

Living with HIV in the 21st Century

Thomas J. Coates, PhD
UCLA Program in Global Health
David Geffen School of Medicine
University of California, Los Angeles

Mark Weston
Riverpath Associates, UK

Brent Hanson
UCLA Program in Global Health
David Geffen School of Medicine
University of California, Los Angeles

Vishal A. Patel, MD
UCLA Program in Global Health
David Geffen School of Medicine
University of California, Los Angeles

Greg Szekeres
UCLA Program in Global Health
David Geffen School of Medicine
University of California, Los Angeles

Robert Remien, PhD
HIV Center for Clinical and Behavioral Studies
Columbia University

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Executive Summary

Treatment for HIV is getting better and better, and there is a sustained commitment at the present time to bring HIV treatment and care to resource-poor settings. But HIV prevention has proven far more difficult than anyone imagined. Motivating behavioral changes in the first place is not easy, and sustaining them is even more difficult. Of the myriad technological approaches proposed, only male circumcision and use of anti-HIV treatments to prevent mother-to-child transmission of HIV have proven efficacious. This means that HIV transmission is occurring at a rapid rate in many parts of the world, and the number of people living with HIV will continue to increase.

We have prepared a review of some of the issues confronting living with HIV in the 21st century. We have attempted to draw on literature and experiences from around the world. The topics we address could each be chapters in a book, or even entire books themselves, and we undoubtedly have overlooked several important issues.

Any efforts to think through what it means to live with HIV in the 21st century needs also to give voice especially to those living in resource poor settings and the people and organizations working to provide services to those who need them. We did not have time in the preparation of this document to explore those issues as fully as we might like, but elaborations of these and other themes require that input.

Following are some of the issues we identified in our brief and quick review, and from our own experiences in living with HIV, in living in communities highly affected by HIV, and in working in partnerships with individuals and communities in resource poor settings. This brief is intended to stimulate discussion and planning, and not at all as a definitive document. We hope that some of the thoughts are helpful.

- **Number of persons living with HIV:** Accurate projections of the number of persons living with HIV over the next 10-50 years are needed to plan treatment, care, and prevention services.
- **The natural history of HIV infection:** Programs of any kind to provide diagnosis, support, care and prevention to persons with HIV must take into account the natural history of HIV infection and how it affects individuals' lifestyles and perceptions.
- **Post-test Support Services** A whole spectrum of supportive services is needed that works to help people at various stages of the diagnosis spectrum from the immediate reactions to finding out that one has HIV, to learning to live with it, to accessing treatment when necessary. The HIV diagnosis may exacerbate pre-existing psychological and psychiatric conditions and more emphasis needs to be placed worldwide on recognizing and treating these conditions.
- **Consequences:** The consequences of HIV disease to individuals, families, and communities can be momentous. Community-based strategies for identifying and ameliorating these consequences are essential. Consequences can be more severe for those already at the greatest vulnerability such as young people, women, minorities, and those with mental health or substance use problems.

- **Orphans** are at higher risk for a variety of poor outcomes. They are missing out on structures that assist them in growing up and benefiting from whatever society has to offer. They are probably at higher risk for becoming infected with HIV themselves. The right solutions are not known, and considerable effort should be devoted to providing and evaluating alternative approaches to helping orphans deal with their life circumstances.
- **Adolescents and young people:** Over half of new infections in the world occur in people under the age of 25. Especially in sub-Saharan Africa, young women and men acquire HIV as adolescents or young adults. There are relatively few models or programs to assist adolescents in high risk areas to learn about their HIV infection and how to live with it, especially if they are entering their reproductive years.
- **Pediatric support and treatment** lags far behind support and treatment for adults, and pediatric formulations for many drugs are lacking in resource-poor settings. Efforts to provide family-based models of care and support are essential, as is the imperative to provide pediatric formulations.
- **Treatment has expanded** thanks to efforts by activists and others to expand trade agreements and support the dissemination of generics. The resource-rich countries are assisting with treatment expansion, but the sustainability of such efforts needs to be examined and assured.
- **Sex and sexuality:** People with HIV will be living longer as a result of treatment, and fulfilling and satisfying sexual lives are an essential part of quality of life. So much emphasis has been placed on prevention, but as HIV becomes more of a chronic disease, emphasis will also have to be placed on how individuals can live with HIV and also have quality of life sexually.
- **Health and human rights:** Only six in ten countries in the world have laws and regulations that prohibit discrimination against those living with HIV. Marginalized populations remain vulnerable. There is need to support concrete legal changes and language in multi-national declarations that address stigma and discrimination.
- **Sexual and reproductive health:** It will be essential to address the sexual and reproductive health needs of persons with HIV. So many people who are infected are young, and can expect to live a long life if they have access to treatment. Naturally, they will want to have children, and strategies need to be evolved to make that possible and to ensure that parents can live to see their children grow up.
- **Prevention for positives:** Helping HIV-infected individuals not pass the infection onto others is a top priority. Most people, upon learning that they have HIV, take protective actions. But there are some who need extra assistance, and this should be a priority. It will also be important to protect the civil rights of those who have HIV.

- **Coping strategies that help people to live with HIV:** Support civil society groups, especially those formed and run by HIV+ individuals, that advocate at local and regional levels; support leadership development for persons with HIV. Work with religious groups to use spirituality and religiosity in positive ways to decrease stigma and discrimination against persons with HIV;
 - Support activities regarding media portrayal of HIV/AIDS in a positive light
 - Publicize exceptional examples of programs and other strategies that address the needs of persons with HIV
 - Support activities that extend the lessons of HIV/AIDS to other disease and stigmatized groups
- **Advocacy and leadership:** People with HIV have often been in the forefront of advocacy efforts, and that voice has been enormously helpful in ensuring that resources are available and that programs are appropriate and useful. As we move on in the epidemic, it will be essential to develop leaders for the next generation who are aware of the special needs and issues of persons living with HIV
- **Mental health services** are always under-funded, even in developed countries, but are woefully inadequate in resource poor settings. HIV raises additional mental health issues and attention needs to be given to documenting mental health problems and marshalling resources for mental health resources both in developed and in developing countries.
- **Other interventions—What Helps?** A variety of strategies can provide psychological, social, and economic and subsistence support to persons with HIV and may be essential in an overall and comprehensive program.

We have identified at least two other areas that we did not have time to explore, but would hope to think through in the future. Others can certainly be added to this list, but we did not want them omitted from any current discussions.

- **Gender:** HIV is impacting men and women, sometimes in beneficial and sometimes in harmful ways. HIV has pointed a light on gender issues, and the special complications of being in a vulnerable role in society and also HIV-infected. We suggest reading the paper by Grieg et al that came out of a Ford-sponsored think-tank in Sydney in July, 2007. This paper will be published along with others in a special issue of *AIDS* prior to the Mexico City AIDS Conference.
- **Prisons** are a special case. The issues regarding prisons, health care, human rights, and access to services is complicated and varies by jurisdiction. We are appending a paper prepared for The Ford Foundation by Sawires et al that describes reforms needed for the US prison system. It will be important that in-depth analyses be done of the prison systems of the countries with the largest epidemics to determine policy and programmatic recommendations and reforms needed.

I. The Number of People Living with HIV

UNAIDS estimates that, worldwide, there are 33.2 million people living with HIV today. This includes 15.4 million women and 2.5 million children. In 2007, there were 2.5 million new infections, of which 420,000 were children. Furthermore, in 2007, 1.7 million adults and 330,000 children died from AIDS (UNAIDS 2007).

Projections of the number of people living with HIV over the next quarter to half-century are needed. We were not able to find projections of the numbers of persons expected to be living with HIV over the next 10 to 50 years in the world. These projections are needed in order to plan well for prevention and treatment needs. Such projections must take into account increased longevity due to improved treatment and

access to those treatments, current and projected incidence that takes into account various prevention scenarios as well as the potentially increased transmission due to a greater number of people living with HIV, and decreased infectiousness.

Clinical Manifestations of Stage I

- Fever, malaise, diarrhea, neuralgia
- Arthralgia, sore throat, headaches
- Lymphadenopathy
- Maculopapular rash
- Ulceration
 - Oropharynx
 - Anogenital area
- Neurological symptoms
 - Meningitis
 - Neuropathy
 - Myelopathy
 - Encephalopathy

II. The Stages of HIV Infection

UNAIDS estimates that, worldwide, there are 33.2 million people living with HIV today. This includes 15.4 million women and 2.5 million children. In 2007, there were 2.5 million new infections, of which 420,000 were children. Furthermore, in 2007, 1.7 million adults and 330,000 children died from AIDS (UNAIDS 2007).

HIV infection can cause a spectrum of clinical problems and has a variable course, depending on factors such as a patient's genetics, medical history, and access to care. HIV infection can be characterized by four stages (NIH 1995).

Stage I: Primary HIV Infection (PHI)

Primary HIV infection is the period of time when the virus first establishes itself in the body— between when a person is first infected and when the body produces antibodies against the virus. Most people develop antibodies within three months after infection, while some can take up to six months. At the time of PHI there is sometimes a high rate of viral replication, leading to a transient rise in HIV viral load and concomitant immunosuppression due to a short-lived fall in the CD4 count (Guss). This may result in manifestations of HIV disease which are normally seen later in the infection, for example oral candidiasis (thrush) (Guss). Also, during this time individuals can be highly infectious given the high viral load (Kahn 1998). An acute viral syndrome of primary HIV infection, also referred to as seroconversion illness, typically lasts a couple of days to a few weeks, and may present with symptoms such as headache, fever, malaise and maculopapular rash.

Stage II: Asymptomatic HIV Infection

After Stage I, HIV antibodies continue to be detectable in the blood. The amount of virus in blood and lymphoid tissues falls to low levels and the rate of HIV replication is slow, although it does not cease. CD4 lymphocyte counts are often within normal limits, or generally above 350 cells/mm³ (Guss). The duration of this phase is highly variable, but may persist for 10 years or more, during which time HIV slowly erodes aspects of the host immune system. Although the patient may have no signs or symptoms during this stage, patients who are asymptomatic are still infectious and can spread the disease.

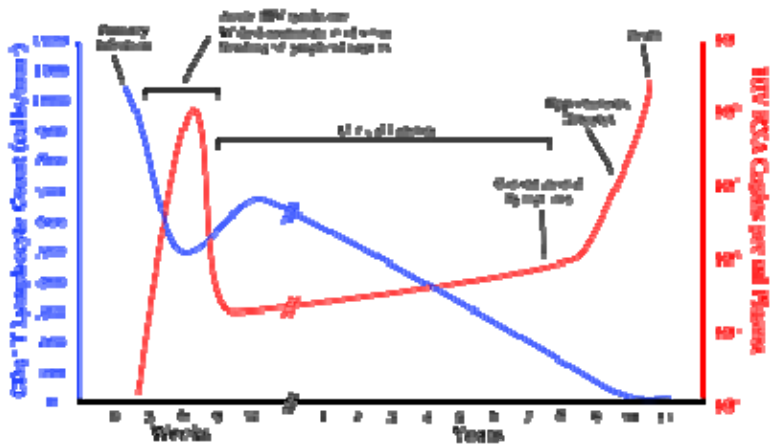
Stage III: Symptomatic HIV Infection

As the immune system becomes compromised by HIV infection, patients may begin to experience HIV disease symptoms, such as skin rashes, fatigue, night sweats, mild weight loss, oral ulcers, and fungal skin and nail infections (Kahn 1998). Most, though not all, will experience relatively mild symptoms such as these before developing more serious illnesses. As the disease progresses, some individuals may become quite ill even if they have not yet been diagnosed with AIDS, the late stage of HIV disease. Typical problems include chronic oral or vaginal thrush (caused by *Candida*, a fungus), recurrent herpes blisters (cold sores), ongoing fevers, persistent diarrhea, and significant weight loss.

Stage IV: AIDS

When immune system damage becomes more severe, HIV-positive individuals may experience opportunistic infections and cancers (those that do not ordinarily cause illnesses in people with normal immune systems). Some of the most common opportunistic diseases include *Pneumocystis jiroveci* pneumonia (PCP), *Mycobacterium avium* complex (MAC), cytomegalovirus (CMV), toxoplasmosis, and candidiasis (Holmes 2003). An AIDS diagnosis is given to an HIV-positive person who has a CD4+ T-cell count of less than 200 cells/mm³ or a history of an "AIDS-defining illness." (CDC 1992)

A graphical representation of the four stages is depicted below (Wikipedia.org).



III. The HIV Diagnosis and Its Immediate Aftermath

It is a near universal experience that when one hears or reads the words “you have HIV”, the individual’s definition of self changes, regardless of culture, race, age,

geography, social or economic status, or relationship status. For some, it is a total surprise; for others it is a confirmation of what he/she has already suspected. For most, it is an isolating and daunting moment with significant psychological ramifications.

Typically, the psychological issues associated with HIV evolve for individuals and families over a dynamic course of HIV illness, and vary depending on illness stage (Havens 2000, Rabkin 1994). With antiretroviral therapy (ART), there has been a shift in emphasis from coping with severe illness, death and dying, and multiple losses, to living with and managing HIV as a chronic health condition. However, this has not eliminated the psychological impact of infection. Coping with the uncertainty of one's future health and HIV stigma remain difficult psychological challenges that permeate many facets of life, even in the context of optimal access to ART. People living with HIV may exhibit a variety of responses requiring different types of medical attention and psychological support.

You have HIV

- Definition of self changes
- Dynamic changes over the course of HIV infection
- With ARV—shift from coping with severe illness to coping with chronic illness
- Rethinking priorities and goals
- Decisions about disclosure
- Regret, shame, despair
- Complicated by histories of traumatic experiences
- Can exacerbate pre-existing conditions

First are relatively normative responses. Upon learning the diagnosis, the person needs to integrate new information into his/her existing identity that translates into questioning assumptions about many aspects of one's life, rethinking priorities and goals, and acquiring new skills that may be necessary to accomplish reformulated goals. The person is likely to experience alternating feelings of shock, disbelief, panic, fear, guilt, shame, anger, despair, hopelessness, and/or numbness.

Supportive counseling and/or increased access to existing social supports may be

sufficient for helping individuals cope with these feelings.

Second are responses complicated by histories of stressful or traumatic experiences. For some HIV-infected individuals, psychological distress is in response to real or feared societal response such as loss of home or employment; rejection from partners, family, or community; and violence. In such cases, individual and/or family psychotherapy with a mental health professional may be helpful in responding not just to HIV, but to the context of the infected person's life.

Finally, for some HIV-infected individuals, there may be exacerbations of pre-existing psychiatric disorders, including substance abuse/dependence or precipitations of new onset disorders, in which psychiatric syndrome-specific treatment, sometimes including psychopharmacology, must be among the interventions provided. Studies have shown that adults and children living with HIV and/or at risk for acquiring HIV, including adults and adolescents, are at elevated risk for psychosocial distress and psychiatric conditions, particularly depression (Bing 2001, Lipsitz 1994, Lyketsos 1994, Mellins 2006, Mellins 2002, Williams 1991). While the specific role of HIV is not clear, a number of these studies have found clear and important associations between the prevalence of psychiatric disorders and psychological symptomatology and poor quality of life,

elevated sexual risk behavior, poor adherence, and poor health outcomes. For example, chronic and intermittent depressive symptoms in HIV-positive women are associated with disease progression, lower CD4 cell count, and higher baseline viral load levels; and, in general, women with chronic depression have mortality rates twice as high as those with little or no depressive symptoms (Cook 2004, Ickovics 2001).

HIV infection can have a number of consequences:

- Increase in mental health problems
- Stigma
- Social isolation
- Increases difficulties for displaced populations
- Places heavy burden on caregivers
- Disruptive effect on families
- Economic effects due to loss of income; costs of funerals
- Makes women more dependent

IV. Consequences of Living with HIV

The discovery that one is infected with HIV has been shown to be associated with reduced mental health in China, the United States, and South Africa. Stress, depression, and mental illness are strongly linked to the stigma surrounding the virus (Freeman 2007, Sun 2007, Vanable 2006) and have residual negative effects on physical health, possibly due to reduced adherence to medications (Rintamaki 2006, Vanable 2006).

Stigma has been linked to higher risk behaviors in France, South Africa, and China (Mahajan et al, in press). In South Africa, it has been shown to deter people from testing and accessing prevention of mother-to-child-transmission (PMTCT) services such as safe infant feeding (Mahajan et al, in press).

HIV-positive people are at risk of social isolation (Emlet 2006). Among drug users in China, this was associated with poor ART outcomes (Knowlton 2007).

Discrimination crosses borders, with refugees mislabelled as harborers of the virus. Providing prevention and treatment to refugee populations is problematic; asylum seekers can be approved or refused based on sero-status. The Southern African HIV Clinicians Society has developed treatment guidelines for displaced persons, but they have not been widely implemented.

HIV/AIDS is a long illness that can place a heavy burden on caregivers and have a disruptive effect on families; in Malawi, caregivers reported that intra-household tensions and stress grew (Chimwaza 2004). Children orphaned by AIDS, moreover, are at heightened risk of psychological and behavioral problems (Cluver 2007, Stein 2003).

AIDS also has economic effects on families, due to the costs of treatment, care, having to miss or retire from work, and funerals. Long-term economic prospects may be impaired if children are withdrawn from school because of financial constraints or the need to care for sick relatives. In Asia, the costs of treatment to households in the pre-ART era were over double national per capita income (Bloom 1993). In two-thirds of AIDS-affected households in a study in Zambia, disposable income fell by 80% (Nampanya-Serpell 2000). Lost earnings forced poor households in India to draw down savings and sell off assets (Basu 1997).

As HIV/AIDS becomes feminized, its economic impacts are increasingly felt by women. Women may become more dependent on their male partners and less able to lobby for and receive treatment. They also frequently experience social consequences. Women are often ostracized because of their infection, which they are seen as having brought on themselves through promiscuous behavior. In Namibia, women have been denied care by their extended families (Thomas 2006). In Kenya, HIV-positive widows can be thrown out of their homes and disowned by families (Ambasa-Shisanya 2007).

HIV orphans children and disrupts families.

One of the biggest debates in the field is whether to take children out of communities—i.e. place them in orphanages—or build support within communities so that they can thrive there. We do not have the solution to this, but it is a debate in the field today.

In a similar vein, approaches to protection of the next generation might need to consider a variety of strategies for leadership training and for ensuring that the broadest sectors of society, including those orphaned by AIDS, have access to education and opportunities in society.

V. Orphans and Disrupted Families: A Special Case

Nine percent of children in sub-Saharan Africa have lost one or more parents to AIDS. One household in six is caring for an orphan (UNAIDS 2006a). Some children become orphans before their parents die. In Russia, for example, some HIV-positive mothers abandon their children in hospitals or to state institutions and care homes (Intigrinova 2004).

Many orphans in Africa have to care for their siblings, with child-headed households an increasingly common feature of southern African communities (Kang 2008). Many others are separated from them. In Zambia, more than half of heads of households caring for orphans reported that they have been separated from siblings (USAID 2002). The large majority of AIDS orphans are taken in by extended families; many are looked after by their grandparents. This places an additional burden on families that are often already poor, and means they have fewer resources to invest in the food, health, and education of each child. Some AIDS orphans, including young children, are sent out to work to pay for their keep (UNAIDS 2006a).

Children orphaned by AIDS face health risks even if they themselves are uninfected. They may receive less food than children whose parents are still alive and have poorer access to vaccines and treatment for other illnesses. In Zimbabwe, female adolescent orphans were more likely to have had sex and unplanned pregnancies, and were more likely to acquire a sexually transmitted disease than non-orphans (Kang 2008).

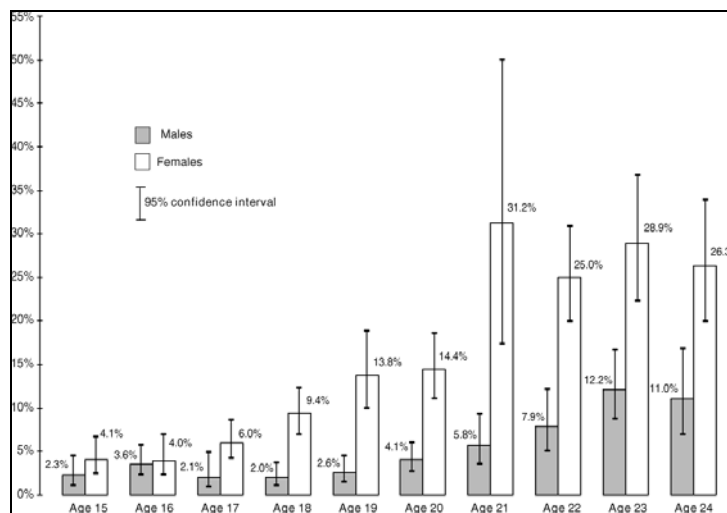
The psychological stresses can also be profound. In a study in Uganda, AIDS orphans were found to be more prone to anger, depression, and anxiety, with 12% wishing they were dead, compared to 3% of non-orphans (Atwine 2005). HIV/AIDS orphans, moreover, are sometimes stigmatized (Monasch 2004). On the other hand, 86% of heads of households that have taken in orphans in Zambia reported that the children were somewhat or very happy (USAID 2002).

In terms of education, studies on AIDS orphans in particular are thin on the ground, but orphans in general in sub-Saharan Africa are less likely to receive an education than non-orphans from the same household; 74% of non-orphans attend school, compared to 69% of orphans who have lost one parent, and 64% of those who have lost two parents (Monasch 2004). In Tanzania, 71% of children who live with their parents attend school, compared with 52% of children who have lost both parents (UNAIDS 2004a). A study in Kenya, meanwhile, calculated a decline of 5% in school attendance after the death of a parent (Evans 2005).

VI. Adolescents and Young People Living with HIV

Addressing HIV/AIDS in youth and adolescent populations holds challenges stemming from differences in attitudes and beliefs, physiology, risk behaviors, and a lack of programs. Children present even more specific needs and greater challenges.

Young people may not understand the full consequences of their actions. A survey in South Africa showed 62% of HIV-infected young people thought they had little to no risk of HIV infection (RHRU). The consequences of this manifest in prevalences of 10.2% among 15-24 year olds (Pettifor 2005). While knowledge of HIV may be adequate, perceived self risk is dauntingly inaccurate in this age group.



HIV prevalence by age and sex among 15-24 year olds, South Africa, 2003. (Pettifor 2005)

Transmission to young South African women is highly efficient, estimated at 0.74-1.0 per-partnership transmission probability. This probability is as low as 50% in other populations (Pettifor 2007). This may explain the much higher prevalence in young women than men of the same age group, 15.5% to 4.8% respectively (Pettifor 2005).

There is scant literature available concerning HIV prevention efforts directed at HIV-positive people outside the United States, and even less regarding adolescents (Johnson 2007). In Romania, 50% of AIDS cases have been pediatric and resulted from poor health care conditions in the 1980s (Johnson 2007). These former pediatric patients have now reached sexual maturity, which requires prevention efforts to be

aimed at HIV-positive young people. The lack of programs established for this age group presents a risk of increased HIV spread, and translates to other parts of the world where similar ages have been infected either vertically or horizontally.

Several results from the survey in South Africa offer keys to providing tailored prevention interventions. The best predictor of condom use at last intercourse is condom use at first intercourse. This, coupled with high efficiency of transmission in young females, requires comprehensive sex education at an early age (Hendriksen 2007). Having older partners increased risk for HIV acquisition among young people in South Africa, but the highest risk was for partners 1-4 years older than the young woman, suggesting interventions with slightly older males may be important in reducing HIV risk for young women (Pettifor 2005). Women in the workforce are less likely to be HIV infected than men, the reverse of what is true in South Africa generally (Colvin 2007). This means that the young women most likely to get infected with HIV are the least likely to enter the formal workforce. Workplace programs will not reach those at highest risk for HIV (Mahajan 2007).

We have not done a good job of protecting youth from HIV.

But we have done even less to address the problems of adolescents living with HIV.

This is an area of immense need, given the high infection rates among young people, especially in sub-Saharan Africa.

Pediatric medical practices in regions affected by HIV have had to switch from treating acute illnesses usually associated with infants to a fatal, chronic illness. According to pediatric HIV physician Avy Violari of South Africa, until July 2007 “there was no comparative, randomised trial to inform guidelines” on initiating treatment (Carter 2007). Violari’s study showed immediate treatment of infants could reduce mortality by up to 75% (Violari 2007). The newness goes to show the dearth of established practices in treatment for this group.

VII. Treatment

The XIII International AIDS Conference held in Durban, South Africa in 2000 marked the beginning of a phase of new efforts to address the devastating spread of HIV/AIDS in low- and middle-income countries. These efforts were catalyzed by grassroots mobilization focused on expanded treatment access. The success of the Brazilian national AIDS program became both a model and an inspiration. During the intervening eight years, unprecedented energy, funding, and planning have begun to produce significant improvements in the national health care systems of a substantial number of resource-constrained countries.

Antiretroviral medications continue to be the cornerstone of effective HIV treatment (PCPTI 2005). A focus of international efforts against HIV has been to provide treatment in both resource-rich and resource-limited countries. With adequate antiretroviral treatment, individual quality of life improves dramatically regardless of the environment the patient lives in (resource rich vs. resource limited) (Cunningham 2005). These efforts have seen progress towards a goal of universal access to treatment. As of

June 2005, 21 countries were providing antiretrovirals to at least 50% of those in clinical need (UNAIDS 2005).

In Africa, the number of people on ART more than doubled in 2005 alone, with roughly one in six people who needed treatment receiving antiretrovirals by December 2005 (Akileswaran 2005). In South Africa, the number of people receiving antiretrovirals grew from fewer than 5,000 in early 2004 to approximately 190,000 by the end of 2005.

The XIII International AIDS Conference in Durban in 2000 was a major turning point.

Treatments are extending lives and improving quality of life in the developed world; has the potential to do the same in resource-poor settings; an issue is the dependability of continued treatment access

As of 2005, 21 countries providing ART to at least 50% of those in clinical need of treatment

One in six people in sub-Saharan Africa in need of treatment are receiving it

Expansion of trade agreements, TRIPS, Doha Declaration, and WHO efforts at certification have expanded treatment access

In other regions, governmental support also provided increased access to treatment. By early 2006, Cambodia was delivering antiretrovirals to more than 12,000 people (Malaysia 2004) and more than 20,000 individuals in 28 provinces in China (China 2005). Of developing regions, Latin America and the Caribbean currently has the highest coverage for antiretroviral therapies (68%), with 315,000 individuals on treatment at the end of 2005. An estimated 250,000 and 350,000 deaths were averted worldwide in 2005 as a result of increased treatment access (UNAIDS 2005).

Expansion of treatment access via provisions in trade agreements (TRIPS, WTO) is exploding the once held belief that ART programs could not succeed in resource-limited settings or among high-risk populations (GHPWG 2004). Available evidence reveals that adherence to

antiretroviral regimens in low- and middle-income countries is at least equal to, and often greater than, rates of adherence reported in high-income countries (Nemes 2004). In Haiti, 87% of adults and 98% of children were living one year after initiating antiretroviral therapy, with the typical adult experiencing a CD4+ T-cell count increase of 163 cells/mm³ (Severe 2005).

Furthermore, programs in Argentina, Brazil, China, Hong Kong Special Administrative Region, and elsewhere are effectively delivering antiretrovirals to HIV-infected injecting drug users (IDUs) with high treatment adherence, dispelling the notion that such individuals cannot reliably participate in, and benefit from, AIDS treatment initiatives (OSI 2004).

Before the introduction of antiretroviral treatment, the time frame from HIV infection to the diagnosis of AIDS was generally between 10-12 years (Moore 1999). In resource-limited settings from the time between the occurrence of first AIDS-defining events and death was between 6 and 19 months (Schneider 2003). For comparison, the same median survival in resource-rich countries was found to be between 9.5 and 22 months.

Since its introduction and use as the staple of therapy, studies have shown that the long-term survival of patients has increased to a mean survival time of 21.5 years from infection to AIDS and 10.6 years after diagnosis of AIDS to death (Fang 2007). Antiretrovirals have made such drastic increases possible, altering the landscape of HIV morbidity and mortality and making this disease a chronic one. And while major problems of co-infection remain with tuberculosis and other illnesses, the largest predictor of survival with these other co-infections continue to be early access to ART (Losina 2006). These data add weight to the argument that in order to minimize mortality, ART should be initiated at an earlier threshold than currently recommend worldwide (CD4 <200) (Wood 2005).

Unfortunately, at least 80% of those in clinical need of antiretroviral drugs do not receive them. In India alone, of the estimated 770,000 individuals that needed antiretroviral drugs in 2005, only about 40,000 were believed to be receiving the drugs. (ITPC 2005).

VIII. Sex and Sexuality

Sex and sexuality

- Initial diagnosis results in decrease in sexual activity
- Resuming sexual activity difficult; need to disclose serostatus; fear of rejection; fear of infecting others
- Can contribute to loneliness and despair
- People with HIV are not likely to engage in sexual activities that might infect others, but a minority do
- Concerns that access to treatment diminishes concerns about transmitting or acquiring HIV

Typically, when someone is first diagnosed with HIV or AIDS there is a significant decline in sexual interest and activity, especially when people are symptomatic with HIV-related illness. However, and especially in the context of access to effective ART, most people will want to resume sexual activity with time (Remien 2001, Shapiro 2007). The process of re-engaging in sexual activity and romantic relationships can be difficult as many feel inhibited by anxiety over disclosing serostatus with fear of rejection from potential partners, fear of infecting others, and negotiating safer sex. These fears are anxiety producing and contribute

to feelings of loneliness and despair, but they can be overcome and sexuality can remain a vital part of life (Remien 2002).

For most people, sex is an integral part of life and quality of life, while for some it is integral to their survival (Remien 2000). A fairly large body of evidence consistently demonstrates that practice of unprotected intercourse varies by partner type, with unprotected sex more likely to take place within the context of established

relationships(Dolcini 1995, Marin 1997). For many women (and men) pregnancy desire and intent are motivating factors for engaging in unprotected sex, in spite of the presence of HIV (Paiva). Further, many women are not always in control of their sexual lives. Rape, forced sex, and cultural expectations may interfere with prevention efforts (Connors 1996, Farmer 1999). All of these realities must be considered in the prevention agenda, as people living with HIV often hear the message (whether real or imagined) that they have no legitimate right to a full sexual life after an HIV diagnosis.

Most people living with HIV do not engage in sexual risk behaviors with seronegative or unknown status partners (Higgins 1991, Marks 2005, Remien 2007, Wienhardt 2004), but a sizeable minority continue to present a public health risk (Remien 2007, Wienhardt 2004). ART availability has introduced a new dynamic in which a false sense of security may arise due to a belief in reduced infectivity associated with reduced or “undetectable” viral load (Dilley 1997, Kelly 1998, Remien 2005, Remien 1998). Additionally, there is the concern that medical treatment advances may lead to a diminished sense of negative consequences of HIV infection and an increased complacency towards safer sex practices (Kravcik 1998, Ostrow 2002). We have also witnessed an increase in viral resistance in people living long-term with HIV (Richman 2004) and an increased frequency of drug resistant virus in newly infected individuals (Grant 2002, Little 2002). Thus, there is a growing public health concern about transmission risk behaviors among people with antiretroviral-resistant HIV infection (Blower 2001, Blower 2003, Chin-Hong 2005, Kozal 2004, Sethi 2004).

Mental health factors can play a significant role in the ongoing transmission of HIV; numerous studies have reported an association between negative affective states, including specific psychiatric disorders, and increased sexual risk behavior in both adolescents and adults. This association has been seen across a wide range of populations, including adult men and women (Kelly 1993), men who have sex with men (Marks 1998, Martin 1998, Strathdee 1998, Thompson 1996), HIV-positive adults (Kelly 1993), minority women (Champion 2002, Hutton 2001), substance users (Camacho 1996), gay and bisexual men (Rogers 2003, Thompson 1996) and adolescents and young adults (McNair 1998, Ramrakha 2000). Until recently, most HIV prevention programs have targeted the uninfected. Stimulated in part by advocacy groups such as Greater Involvement of People with AIDS (GIPA), researchers and clinicians have recently come to recognize the importance of including HIV-positive people in safer sex interventions.

IX. Legal Conditions and Impediments

Unfortunately, by 2006 it was clear that, despite significant strides, many of the goals set out in the 2001 Declaration of Commitment on HIV/AIDS had not been met. When the UN developed its five-year follow-up, the Political Declaration on HIV/AIDS (Political declaration on HIV/AIDS 2006), many saw an opportunity to redouble global efforts and concretize the steps that could lead to lasting change. Instead, governments stymied the quest for precision by using vague language, and they backed away from accountability by failing to set new benchmarks for measuring success.

Remarkably, funding for HIV/AIDS programs worldwide has risen nearly 30-fold over the last decade (UNHCHR 2006). But the current U.S. administration has directed its much needed funds away from evidence-based programs to ones that employ ideologically-driven strategies of dubious efficacy. Equally troublingly, the United States has persistently pushed to drop the term “human rights” from international consensus documents about HIV/AIDS (Gruskin 2005).

At the state level, the need for concrete legal changes persists. Only six in ten countries in the world have laws and regulations that prohibit discrimination against those living with HIV (UNAIDS 2006b). For those states that have anti-discrimination laws, enforcement remains a major obstacle. Nearly half of all countries still have laws that may directly interfere with an effective response to the disease, including laws that criminalize same-sex sexual activity, prohibit condoms in prisons, and disallow needle exchange (UNAIDS 2006b). Government programs that perpetuate misinformation about the disease and laws that discriminate on the basis of sex are other examples of state-sponsored barriers to progress that have no justification at this stage in the epidemic.

In both international and national policymaking, marginalized populations remain dangerously neglected. For example, despite great urging by civil society groups, the 2006 Political Declaration on HIV/AIDS failed to specify that men who have sex with men, sex workers, and IDUs are populations in particular need of protection. By instead using the vague and undefined term “vulnerable groups,” the document left too much room for states to avoid real commitments to these politically unpopular groups.

Despite the prominence of health and human rights at the international policy level, and despite the fact that health and rights can strengthen and reinforce one another, many health professionals on the ground remain, to this day, unfamiliar with human rights. In most countries in the world, health professionals are not taught anything about human rights (Hunt 2007). Even those who have heard of the concept sometimes believe that human rights are something that might cause them problems or get them into trouble. Fewer still are familiar with some of the nuanced principles of the right to health. Examples of such little-known details include the fact that the right is subject to progressive realization and to states’ resource constraints, though these limits may not be used by states to avoid their obligations (Hunt 2007).

Need for concrete legal change persists

- UN Declaration of 2006 backed away from specific commitments and used vague language to refer to risk groups
- Only 60% of countries have laws and regulations prohibiting discrimination against people with HIV
- About 50% of countries have laws that interfere with effective responses to HIV
- Marginalized populations remain neglected
- Health professionals remain ignorant about human rights

X. Sexual and Reproductive Health: The Words that Cannot Be Spoken

For many HIV-infected persons, pregnancy desire and intent is a motivating factor for engaging in unprotected sex, despite the presence of HIV (Cooper 2007). There is growing evidence to suggest that

HIV infection modifies, but does not remove pregnancy desires

- There is a great need to link reproductive health services to HIV services
- Even programs to prevent mother-to-child transmission are not linked with reproductive health services

HIV infection modifies, but does not remove, individuals' desires to have children (Myer 2007). While most attention to fertility desires among HIV-infected individuals has focused on women, there is mounting evidence to suggest both that HIV-infected men often desire children (Paiva 2003), and that they have a substantial influence over their female partners' fertility-related behaviors. Thus, efforts to address fertility-related issues among HIV-infected individuals must target women and men alike.

Given the disproportionate impact of HIV on the reproductive lives and health of women, the failure to link HIV treatment programs to reproductive health services contributes to the disproportionate negative impact of HIV on women's health. Basic components of primary health care, most notably access to effective forms of contraception, are often not provided as part of routine HIV care and treatment. The synergy between reproductive health care and HIV prevention activities has been slow to materialize on the ground. In light of evidence that preventing unplanned pregnancies among HIV-infected women may be the most cost-effective form of PMTCT (Sweat 2004), the failure to effectively integrate reproductive health care services into HIV care and treatment represents a substantial missed opportunity in HIV prevention (Myer).

In most countries, even PMTCT programs, which come closest to linking HIV and reproductive health care services, struggle to bridge this divide and are traditionally seen as a prevention intervention located within maternal and child health services. There are conceptual, historical, and operational reasons why PMTCT in many countries is seen as a stand-alone prevention intervention with little or no connection to the national HIV care and treatment program at either central or local levels. This view is perpetuated by the structure of international donor support; it has resulted in PMTCT programs failing to benefit from the advances made in care and treatment over the past five years and contributes to the shortcomings of these programs in most heavily affected regions.

VIII. Prevention

There are many structural and contextual barriers impeding the implementation of effective, coordinated prevention and care programs for PLWHA, including the long-standing practice of separating prevention and treatment. In the U.S. model for example, prevention is in the domain of public health, while treatment is done through the medical care system. In resource-constrained countries where both public health and medical systems may be weak, it is imperative for an innovative public health approach to combine the two and build on existing strengths.

There are numerous obstacles that shape and sometimes distort the response to HIV/AIDS in different countries, all of which cannot be addressed in one paper. We focus here on the most salient for which we can offer concrete and achievable

recommendations for integrating HIV prevention into HIV care and treatment programs for PLWHA worldwide.

Considerable stigma is associated with being HIV positive. In many contexts, discussing sex, homosexuality, condoms and ART remains taboo. If patients feel a need to conceal their HIV-positive status within their social network, they may attempt to hide the medication, change dosing schedules, or suppress observable side effects of treatment, all of which may have implications for adherence (Klitzman 2004). Similarly, they may also refuse to use protection during sex, for fear it may be interpreted by partners that they are HIV positive.

A lack of political will and ideologically motivated, rather than evidence-based, policy has impeded national prevention and treatment programs. For example, the Federal ban on needle exchange programs in the United States and the prohibition of methadone for opiate dependent people by the Russian government have driven vulnerable populations away from appropriate treatment and care and have contributed to HIV transmission rates. Similarly, the criminalization in many countries of sex work, same-sex sexual activity, and engaging in unprotected sex without disclosure of an HIV-positive status is not only discriminatory but is known to impede HIV prevention and treatment programs.

Presenting a fundamental challenge, stigma and taboos impede communication between patients and healthcare providers about sex, disabling opportunities for sexual risk reduction. Healthcare workers can even deny the sexuality and the desire of HIV-positive women and men to have children. If patients are unable to comfortably discuss these issues with health care workers, they may opt to drop out of care rather than confront the disapproval (Neale 2007). Protective laws and policies and reduced stigma could contribute to reduced HIV transmission, via pathways such as reducing the prejudice associated accessing current prevention strategies like needle exchange, condoms, risk-reduction counseling, and reproductive health planning,

Positive prevention is a direction of prevention efforts that focuses on the HIV-positive rather than HIV-negative individual. Results from a literature review showed positive prevention efforts reduced unprotected sex and acquisition of STIs (Crepaz 2006). Similar results were found among youth in the United States (Rotheram-Borus 2001).

“Prevention for positives” usually refers to programs that assist HIV-positive individuals from spreading HIV to others

- Prevention needs to become the standard of care in treatment for HIV
- Taboos associated with discussing sex, homosexuality, and injection drug use are high in many clinical settings
- Lack of political will and ideologically motivated prevention strategies
- Impeded communication between providers and patients

IX. Coping Strategies and Conditions that Facilitate Living with HIV

The care and support of family members has been found to improve the psychological well-being of AIDS patients, particularly in terms of dignity and belonging (Skevington 2003).

A study of HIV-positive African American injecting drug users in the United States found that diagnosis and acceptance of HIV infection triggered a reduction in drug use, assisted by drug treatment programs and HIV support groups, and re-entry into extended family support networks (Bletzer 2007).

Accessing support is facilitated by disclosure of one's HIV status. Studies in Tanzania have found very low rates of disclosure (below 30%) between infected women and their partners (Antelman 2001, Grinstead 2001). This is in part due to the threat of discrimination and violence after disclosure, as reported among African women in 1995. A more recent study in Cote d'Ivoire, however, found that 82% of women who disclosed to partners received an understanding reaction and moral support (Rothenburg 1995). In South Africa, disclosure by women to loved ones, neighbors or professionals enabled them to receive material assistance (such as cash and other goods from family members), emotional support (including help with child care) and access to institutional support such as grants and healthcare (Norman 2007).

Disclosure also reduced stress and allowed women to connect to networks of HIV-positive peers; being integrated into social networks is a predictor of improved psychological well-being among those infected with HIV (Simoni 1995). Activism and advocacy can provide a further boost, as they give people a sense of self-efficacy and enable them to break down some of the taboos and stigma surrounding the virus (Norman 2007).

Spirituality can also help (Tuck 2007). In the United States, people reported increased faith since becoming infected with HIV (Cotton 2006); increased religious belief in the wake of infection is associated with slower progression of the disease (Ironson 2006). In South Africa, on the other hand, some view HIV as a Satanic affliction (Hlongwana 2007), while among mentally ill Puerto Rican women in the United States, some HIV-positive individuals had been ejected from their faith communities (Loue 2006).

The above supporting factors contribute to happiness and hope. There is a clear link between happiness and health; happy people have stronger immune systems and recover more quickly from surgery (Layard 2005). Where people have hope and plans for the future, moreover, they may be more likely to access and adhere to antiretroviral therapy (Bernays 2007). Goal-directed thinking increases self-esteem and reduces depression, which may affect responses to treatment (Snyder 1996).

Coping Strategies and Conditions

- Care and support of family members
- Acceptance of HIV serostatus
- Social support
- Disclosure is helpful in accessing support
- Disclosure also reduces stress and allows women to connect with networks of HIV-positive peers
- Spirituality can help
- Happiness and hope are essential

X. The Need for Mental Health Services

Adults and children living with HIV, and those at risk for acquiring HIV, have elevated rates of psychological distress and psychiatric co-morbid conditions, especially mood and anxiety disorders (including post-traumatic stress disorder), and substance use disorders (Bing 2001, Lyketsos 1994). This psychiatric co-morbidity in the context

of HIV can contribute to increased substance use and sexual risk behavior, poor treatment adherence, interpersonal violence, and other maladaptive behaviors, as well as more rapid disease progression and diminished health outcomes (Leserman 2003, Ramrakha 2000, Tucker 2003). Substance abuse can contribute to poor immune functioning and disease progression among PLWHA. Among other problems, alcohol use can modify liver drug metabolism, thus complicating treatment for patients with HIV/HCV co-infection, as alcohol may compromise pegylated interferon therapy and favor liver disease progression (Kresina 2002). Similarly, mood disorders, particularly depression, has been associated with HIV disease progression and poor quality of life among PLWHA (Evans 2002, Pence 2007).

It has become increasingly evident that mental health vulnerabilities “travel together” and contribute to ongoing HIV transmission in many regions of the world. Yet, as recently noted by Sweat and colleagues (Sweat 2004), the provision of psychosocial services for PLWHA pales in comparison with the growing needs of PLWHA living in impoverished and underserved communities. The high prevalence of comorbid medical and psychiatric conditions among PLWHA highlight the pressing need to co-locate different services and specialists to provide comprehensive care for individuals with special needs and overlapping medical and psychological conditions.

The unavailability of safe and easy access to needle and syringe exchange programs (NSEPs) and safe injecting environments for IDUs contributes to ongoing transmission of HIV in this population as well as continued spread of HIV through sex within their social and sexual networks. Several studies have shown that once HIV-positive substance users have access to the necessary support, they are able to adhere to ARV regimens and hence experience treatment benefits despite the complex circumstances involved in their treatment (Altice 2004, Purcell 2004).

As treatment roll-out occurs in developing countries, there is an urgent need to formulate and test innovative management and preventive strategies among people with mental health and substance abuse problems in order to minimize loss to follow-up, improve adherence to ART, and help individuals and their partners live healthier and safer lives, instead of continuing or resuming transmission risk behaviors (eg, sharing injection equipment or engaging in unprotected sex). The provision of ART without accompanying mental health and substance use services will leave us falling short of our potential to make a true and lasting beneficial impact on the HIV pandemic.

XI. Interventions: What Helps?

Social support can have a major impact on the well-being of those living with HIV/AIDS. The Chinese government has established “Warm Homesteads” in many towns to provide care for people living with the virus. The Homesteads provide treatment, HIV/AIDS education and counselling, and have reportedly helped prevent people from losing hope (Sun 2007).

In Botswana, a National Orphan Program gives monthly food baskets, assistance with the costs of transportation to school, and school uniforms to orphaned households. Counseling is also provided. Malawi has adopted a similar model that promotes community-based programs of orphan support. The National Plan of Action for Orphans

and Vulnerable Children attempts to improve access to education, healthcare, food and water, and sanitation (Phiri 2002).

Coping group interventions have also achieved some success. A group intervention in the United States that aimed to help those with a history of childhood sexual abuse cope with HIV infection was found to reduce unprotected sexual intercourse. The intervention was based on cognitive behavioral treatment strategies and training in risk reduction skills (Sikkema 2008).

Microfinance programs in Mexico and South Africa, meanwhile, have had positive impacts on health, although there have been few studies of their impact on people living with HIV/AIDS. Mexico's PROGRESA program provides economic assistance to poor families in return for their participation in health programs. Families have to make regular visits to health centers, where children receive immunizations and nutritional supplements and adults receive preventive check-ups and education on health, hygiene, and nutrition. A randomized controlled trial found the program reduced the incidence of illness among children by 23% and also improved adult health (Gertler 2001). The Intervention with Microfinance for AIDS and Gender Equity (IMAGE) study in South Africa found that small loans provided to poor women and accompanied by gender and HIV/AIDS training helped reduce intimate partner violence--a risk faced by many women living with HIV/AIDS--by 55% in two years. Women in the program also reported improved levels of hope and became more involved in their communities (Pronyk 2006).

Cash transfers by governments are a further stimulus for improved health. South Africa's expansion of its pension system in the 1990s sharply increased the income of many poor households. In households that pooled their pension income, children grew faster and adults were less likely to skip meals and had lower rates of depression. Although no link was found to HIV/AIDS, those indicators that improved are strong predictors of overall health (Case 2001). Poor children receiving South Africa's Child Support Grant, meanwhile, were more likely to be enrolled in school than non-recipients. Education is a further driver of good health (Case 2005).

Social support and coping skills interventions have proven quite helpful for persons with HIV on a range of issues.

Resources are essential; microfinance and cash transfer programs may be essential

Botswana provides a range of services including food and nutrition as well as schooling.

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