appearance of clinical symptoms, the pattern and extent of its spread was not immediately apparent.

HIV infection is now a pandemic that affects almost every country, although certain groups and communities are affected disproportionately. In spite of the greater understanding that we have of the epidemiology of HIV infection and the advances in knowledge of prevention and treatment, it remains a stigmatizing condition for the sufferer as well as for his or her family. It is striking that the management of a medical problem should produce such discord among and between community leaders, politicians, and clinicians as well as those infected with HIV. There can be few other medical conditions that highlight the contentious political issues of unequal access to health care; the effects of poverty on the spread of the epidemic; gender inequality in medical care, as well as the role of gender and stereotypes in transmission and prevention; inequity in the pricing of medical treatments, and the care and support of infected children, among many others.

The adverse psychological consequences of knowing that one is infected and having to cope with a chronic illness can at times be as challenging as the illness itself. HIV is increasingly recognized as an illness that affects families and not just individuals. This is not only because the infection can be passed on between partners and from an infected mother to her child, but also because for every individual infected with HIV, there is a family or community that is affected emotionally, socially and financially by that individual’s illness.

The role of the therapist is crucial in helping individuals, couples and families cope with an increasingly lengthy period of chronic illness. Therapy can help the infected individual and family adjust to the crisis of an HIV diagnosis, sustain themselves through periods of uncertainty, and cope with feelings generated by anticipatory loss. They can also help to prevent further transmission of HIV through education and supporting informed decision-making around risk behavior. Therapists can also help members of specialist HIV healthcare teams deal more effectively with the complex and sometimes emotive and ethically sensitive issues that arise when caring for these patients and their families.

Global epidemiology
UNAIDS estimates that there are currently 39.5 million people living with HIV worldwide, with 4.3 million new infections in 2006 and 2.9 million deaths in that year. More than 2 million children up to age 14 are infected with HIV; the majority of them from sub-Saharan Africa. The global incidence rate of HIV appears to have peaked and stabilized during the late 1990s, and therefore the rate of new infections might have reached a plateau. While this gives cause for some optimism, there are still very high rates of infection in many regions and countries, especially in sub-Saharan Africa. South Africa, Botswana, Swaziland and Namibia are four severely affected countries in that region and there is no evidence of a decline in the epidemic there. The effectiveness and more widespread availability of anti-HIV drugs may be a contributing factor to the increasing number of people worldwide living with HIV. This is in spite of the fact that only one in five people who need antiretroviral drugs receive them. Universal access to testing, treatment and care remains a distant goal.

The global HIV epidemic unfolds at an uneven pace, with different regions, countries, groups, ages and genders affected. In China, for example, infection rates among intravenous drug users is high and the overlapping risk of unprotected sex is likely to see infection rates increase in the wider population in the coming years. The Russian Federation has the biggest AIDS problem in Europe, while the epidemic in Eastern Europe and Central Asia, having risen more than 50% since 2004, continues to expand. Unprotected heterosexual contact in Asia accounts for the majority of the estimated 8.3 million infections in that region. Access to anti-HIV drugs is more widespread in Thailand, while few among India’s 5.5 million HIV infected people receive medication. The epidemic in the United States showed signs of stabilizing and even declining in certain communities in recent years. However, both in Europe and the U.S., there is evidence of a resurgence of the epidemic among men who have sex with men.

Preventing the spread of HIV infection relies on behavior change. Evidence suggests that there is not a single method or approach that can be universally applied to achieve this. However, experience has demonstrated that there needs to be unequivocal commitment to HIV prevention from a country’s leadership, allocation of resources to develop prevention programs, close monitoring of these programs, and a willingness to persist with these programs especially after they first show signs of success.
**Medical care and treatment**

On the medical front, there have been rapid developments over the past decade in the detection, monitoring and treatment of HIV, as well as a clear understanding of how to prevent its further spread. Medical care for HIV has rapidly progressed from the crisis management, symptom control and palliative support that most characterized care in the first decade, to promoting early detection of infection through voluntary testing, close monitoring of the impact of the infection on the immune system, and timely treatment with a range of medications. Anti-HIV drugs interfere with the way the virus tries to reproduce itself in cells. They cannot kill the virus completely, but they can reduce the ability of HIV-infected cells from producing new HIV particles, which could go on to infect more cells. There is also a wide range of drugs used for treating and preventing specific infections that affect those who are immuno-compromised and specifically for individuals with HIV disease.

There are two main categories of anti-HIV drugs currently available and these are most effective when taken in a potent combination of three or more at the same time, which is called combination therapy of ARVs (antiretrovirals). The main categories are reverse transcriptase inhibitors and protease inhibitors, while a third category of drugs, known as fusion inhibitors, are available for those who have limited treatment options due to the side effects of the others or where drug resistance has developed. The actual number of drugs taken and the specific regime varies from individual to individual, taking into account their stage of HIV infection, the results of laboratory tests that give an indication of immune system functioning and viral load, previous treatments, side effects and whether resistance to a particular drug has occurred. Decisions about treatment demand careful assessment. The advantages of therapy must be weighed against known and possible side effects that may impair the functioning of certain organs and systems, as well as the patient’s mental state. When to start treatment and which specific combinations to start with also depends on a number of factors, which is why most people in developed countries infected with HIV are treated by specialist physicians. These treatments are complex, expensive and their effects require careful monitoring. However, assuming that the infected person is able to tolerate the therapeutic regime, HIV infection can now be managed for a seemingly indefinite period of time. Those in resource poor countries might not always have access to specialist medical care and this has direct implications for morbidity and mortality in these populations. Studies have shown that some patients develop neuro-psychiatric disturbance, including depression and psychosis, as a direct result of taking certain prescribed anti-HIV medications (Fumaz et al., 2005). For others, pre-existing psychiatric symptoms may decline as a consequence of their anti-HIV treatment (Low-Beer et al., 2000), presumably because of indirect effects such as improved quality of life as well as the direct effects of medication on mental health. There is also evidence for increased healthcare utilization among HIV-infected individuals suffering from mental health disorders (Mijch et al., 2006). The model of joint consultations, underpinned by the biopsychosocial approach between patient, physician and mental health professional (McDaniel, Hepworth & Doherty, 1992) may help to alleviate this.

**Psychological consequences of HIV infection**

While advances in medical treatments for HIV infection have dramatically improved survival and quality of life among those who have access to specialist
medical care and modern anti-HIV medication, thereby reducing mortality rates from HIV in most developed countries, people still become ill and die from AIDS. Long-term survival carries with it its own difficulties and challenges, especially for those who have endured uncertainty over a prolonged period of time. Fears of being ostracized socially, serious illness and death affects most people living with HIV and these fears can produce symptoms of anxiety, depression, dysthymia and, in rare circumstances, psychosis (Gallego et al., 2000). Many of the adverse psychological consequences of HIV infection are related to its social context, which is especially marked by fear of contagion, ostracism of those infected and marginalization of those both infected with the virus, as well as the family and primary support providers of those indirectly affected.

Mental health problems may also pre-date infection with HIV and in some cases are pre-disposing risk factors. Untreated depression, alcoholism, drug dependency and low self-esteem can increase risk for HIV (Fernandez & Ruiz, 2006). The diagnosis and treatment of mental health problems in the general population is therefore relevant to the prevention of HIV transmission.

Much research has been published over the past 25 years describing the psychological implications of HIV infection as well as psychological barriers to the prevention of infection. A wide range of mental health problems associated with HIV infection has been described that affect up to 70% of diagnosed individuals at different stages of their illness (Fernandez & Ruiz, 2006). Mental health problems also extend to those with unresolved morbid fear of HIV (commonly termed the worried well) among undiagnosed and presumably healthy individuals that can also prompt the need for specialist psychotherapeutic intervention. Mental health problems associated with infection and its medical treatment, the effects of stigma and social rejection, dementia and other neurological disorders, as well as sexual and relationship problems are commonly recognized in people infected with HIV (Hilsabeck et al., 2005).

Notification of a positive HIV test result may cause an intense though transient adjustment reaction, characterized by shock, despair, helplessness, guilt, grief, loss of self-esteem, as well as anxiety and depression, in most individuals. The nature, duration and intensity of the reaction and subsequent coping will determine whether more specialist psychotherapeutic intervention may be necessary. Those who have a history of mental health problems may be more predisposed to psychological distress at the time of diagnosis and when individuals develop HIV-related symptoms (NIMH, 2006). Vulnerable individuals with personality difficulties, poor coping skills, a history of substance misuse and those who lack social support are more prone to persistent mental health problems upon and following diagnosis of HIV infection (Catalan et al., 2000). Suicidal thoughts are also common among those infected and there is some evidence for increased risk of acting on these thoughts (O’Dowd et al., 1993).

The range of psychological problems faced by individuals from the early days of the epidemic continue to impact upon those diagnosed with HIV, while new challenges have arisen in response to emerging and sometimes unforeseen issues. The “early” days of HIV infection were characterized psychologically by the various consequences of social stigma, emotional vulnerability after diagnosis in the light of it being an untreatable and usually fatal disease, and having to cope with multiple losses, often including significant loss within the individual’s own personal support network. In the last decade, the emphasis in published research into the psychological sequelae of HIV has expanded to include coping with chronic illness, the deleterious impact of HIV on families, especially to patterns of care and support, the social and emotional problems of orphanhood, as well as coping with complex medical regimes and adherence to anti-retroviral treatment regimes.

Emerging challenges include the management of co-infections that may accompany HIV, such as Hepatitis C and tuberculosis, and the reversal of hope and optimism among those whose HIV infection is being successfully treated as a result of the additional infections.

The impact on families
Most psychosocial research in this area has focused on the impact of HIV infection on the individual. Only recently has there been a shift in emphasis towards a more expansive examination of psychological processes that affect people...
HIV Disease

with HIV in a family and relational context. This is surprising as HIV infects individuals but it also affects a whole network of significant relationships, especially those who provide the majority of the day-to-day social support to the infected individual (Bor & du Plessis, 1997). It has been observed that, while traditionally, biological family members provide practical, emotional and social support in times of illness, this typical pattern of support is not necessarily available when the individual concerned has HIV (Bor & Elford, 1998). This may be due to the deleterious effects of social stigma, poverty, illness and incapacity or loss among other family members who may themselves be unwell with HIV or may have already died. A breach in emotional, social and practical support may also follow from previous schisms in family relationships that pre-dated a diagnosis of HIV infection. This might emanate from a wide range of issues and events such as a background of sibling rivalry, disclosure of sexuality within the family, or an extra-marital relationship, among many possible causes. The diagnosis can either exacerbate existing tensions or may be the precursor to healing rifts in family relationships.

Working with those infected with HIV has prompted researchers and clinicians alike to re-examine accepted definitions of the family and to take into account the diverse social networks affected by the disease. “Family” has come to include not only relatives who are blood relations, but others such as those who share a household, or who are part of the index person’s self defined social network, including friends and partners. Family can also include any provider of social, emotional or practical support. Many family members appear to be affected by the same emotional and practical issues that affect HIV infected individuals.

Learning about patterns of disclosure of HIV status within the family also helps to discern who is a close or more distant family member. Research has demonstrated that disclosure of HIV status within the family is selective and incremental, and not always a carefully planned event (Bor, du Plessis, & Russell, 2004). Adjustment to illness among caregivers is also a complex two-way, reciprocal process whereby the infected individual and caregiver take subtle cues from one another in terms of how they appear to one another to cope. There is a circularity in patterns of coping that has been observed: family members cope better when the HIV infected person is coping well, and also appears physically well, and in turn provide better support. Some family members, understandably, find it difficult to maintain a supportive and positive outlook in the face of illness and this in turn affects how the infected individual copes.

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Psychological problems among family members can also continue after the infected relative or partner has died. For example, a surviving gay partner might be excluded by other biological family members from social rituals, taking control of the estate or even child custody arrangements (Richards, Wrubel, & Folkman, 1999-2000), consigning that surviving individual to disenfranchised grief, and increased risk for mental health problems (Doka, 1989).

Living with a disease that may lead to the death of the infected person brings emotional upheaval and distress to a relationship. This is especially relevant to HIV-serodiscordant relationships (where one partner is infected), which may be “unbalanced” as a consequence of infection. The dynamics of these relationships is complex given the implications of disclosure to one’s partner, the risk of transmission within the relationship as well as strain on patterns of intimacy, care and support (Palmer & Bor, 2001) sometimes necessitating marriage or couples therapy.

**Terminology of HIV Terms**

**Adherence:** The act of taking medical treatment exactly as prescribed.

**AIDS:** The diagnostic term, Acquired Immune Deficiency Syndrome, relates to the presence of specific and defining illnesses relating to infection with HIV. This term is used less frequently now days and instead, physicians increasingly refer to *primary HIV infection*, *HIV infection*, *symptomatic HIV infection* and *advanced HIV disease*.

**Antiretrovirals (ARVs):** Substances that act against viral pathogens such as HIV.

**CD4:** A molecule on the surface of some cells onto which HIV can bind. The CD4 cell count reflects the status of the immune system. A high count suggests healthy immunity while a low count leaves the host susceptible to infection.

**HAART:** Highly Active Antiretroviral Therapy, a term used to describe anti-HIV combination therapy with three or more drugs.

**HIV:** Human immunodeficiency virus is the virus that, untreated, can cause illness (AIDS) and lead to death. There is however no cure for HIV.

**HIV antibody test:** A highly accurate and simple blood or saliva test that determines whether HIV antibodies are present. Antibodies are a marker of infection. A positive test result indicates the presence of virus, and therefore of HIV infection.

**Resistance:** A drug resistant HIV strain is one that is less susceptible to the effects of one or more anti-HIV drugs because of its genotype.

**Sero-discordance:** The “imbalance” that exists in a relationship where one partner is infected with HIV while the other is negative.

**Viral load:** Measurement of the amount of virus in a sample. HIV viral load indicates the extent to which HIV is reproducing within the body. A high viral load suggests extensive viral activity and replication, which is likely to be harmful to one’s health.

**Children, Young People, Families and HIV**

Children who have acquired HIV through vertical transmission (i.e. mother to child) rather than behaviorally (i.e. sexual activity, drug-taking, sexual abuse) can face different, yet similar difficulties. Since the latter part of the 1990s in the UK, pregnant women have been encouraged to test for HIV and need to “opt out” to not be tested. This has significantly reduced the number of HIV positive infants born to infected mothers to less than 1% of this population. While this has been recognized as a significant advance, the number of children living with HIV continues to increase. The age...
range 15–24 years old is now the highest risk group, with females making up more than half the numbers.

In developing countries where health resources may be more limited and where women may face significant obstacles in persuading their partners to use condoms, the proportion of infected children born to infected mothers is significantly higher than in developed countries. Furthermore, increased migration and displacement due to war and poverty has resulted in an increase in the number of children living with HIV in some developed countries. The majority of HIV infected children, like their parents, come from already marginalized communities, face a significant number of social problems including immigration, displacement, language and cultural differences and these also may negatively affect access to health and social services.

Increasingly, as children infected with HIV are living longer, new challenges have emerged. For many infected children, they face the knowledge that not only are they carrying a potentially lethal virus, but also they have to cope with a parental caregiver who is similarly infected. Many of these young children have already lost a parent(s) or other family members from this disease. For the affected child, they may be brought up in a household where the focus is on continuing ill health. Siblings may be expected to take a care giving role and carry significant responsibilities beyond their years. The infected child who attends school may have frequent absence, require medication during the day, and also experience the side effects of these potent drugs. The question of disclosure raises emotional upheaval within families. Only recently has research been undertaken on the long-term mental health of the HIV positive child.

Parental disclosure to the child and between the child and other systems (e.g., school) is an ongoing process and not a singular event. Failure to disclose can lead to emotional difficulties, adherence problems and, later, HIV transmission where a child is sexually active. Disclosure needs to be understood as two separate processes. Firstly, what the child needs to know, and secondly, the area of wider disclosure to those who may need to know for the child’s benefit (see Table 1).

Clinical experience has shown that when children learn about their diagnosis, they generally manage this knowledge well. Counseling and family-based therapy can help all concerned to consider what, when, how and to whom to disclose and the likely effects of inappropriate disclosure. Young people are now living longer with HIV and, like any other, need to find their place in the world. However, their developmental milestones and needs should take into account appropriate psycho-educational guidance. This might include discussion and advice about transmission, keeping healthy, identity, where to find relevant information and peer support.

The current challenge in Western countries is the area of “transitioning.” As teenagers reach the age of 15 or 16 years, they are being introduced to adult HIV services. These transitional events raise new and exciting challenges for everyone involved. Some young people embrace this and the transition process flows smoothly, while others baulk at the change and safety of attachments and start to act out. Adherence amongst adolescents inevitably becomes problematic, especially if disclosure occurs fairly late. Family focused approaches are essential and comprehensive psychiatric, psychological and neurological assessments are key elements in the ongoing management of children and youth with HIV.

**Adherence to medication**

Early in the HIV pandemic, the challenge was to find effective antiretroviral medication. Now the challenge is to facilitate access to medication worldwide and to ensure that those with access can tolerate and benefit from the medication.

Many of the improvements in quality and duration of life in HIV patients are contingent upon extraordinarily high levels of adherence to medication regimes in the order of 95% levels. Poor adherence can lead to treatment failure due to viral replication and the development of viral resistance, both of which may accelerate disease progression and eventual death.

The problem of poor adherence is not unique to HIV; it is a challenge in the treatment of many medical conditions varying from the routine use of antibiotics in acute infection to the treatment of chronic conditions such as diabetes or hypertension.

Adherence is best supported by providing the conditions for well prepared, motivated patients with a good understanding of their disease. The factors influencing adherence are varied and complex and are summarized in Table 2.

Adherence is a complex issue and one best addressed by every member of the wider health care team utilizing their particular skills, especially therapists. They can use their expertise to assess patients for likely difficulties with treatment adherence and help the patient and physician achieve realistic and achievable goals for treatment. It is helpful to have a good understanding of HIV and its treatment and to forge good working relationships with treating physicians. Mental health professionals are best placed to explore the

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**Table 1**

**STEP-BY-STEP GUIDE TO HIV DISCLOSURE TO CHILDREN**

**Developmental Model**

1. **0–4 years (very young):** no disclosure as yet. Carry on consultation with child present. Aim: build the child’s confidence in health care system.

2. **5–7 years (early disclosure).** Introduce ideas of good health; exercise; looking after teeth; medicines keeping body healthy; and introduce ideas of “goodies and baddies” in the body. Aim: understand medicines support a healthy body.

3. **8–11 years (partial disclosure).** Talking about “baddies” being a virus; idea of “clever virus”: impact of stopping medicines making “clever virus” stronger (resistance). Aim: naming of infection as HIV virus (within context of private information and circles of care)

4. **11–14 years (full disclosure).** Review understanding; transmission; future considerations. Aim: full disclosure.
impact of health related beliefs, mental health problems, practical and behavioral impediments and the effects of relationships on adherence. It is a challenge that is best treated collaboratively, sometimes in joint consultations that include patient, physician and therapist.

Therapists in independent practice, not attached to a medical team, may find that they can act as a sounding board where patients can explore ambivalence or difficulties about treatment without feeling they are letting down the medical team or being a “bad” patient. The impact of starting treatment on family and other relationships can be significant. The patient may not have disclosed the HIV status to family, partner or children, and may decline treatment or omit doses to avoid discovery. The success of treatment may be dependant on facilitating disclosure. Some patients may have difficulty starting treatment due to social and financial difficulties, such as homelessness or immigration problems. The more stable a patient’s social situation, the greater the likelihood that potential barriers to adherence can be identified and addressed.

Adherence can also be a problem for patients well-established on therapy. The long term use of antiretroviral therapy can be associated with a number of side effects including gastro intestinal problems, hyperlipidaemia, neurological and psychiatric symptoms, and body shape changes associated with changes in fat metabolism, termed lipodystrophy. These can affect quality of life to such an extent that the patient contemplates breaks in their medical treatment resulting in drug resistance and therefore unchecked disease progression. Body dysmorpia related to lipodystrophy can be associated with depression and social withdrawal. In some communities, these physical changes signify HIV thus leading to perceived and actual stigma. Exploration of these factors in the therapeutic setting can help maintain adherence, avoid impulsive treatment breaks or, where a patient genuinely wants to stop, allow for planned treatment interruptions with appropriate medical support.

As with any chronic and potentially life threatening condition, relationships can become stuck and dysfunctional patterns can emerge. Family therapists have a unique set of skills they can use when working with those affected by and infected with HIV. Firstly, they can provide a biopsychosocial perspective to dealing with the challenges posed by this disease. Secondly, they can provide a dynamic link between the individual, family and medical systems. Thirdly, they have specific skills in facilitating open communication throughout the lifecycle and across generations, which is especially relevant in a disease that affects children and adults (Bor et al., 2007). Finally, many family therapists value a non-judgmental and an explorative approach which is highly suited to discussing sensitive matters concerning fidelity, sexuality, disclosure, fertility, and dying, as well as helping people make informed choices about their lives. They strive towards helping people to find their resilience in the face of multiple challenges.

### Resources for Practitioners

**American Psychological Association**

www.apa.org/pi/aids

Provides training, information and resources for HIV researchers.

**National AIDS Manual**

www.aidsmap.com

Contains user-friendly online information for clients, research summaries and advocacy.

**British HIV Association (BHIVA)**

www.bhiva.org

Provides professional guidelines and information on HIV concerning children and adults. Good guidelines on support, adherence and on responding to the recent criminalization of HIV transmission.

**National Institute of Mental Health**

www.nimh.nih.gov

The Office of AIDS supports behavioral research associated with HIV prevention, treatment and identifies needs for scientific inquiry. It also supports an annual family and HIV/AIDS meeting.

**National Institutes of Health**

www.niaid.nih.gov

Through the National Institute of Allergy and Infectious Diseases, this site provides useful information on the epidemiology of the epidemic, pathogenesis of the virus, treatment, prevention and supports research.

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**Table 2**

**Psychosocial Factors That May Impair Adherence to Treatment**

- Poor understanding of HIV
- Poor understanding of medication itself—e.g. side effects, number and size of pills, particular food and water intake requirements
- The specific regime and how this affects the lifestyle of the patient—e.g. hours and times of dosing, where the person is at the time of being required to take the dose; the prospect of taking medication indefinitely;
- The social significance of being prescribed medication for the first time for the patient; i.e. this could challenge the patient who has so far come to terms with the diagnosis by avoiding the issue, to feel that he or she has to face up to it
- Negative attitudes towards medication generally
- Fears that stem from the experiences and adverse side effects of friends as reported to the index patient
- Social and environmental factors—e.g. social support for taking medication, issues surrounding disclosure of HIV status, lifestyle factors such as people living busy social or unpredictable lives, as well as co-morbid substance abuse. There is a secondary issue of altruism; some patients “share” their medication with other family members, thereby inadvertently diminishing the effect of the medication
- Poverty, which may limit dietary advice or preclude refrigeration of certain medications
- Certain health beliefs (e.g. concerns about side effects or ambivalence towards treatment)
- Mental health and psychiatric disorders—psychotic, mood, anxiety disorders, past exposure to traumatic life events; cognitive impairment (dementia)
- Psychological and psychiatric side effects of some prescribed medications; negative attitudes towards treatment
- Variables relating to the doctor-patient relationship
THE JOINT UNITED NATIONS PROGRAMME ON HIV/AIDS
www.unaids.org
Coordinates the global campaign through research, funding, policy and education, and also publishes an annual update on the epidemiology of the epidemic.

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CRIMINALIZATION OF HIV TRANSMISSION: THE THERAPIST’S DUTIES

Therapists and counselors working with HIV positive people have long been aware of ethical and moral conflicts for themselves and their patients in the area of HIV disclosure and prevention. The principle of upholding patient confidentiality may conflict with the need to prevent harm to others where a client declines to tell a partner with whom they are having unprotected sex that they are HIV positive. Therapists often have to work in the uncomfortable domain between their commitment to non-judgmental relationships and the need to mitigate against harm to others. If a client continues to place a partner at risk, most professional codes of practice would support the professional in unilaterally disclosing to the partner at risk, but this is not yet an obligation. Such disclosures are best decided on a case-by-case basis and in consultation with the medical team. It should always be a last resort. Now, in several Western countries, the reckless or intentional transmission of HIV or exposure to the virus has become a legal matter for which there can be severe consequences. There have been a number of convictions of HIV-positive people where this has been found to be the case. This seems to place an obligation on the patient to disclose, or at least protect, their sexual partners. Therapists may find that case notes are subpoenaed or face the prospect of liability should they fail to address issues such as prevention and disclosure with their patients. Therapists should be proactive in this regard and raise the matter of the patient’s need to protect their partners from risk of infection even if the patient does not. A record of such discussions should always be entered into the case notes.

It is usually fear rather than malice that leads a person with HIV to not disclose their status. HIV is still stigmatizing and people face a genuine risk of rejection, prejudice or even physical harm if they disclose. During therapy it is helpful to work through the clients beliefs and fears about disclosure. The process can be facilitated through role-play in sessions, or in a joint session where the client tells the partner, providing a safe environment in which disclosure can take place and the complex and sensitive issues can be explored.

REFERENCES

AMANDA EVANS, MSC is a Chartered Psychologist with 20 years experience of working with people with HIV through all stages of infection. She works in the HIV treatment center at the Royal Free Hospital in London with patients, partners and families affected by HIV and from widely diverse backgrounds. She has managed the HIV testing clinic in the Royal Free for many years, where she has overseen the introduction of voluntary rapid testing for an outpatient population. She is closely involved in developing policy, training colleagues, and caring for newly diagnosed patients. She maintains an interest in the psychological impact of HIV related lipodystrophy, the provision of counseling and testing services for HIV, and in development of individual prevention strategies.

DEBBIE LEVITT, MSC is a Chartered Psychologist working in the infectious disease directorate at the Royal Free Hospital. She has specialized in working with children and families for the past 19 years and leads the psychotherapy service for pediatric and antenatal HIV. Her work involves developing policy and services for patients from diverse cultures and backgrounds. Her clinical practice blends systemic and cognitive-behavioral therapeutic approaches. She is an active member of the UK Pediatric HIV Psychology Network and is committed to a project in sub-Saharan Africa which focuses on the Pediatric Rollout of ARVs. She also runs a specialist counseling service for doctors and medical students working in the health service.
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Immunodeficiency Syndromes, 38, 5, 560-563.


CONSUMER UPDATE BROCHURE

Here is a sample of the Consumer Update brochure on Families Living with HIV Disease. This brochure is designed to educate consumers and to market your services, with space on the back to imprint your name and contact information.

MARKETING TIPS

To market your services to individuals and families who may be faced with this issue, distribute copies of the Consumer Update brochure to:

- Physicians and nurse practitioners in family practice
- Local hospitals and urgent care facilities
- Churches, synagogues and temples
- Community resource centers
- School and university counseling programs
- Mental health agencies and health fairs

How to order

These brochures are available for purchase in packs of 25. The cost per pack is $8.75 for members and $11.25 for non-members. Contact AAMFT Member Services by e-mail at central@aamft.org or by phone at 703-838-9808. Order online at www.aamft.org.

Consumer Update brochures are also available on the following topics:

- Adolescent Behavior Problems
- Adolescent Self-Harm
- Adolescent Substance Abuse
- Adoption Today
- Alcohol Problems
- Alzheimer’s Disease and the Family
- Asperger’s Syndrome
- Attention-Deficit/Hyperactivity Disorder
- Bereavement
- Bipolar Disorder
- Bipolar Disorder in Children and Adolescents
- Body-focused Repetitive Disorders
- Borderline Personality Disorder
- Caregiving for the Elderly
- Childhood Sexual Abuse
- Children and Divorce
- Children of Alcoholics
- Children’s Attachment Relationships
- Chronic Illness
- Depression
- Dissociative Identity Disorder
- Domestic Violence
- Eating Disorders
- Effect of Anger on Families
- Female Sexual Problems
- Gay and Lesbian Youth
- Genetic Disorders
- Grieving the Loss of a Child
- Infertility
- Infidelity
- Male Sexual Problems
- Marital Distress
- Marriage Preparation
- Mental Illness in Children
- Multiracial Families
- Obsessive Compulsive Disorder
- Online Infidelity
- Panic Disorder
- Phobias
- Postpartum Depression
- Post-Traumatic Stress Disorder
- Rape Trauma
- Schizophrenia
- Substance Abuse and Intimate Relationships
- Suicidal Ideation and Behavior
- Suicide in the Elderly
- When Your Adolescent Acts Out Sexually