



# Integrating Psychosocial and Medical Support: Addressing the Needs of PLWHA

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The HIV/AIDS pandemic has become one of the greatest challenges of the new millennium. In addition to affecting the health of the body and potentially shortening human life, HIV infection also causes a variety of other problems: psychological, economic, social, and spiritual. As a result, people living with HIV/AIDS (PLWHA) often get depressed, experience anxiety, and feel hopeless; they may lose their job, income, housing, healthcare, and mobility, and thus their economic status; and as a result of discrimination and stigmatization, they often experience social isolation and crises in faith.

Those infected with HIV in Eurasia are predominantly injection drug users (IDUs), commercial sex workers (CSWs) and their clients, and men who have sex with men (MSM). These groups are at high risk for acquiring and transmitting HIV due to their behaviors and, as such, they are often stigmatized and excluded from many institutions within so-called “normal” society. Counseling and testing (C&T) programs with psychosocial and legal support components, antiretroviral therapy (ART), and comprehensive care and support services can help PLWHA better cope with the infection; improve the quality and length of their lives; and prevent further transmission of the disease.

The vast majority of PLWHA in Eurasia have no, or very limited, access to the above mentioned services. According to WHO estimates, only 1 percent of the people who need ART in Eurasia have access to it. Counseling is not always provided to people getting tested for HIV or those receiving ART due to lack of capacity—trained professionals, material and financial resources, etc.—and insufficient political attention to this issue. This poses a serious threat to the mental and social health of the people infected with HIV.

Counseling and psychosocial support services can do much to assist PLWHA to better adhere to treatment regimens and overcome various social, psychological, and economic difficulties in their lives. The psychosocial problems of the HIV-positive can also

be addressed by follow-up consultations, peer support groups, and emotional support provided by religious/spiritual leaders or trained counselors. In Eurasia, psychosocial support for PLWHA is mostly provided by non-governmental organizations (NGOs), the number and capacity of which is inadequate to the current needs. In resource-poor settings psychosocial care can also be provided by lay persons, including family, friends, neighbors, and others in the community. With some technical assistance, these non-professionals can provide sustainable support that will require few, if any, outside resources.<sup>1</sup>

## Finding a Spokesman Hero

One of the most effective ways of delivering HIV/AIDS prevention messages to the general population and supporting PLWHA is having workshops or campaigns that include the participation of influential or famous individuals infected with, or affected by, HIV. A good example of this is Earvin “Magic” Johnson, a world-famous basketball star who contracted the disease 12 years ago. By taking the medicine prescribed by his doctor and closely adhering to his treatment regimens, he has been living for 12 years without developing AIDS, a condition that could have killed him long ago. In the United States, Magic Johnson engages in public campaigns to stop the spread of HIV infection and to give hope and support to individuals and families infected with, or affected by, the virus. He appears on US television shows and in newspapers, billboards, and other advertising media to educate the public and raise awareness about HIV/AIDS; to convince those with the virus to adhere to treatment regimens; to stop HIV stigmatization and discrimination; and to raise money to support PLWHA and research efforts. One Johnson advertisement posted in the subway system pictures him looking majestic and peaceful dressed in white. It says: “Staying healthy is about a few basic things: A positive attitude, partnering with my doctor, taking my medicine every day.” It is hard to imagine a more cost-effective intervention to prevent HIV/AIDS and support PLWHA than having Magic Johnson speak on television. He is an idol for many Americans—

particularly young males in high-risk groups—as well as for people living in many other corners of the world. His words, like his image, are “magic,” particularly when he tells his story of fighting the deadly virus that he has been living with for more than a decade—the painful side effects, such as nausea, that he constantly faces by taking his pills and adhering to his treatment regimen; and the support that he receives from his family, friends, and relatives—inspires many people who are in a similar condition. Being a black person, he has especially become an inspiration to African-Americans, a racial minority among which AIDS is the leading cause of death for young people between 24 and 44 years of age.

### Tending to the Spirit

Another way to provide psychosocial support for PLWHA is to organize spiritual workshops, which can be implemented through collaboration with churches and other religious organizations. The main assumption here is that religion and faith play an influential role in the life of most individuals, including PLWHA, therefore, PLWHA sometimes change their behavior—engage in safer sex, adhere to treatment regimens, etc.—when they participate in religious ceremonies or workshops. Additionally, because of the stigmatization and discrimination associated with HIV and the way it is contracted, PLWHA often experience a crisis in faith, sometimes due to their own internalization of guilt and others times because of rejection by their religious community (see also “Supportive and Palliative Care for People Living with HIV/AIDS” on page 36).

The AIDS Project East Bay (APEB), an organization located in Oakland, California, that combats HIV/AIDS in the San Francisco East Bay area, had a tradition of arranging for bi-weekly spiritual workshops for PLWHA where one of APEB’s health educators, a minister by training, opened each session by playing a spiritual song and then asking participants to interpret its meaning according to their own perceptions and feelings. It was followed by a prayer and a moment of silent tribute to friends who died of AIDS. Free food was provided during the workshop as

an incentive for PLWHA to participate in the event, which was part of the Primary Prevention for Positives (so-called P3) Project, funded through a CDC grant. Although the P3 project—one of four federally-funded demonstration projects in California—existed for less than 18 months because of US federal budget cuts to AIDS prevention programs, the effectiveness of this kind of program cannot be underestimated. P3 can serve as a model to those communities where the AIDS epidemic is most devastating and where faith is an important component in the lives of PLWHA.

### Friends Helping Friends

A more common way of helping with the psychological and practical concerns of PLWHA is through a peer support group. Peers can provide emotional support to people who may not want or need traditional help, or who may want to partake in the program to complement case management or other services. Peer support offers assistance to people infected, or affected, by HIV/AIDS as they deal with the effects of the virus on their lives and information about medication regimens and possible side effects. The format of peer support programs ranges from one-on-one information and peer education sessions to referrals and follow-up consultations; from community- and street-outreach to panel discussions. Sometimes just being able to talk to someone else who is HIV-positive can make all the difference to an individual.



Photo: Kathryn Utten.

Peers can provide emotional support to people who may not want or need traditional help. At Oasis, a residential substance abuse treatment facility in Odessa, Ukraine, a homey atmosphere and camaraderie help ease the difficult transition from drug addiction to sobriety. For those who are HIV-positive, this support is even more critical.

### Stressing the Need for a Holistic Approach

Experience in the field shows that when choosing from the wide variety of programs and measures used to prevent the HIV/AIDS epidemic and improve the quality of life for PLWHA, a comprehensive and holistic approach has been proved to work the best. The motto of APEB says: “Healing mind, body, spirit” as a reminder of their holistic approach. APEB’s high-risk target population receives a comprehensive package of HIV/AIDS related services, includes one-on-one counseling; community- and street-outreach and group education workshops; C&T; ART and prevention case management; primary care service provision (for PLWHA); treatment of opportunistic infections; and legal and psychological support. Because the majority of APEB’s clients are disenfranchised and homeless, they also receive



temporary housing and food to maintain their health, as well as free transportation vouchers to go to APEB for education, counseling, and treatment services. This holistic approach addresses the complex physical, mental, social, and spiritual needs of the population they serve. Because all of these aspects of care are inter-related, addressing one and ignoring another ultimately reflects negatively on the overall effectiveness of interventions.

HIV/AIDS care and support programs should also address the nutritional, social, financial, physical, and day-to-day needs of PLWHA. While industrialized nations have the capacity to address most of those aspects of comprehensive care, many developing countries are constrained to providing only a few services to PLWHA, such as HIV antibody testing or referrals to other community resources for support. A holistic HIV/AIDS care and treatment program in Eurasia could be implemented at the community-level by involving and closely collaborating with local primary care providers, NGOs, churches, schools, and other community-based organizations, each of which would have its own role in the overall AIDS control strategy. Ultimately, the target population would be able to receive C&T, ART, and psychosocial and spiritual support in an organized manner at one location. A case manager would be assigned to each HIV-positive individual to coordinate all aspects of care and refer him/her to corresponding support services as needed.

### Improving Adherence to Treatment Regimens

HIV-positive patients who are taking ART must adhere to the treatment regimens to avoid the development of drug resistant HIV/AIDS, improve the quality of their lives, and live longer. Adherence means taking from 95 to 100 percent of the prescribed doses of medication and following specific dietary guidelines. ART is a complex treatment and presents a great challenge for

almost all patients regardless of their background, especially those who struggle with other medical or psycho-social difficulties.

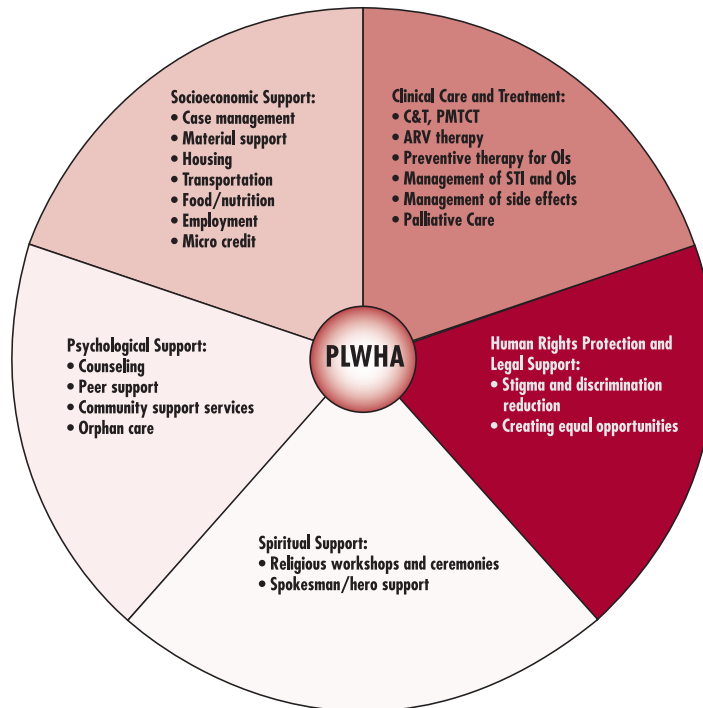
ART available today requires a life-long commitment and a responsible attitude. A case study report from South Africa indicates that two strategies have helped to achieve this: one using simplified regimens that minimize the burden of pills, the dosages, and the risk

of side effects; and a second that implements a solid patient-centered education approach to ensure a good understanding of the treatment by the patient and a strong support system.<sup>2</sup> Thus, there are a number of factors that influence adherence rates. First are factors associated with patient characteristics, such as knowledge, social support, and beliefs. Second, are factors associated with the treatment regimen, such as number of medications taken, frequency of ingestion, complexity of dosing, duration of treatment, side effects, and degree of behavioral change required. Finally, there are factors associated with the patient-

provider relationship, such as knowledge, trust between the patient and physician, consistency, level of supervision, and similar demographic characteristics.

### Trust

Establishing trust is very important. In Eurasia, some patients have lost faith in their healthcare providers as a result of the introduction of fee-for-service payment systems and the degradation of moral norms, especially after the collapse of the Soviet Union. The incentives for providers have also changed. During Soviet times physicians relied on fixed monthly salaries to live on; nowadays the bulk of their income is based on under-the-table payments, which average 70 percent of physician income in most Eurasian countries.<sup>3</sup> This creates an incentive for doctors to see more patients each day or month and encourages them to



**Comprehensive care and support services for PLWHA:** A comprehensive, integrated, holistic approach has been shown to be the most effective model to follow when working to improve the quality of life for PLWHA. The above helps break down and categorize services that fall under broad programmatic areas.

## Comprehensive Care and Support Services for PLWHA

### Socioeconomic Support

- Case management
- Material support
- Housing
- Transportation
- Food/nutrition
- Employment
- Micro credit

### Clinical Care and Treatment

- C&T, PMTCT
- ARV therapy
- Preventive therapy for OIs and TB
- Management of STI and OIs
- Management of side effects
- Palliative care

### Psychological Support

- Counseling
- Peer support
- Community support services
- Orphan care

### Spiritual Support

- Religious workshops and ceremonies
- Spokesman/hero support

### Human Rights Protection and Legal Support

- Stigma and discrimination reduction
- Creating equal opportunities

provide unnecessary care or even extended hospital stays. Therefore, a more effective physician payment system should be implemented for HIV/AIDS patients to help providers regain patient trust.

### Education

Patient education is an equally important component of patient care. Patients need to receive basic information about their health, health risks associated with particular behaviors, and treatment options. This can be implemented by providing written handouts, scheduling consultations, or promoting other forms of information dissemination.

### Case Management

For HIV/AIDS patients, case management and follow-up are also vital. PLWHA need follow-up consultations at least once a month to check for side effects and adherence difficulties, as well as to receive information or referrals to legal support, welfare, or other support services. Case management usually starts with the client intake process. It consists of an interview that lasts approximately one hour, during which a comprehensive assessment is completed. Any immediate needs are attended to through direct provision and referral. Case managers provide support and handle questions regarding basic AIDS information, HIV counseling, testing information, transportation requests, and questions related to health, food, housing, legal assistance, and both in-house and external referrals.

Comprehensive case management is essentially implemented through a four-step process:

- Meeting with the patient to discuss overall medical, social, psychological, and daily living needs.
- Developing a care plan based on the patient's identified needs and the services available.
- Assisting patients in obtaining the services they need, both in-house and within the community.
- Monitoring and making the necessary adjustments to the initial care plan in coordination with other providers as the needs of the patient change.

Case managers refer patients, with their written consent, to other agencies as needed, including but not limited to mental health resources, substance abuse treatment facilities, welfare offices, social security and other benefit programs, homeless shelters, and food pantries. Case managers also refer patients to medical doctors and dentists, legal service providers, and support groups. All of these are services that directly or indirectly affect a patient's adherence to treatment regimens, as well as their overall quality of life.

In addition to mitigating behavioral factors that affect adherence, the availability and accessibility of antiretroviral (ARV) drugs is another challenge in Eurasia. Some researchers argue against initiation of ART in resource-poor countries saying that it may lead to widespread development of resistance.<sup>4</sup> The reason for this is that there is inadequate supply of ARVs to be found in those countries and the chance that existing ARV therapies may fail some day is high due to a non-guaranteed supply of drugs there. WHO and the Global Fund to Fight AIDS, Tuberculosis, and Malaria have

started addressing this issue in the scope of the "3 by 5" initiative, which aims to treat 3 million people by the year 2005.

### Addressing Stigma and Discrimination

In addition to a lack of human and institutional capacity and of donor coordination, addressing HIV stigmatization and discrimination is often cited as a key obstacle to an effective national AIDS response.<sup>5</sup> Stigma is a powerfully discrediting and tainting social label that radically changes the way individuals view themselves, and how they are viewed by others.<sup>6</sup>

People stigmatize an individual who has, or is suspected of having, HIV/AIDS primarily because of fear of the disease. As a result, people may lose their socio-economic status, employment, income, housing, education, healthcare, and mobility. Intolerance and negative attitudes toward PLWHA in Eurasia further stimulate the growth of the AIDS epidemic. The infected and affected individuals often experience guilt, depression, and live isolated from the society. Loss of employment often leads to chronic poverty and homelessness, becoming a further barrier to effective treatment.



When individuals fail to meet societal expectations they become discredited and are rejected, which further isolates them. Most PLWHA suffer or fear stigmatization. Studies from Africa suggest that AIDS stigma is linked to an individual's sense of sexual morality and their fear of breaking taboos.<sup>7</sup> It is thought that the fear of stigma adversely influences people's health-seeking practices. A "conspiracy of silence" exists in which HIV/AIDS is seldom openly discussed, even in heavily affected areas. People do not want to admit that a fatal and disease spread by behavior branded as "immoral" could be rampaging through their community or country.<sup>8</sup> As a result, in places where denial flourishes, people are most vulnerable to the silent spread of the disease. Furthermore, discussions about sexual practices or use of illicit drugs are often taboo and associated with embarrassment, shame, guilt, and rejection. Ultimately, people often hide their HIV status or do not get tested out of fear.

There are a number of strategies to combat the stigma associated with HIV/AIDS. Education of the general population has a central place in this. Communities should be aware of the damage and pain caused by stigma and discrimination. On the other hand, PLWHA need to strengthen their personal ability to resist stigmatization, such as withdrawing from or avoiding confrontational situations, ignoring those who stigmatize, using joking as a way to diffuse discomfort, and not fighting unless in defense. Proper anti-discrimination laws should also be enacted and enforced thereby creating equal opportunities for PLWHA in the work places, at educational and healthcare facilities, and in many other public places.

### Strengthening the Capacity of Healthcare Providers in Eurasia

Most Eurasian countries do not have the capacity, human and financial resources, or experience and expertise to address the growing AIDS epidemic in the region. With more than 1 million people now living with HIV in Eurasia, expanding access to ART for those who urgently need it is one of the most pressing challenges. Providing ARV treatment is essential to alleviate suffering and to mitigate the devastating impact of the epidemic. The challenges are great. Sustainable financing is essential. Drug procurement and

regulatory mechanisms must be established. Healthcare workers need to be trained, a proper infrastructure developed, communities educated, and diverse stakeholders mobilized to play their part.<sup>9</sup>

The existing healthcare infrastructure for HIV/AIDS control in the countries of the former Soviet Union is centralized under Republican or National AIDS Centers and often functions below required international standards. Currently there are few centers in the region that offer C&T services, rapid tests, HIV testing of donated blood, ART, or control of STIs. There is a need for financial and technical assistance to better address the AIDS epidemic by improving current healthcare regulations and services, the healthcare system as a whole, and the NGO network.



Photo: Kathryn Ulan.

Sharing stories of how they first became involved with drugs, as these young people do, is an important part of each patient's ability to address their current situation. The fact that many of these stories bear striking similarities further strengthens the familial bond of support that an effective psychosocial support program fosters.

The *WHO HIV/AIDS Treatment and Care Protocols for the Countries of the Commonwealth of Independent States* require that those who test positive receive counseling and referral to care, support, and treatment, where available. While Eurasian countries have some well-trained specialists, they have no practical experience in conducting ART, control, and HIV/AIDS treatment observation. National protocols should be developed for AIDS case management according to WHO protocols and guidelines as follows:

- National specialists who administer treatment should be trained and provided with the national treatment protocols and issues related to HIV/AIDS treatment should be included in the programs of the graduate and post-graduate training of respective specialists.
- C&T services need to be decentralized throughout the region and expanded into the primary healthcare services. Healthcare workers in most local clinics and hospitals need training and re-training to be able to provide free and anonymous HIV/AIDS C&T, which will require some remodeling of local clinics to be able to provide necessary conditions for effective programs, such as quiet and comfortable rooms, computers, etc.
- Rapid test kits should be provided to trained counselors who provide on-site testing for HIV.
- Medical doctors, nurses, social workers, psychologists, health educators/counselors from governmental organizations and

NGOs, and volunteers from high-risk groups can be trained in modern HIV/AIDS C&T protocols, prevention case management, psychosocial counseling, and administration of rapid testing.

- Basic psychosocial support can be provided by healthcare personnel and incorporated into the care provided in hospitals and clinics.
- Community groups can be trained in the provision of psychosocial care. This will entail training costs, but should not be too expensive to maintain. More costly will be the addition of specialist services.

Given the importance of these services to the overall health and support of PLWHA, their families, and caregivers, they should be included as an integral part of care and support strategies. Training in the provision of psychosocial support should be incorporated into curricula for all healthcare providers. Guidelines for home care services can be developed and should include the provision of basic psychosocial care by community volunteers and family caregivers. Training in professional disciplines—counseling, psychology, psychiatry—should be available for local providers, as well. Strategies for providing psychosocial support need to be developed for specific groups—e.g. women, youth, MSM, CSWs, IDUs, healthcare workers, etc. The maximum possible number of the most needed services should be available at one location. Social services, counseling, and education should be integrated in the medical care setting.

With the financial and technical assistance from international donor organizations, such as the Global Fund, the United Nations, The World Bank, USAID, Open Society Institute, and many others, Eurasian countries will have a stronger capacity to fight the growing HIV/AIDS epidemic and improve the quality of lives of people infected with, and affected by, HIV in the region. ■

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