hiv aids building blocks

BUILDING BLOCKS:

Comprehensive Care Guidelines for Persons Living with HIV/AIDS in the Americas

SUMMARY REPORT

June 2000

PAHO/WHO in collaboration with UNAIDS and IAPAC

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Work team:
Dionne Patz, PAHO
Rafael Mazin, PAHO
Fernando Zacarias, PAHO
Maria Eugenia Gutierrez, PAHO
Paloma Cuchi, UNAIDS/PAHO
Eric van Praag, WHO
Gordon Nary, IAPAC
Jose Zuniga, IAPAC
Stephen Corber, PAHO

Regional Program on AIDS/STI
Division of Disease Prevention and Control
Pan American Health Organization
June, 2000

Facsimile: (202) 974-3695
World Wide Web: http://www.paho.org

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Glossary of Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ADRs	Associated Drug Reactions
ARVs	Antiretrovirals
AZT	Azidothymidine (zidovudine)
CNS	Central Nervous System
DOTS	Directly Observed Treatment, Short-course
GPA/WHO	Global Program on AIDS/World Health Organization
HAART	Highly Active Antiretroviral Therapy
HBV	Hepatitis B Virus
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
IAPAC	International Association of Physicians in AIDS Care
IEC	Information, Education and Communication
IV	Intravenous
MTCT	Mother to Child Transmission (of HIV)
OIs	Opportunistic Infections
OPS	Organización Panamericana de la Salud
PAHO	Pan American Health Organization
PCP	Pneumocystis carinii Pneumonia
PEP	Post-exposure Prophylaxis
PLHAs	Persons Living with HIV/AIDS
STIs	Sexually Transmitted Infections
TB	Tuberculosis
UNAIDS	United Nations Joint Programme on HIV/AIDS
VCCT	Voluntary and Confidential Counseling and Testing
WHO	World Health Organization

Foreword

The Regional Program on AIDS/STI of the Pan American Health Organization (PAHO), Regional Office of the World Health Organization, in collaboration with the World Health Organization (WHO) Headquarters, the United Nations Joint Programme on HIV/AIDS (UNAIDS) and the International Association of Physicians in AIDS Care (IAPAC), convened a series of consultations with national experts to identify the "building blocks", or core components, of HIV/AIDS comprehensive care.[1] These consultations were held in response to numerous requests from health authorities in the Region of the Americas on how they can ensure improved care and, specifically, wider access to antiretroviral therapies for persons living with HIV/AIDS.

This resulted in the development of a ***Building Block Framework*** for HIV/AIDS comprehensive care that depicts three different scenarios for providing HIV/AIDS care. These scenarios outline a series of steps that can be followed in accordance with available resources and skills to achieve the development of a comprehensive care network for persons living with HIV/AIDS (**PLHAs**), their families and caregivers.

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1 The complete summary can be found in the reference, *Proceedings of the Consultation on Standards of Care for Persons living with HIV/AIDS in the Americas*, PAHO/WHO (2000).

Comprehensive Care Guidelines for Persons Living with HIV / AIDS in the Americas

INTRODUCTION

This document provides an operational definition of HIV/AIDS comprehensive care and outlines the core components of HIV/AIDS care. It presents a care model, outlined in a ***Building Block Framework***, that is meant to provide guidance in the development of policies and strategies and promote discussion about the full spectrum of care required to meet the needs of **PLHAs**, their families and caregivers. It is anticipated that this document will serve as an information base from which viable HIV/AIDS comprehensive care programs may be developed.

HIV / AIDS COMPREHENSIVE CARE

HIV/AIDS comprehensive care consists of four interrelated elements (van Praag & Tarantola, 1999):

- ***Clinical management*** (early and accurate diagnosis, including testing, rational treatment and follow-up care)
- ***Nursing care*** (promotion of adequate hygiene practices and nutrition, palliative care, home care and education to care providers at home and family, promoting observance of universal precautions)
- ***Counseling and emotional support*** (psychosocial and spiritual support, including stress and anxiety reduction, risk reduction planning and enabling coping, accepting HIV serostatus[2] and disclosure to others, positive living and planning of the future for the family)
- ***Social support*** (information, provision or referral to peer support, welfare services, spiritual support and legal advice)

Comprehensive care programs for **PLHAs** and their support system(s) should encompass services ranging from counseling to medical interventions, to case management of social service needs, to nutritional support, as well as palliative care, bereavement support and caregiver support. These programs should also serve to improve the emotional condition of affected individuals and ensure they have the means to live a life of dignity and self-respect.

[2] Serostatus refers to whether a person has antibodies to HIV in her blood. Seronegative, or HIV negative, is when antibodies to HIV are not found in a person's blood. Seropositive, or HIV positive, is when antibodies to HIV are found in the blood.

It is a widespread belief that the majority of health care needs of **PLHAs** could be fully addressed by ensuring access to medications, in particular antiretroviral therapy. However, this idea falls short of effectively meeting the complete range of **PLHAs'** medical, emotional, social and economic needs.

Access to medicines should be viewed as one part of providing appropriate clinical management for **PLHAs**. It must be ensured that the elements that constitute the foundation of health care (skilled health providers, laboratory facilities, treatment units, access to counseling and testing, emotional and social support) are firmly in place before concentrating all the efforts and resources to ensuring access to pharmaceuticals.

The development of HIV/AIDS comprehensive care programs should not be considered as a diversion of resources from prevention activities, but as a strategy to widen their impact. These programs should enhance primary prevention efforts and also have preventive effects in and of themselves (secondary and tertiary prevention). As a primary prevention strategy, they should ensure that (1) people who are not infected do not get HIV, (2) those who are already infected do not transmit HIV to others, and (3) those who are already infected do not get re-infected.

HIV/AIDS Care Continuum

Development of appropriate HIV/AIDS comprehensive care should serve to provide guidance on a logical sequence of events that may be used to prioritize actions and establish bridges for interventions of increasing complexity to be carried out at different levels of the health system.

HIV/AIDS comprehensive care should be available and provided at all levels of the health system. This includes: home care, community care, primary care, secondary care and tertiary care. Each of these levels should be points within a continuum of care for **PLHAs** and together integrate a comprehensive care network. To operate properly this network requires:

- Definition of roles and functions within each of the elements of the HIV/AIDS care continuum
- Establishment of the appropriate services and mobilization of the necessary resources to perform these roles and functions
- Construction of bridges between each of the elements of the HIV/AIDS care continuum

If these requisites are in place, it will be possible to meet the individual needs of **PLHAs** at any point in the evolution of HIV infection by providing the most appropriate and timely responses and referrals to services.

HIV / AIDS CARE MODELS

As described previously, HIV/AIDS comprehensive care involves providing a wide range of interventions throughout the entire health

system. However, the majority of countries can not provide all of the services in all of their local health systems. At best they may develop these services through a phased-in approach. On the other hand, some areas may have sufficient resources to permit an expansion of the available responses within each level of care. The complexity and sophistication of the services will vary as a result of the availability of financial, technical and human resources and health infrastructure. However, even in areas where resources are limited, it should be possible to provide a standard of care that ensures the maintenance and improvement of the quality of life and productivity of **PLHAs**.

Principles

The following principles were outlined during the Consultation on Standards of Care for Persons with HIV/AIDS,[3] organized by WHO/PAHO, as essential guidelines in the development and provision of HIV/AIDS comprehensive care systems. To meet the physical, emotional, social and economic needs of **PLHAs**, care should be governed by the following principles:

- ***Respect***: For human rights and individual dignity
- ***Accessibility and Availability***: Appropriate care is provided at the local level
- ***Equity***: Care is provided to all persons living with HIV/AIDS regardless of gender, age, race, ethnicity, sexual identity, income and place of residence
- ***Coordination and Integration***: To ensure a continuum of care across providers and levels of care
- ***Efficiency and Effectiveness***: Efficacious care is provided at reasonable societal costs demonstrated through ongoing monitoring and evaluation

Standards of Care

In order for HIV/AIDS comprehensive care programs to be effective and sustainable, some standards of care need to be agreed upon and applied. Standards need to reflect the optimal and desired levels of the quality, access and coverage of HIV/AIDS care (van Praag & Tarantola, 1999). Once established, standards have to be translated into indicators for monitoring and evaluation purposes.

In theory, standards should be formulated for minimum and optimum levels of care, taking into account possible variations in the resources and skills available, development of new and cheaper technologies, ease of access and affordability in different areas within a particular country (*Ibid*). However, as one of the principles of HIV/AIDS comprehensive care programs is to achieve ***equity*** in the provision of care, the design of HIV/AIDS care programs and their monitoring and evaluation elements should be based on minimum standards which all implementing participants are expected to abide by and use as a reference to evaluate performance.

To determine the standards of care in any particular setting, three different dimensions that influence the choice of standards must be considered.

- The *first dimension* deals with the technical aspects of the intervention to be provided and is determined by the efficacy and effectiveness of the specific interventions.
- The *second dimension* is determined by the social and contextual factors that make efficacious interventions functional under operational conditions.
- The *third dimension* involves the setting of standards and is determined by the level of the health care system providing such interventions (e.g. home-care, communities, health clinics, hospitals, tertiary referral centers).

The standards and norms of care should be defined in each country, for each level of services, and for each population affected. Although there may be universal standards, it is important to emphasize that local standards should reflect the **best care obtainable in current local circumstances**.

Appropriate HIV/AIDS Care

The following table outlines appropriate services to meet the basic needs of **PLHAs**, their family members and caregivers (refer to Consultation Proceedings, 1999). The specific components are outlined in **Annex A** and should be adapted according to specific situations and resources.

Appropriate HIV/AIDS Care
❑ Screening and Diagnostic Services
❑ Counseling and Psychosocial Support
❑ Community Education and Participation
❑ Prophylaxis and Treatment of Opportunistic Infections and other Infections
❑ Nutritional Interventions
❑ Management of Sexually Transmitted Infections
❑ Management of HIV in Obstetrical/Gynecological (Obs/Gyn) Practice
❑ Management of Pain and Palliative Care
❑ Antiretroviral Therapy
❑ Antitumoral Therapy
❑ Neurological and Psychiatric Care
❑ Management of Addictions
❑ Surgical Procedures
❑ Management of Sexual Complaints and Dysfunctions

In determining access to **antiretroviral therapy** it is advisable to have consensus meetings of national experts in each country, in order to establish guidelines for setting priorities of patients to be treated.

In a setting where there are less than optimal resources, individuals should not be treated with substandard antiretroviral regimes (e.g. AZT monotherapy). If there is insufficient money to treat all the eligible patients, the threshold for treatment initiation should be determined. In this way, fewer patients would be treated but all would be receiving optimal therapy.

[3] Consultation on Standards of Care for Persons with HIV/AIDS, Cancun, Mexico, November 1998.

BUILDING BLOCK FRAMEWORK

In order to foster further discussion on what care can be provided in relation to resource availability, three different scenarios are proposed. Appropriate and feasible care alternatives that correspond to the different levels of the health system are outlined in a ***Building Block Framework*** (refer to pages 8-9). The minimum standard of care that countries should strive to achieve is delineated in **Scenario I** and the increasing range and specialization of services that are possible with an increase in resources (physical/infrastructure resources, financial resources, technical resources, support services) and skills (trained health providers) are presented in **Scenario II** and **Scenario III**.

The proposed scenarios are:

Scenario I: In this setting, testing and basic medications (e. g. tuberculosis (TB) prophylaxis, palliative care) are available in a limited amount at all levels of the health system (primary, secondary, tertiary). Interventions are focused on *secondary prevention* activities (i.e. prophylaxis of opportunistic infections, avoidance of potentially harmful behaviors) to avoid further physical deterioration and provide symptomatic relief. Antiretroviral (ARV) therapy is available for the prevention of mother to child transmission (MTCT) at the secondary level of the health system.

Scenario II: In this setting, testing and drugs are available at all levels, including some ARVs at the secondary level of the health system. All **Scenario I** services are provided plus the etiologic treatment of opportunistic infections. Some excessively expensive drugs, such as antitumoral medications, are not available at the primary and secondary levels of the health system.

Scenario III: In this setting, all of the above services are provided plus ARV therapies and specialized services.

In each building block, elements should be read from top to bottom i. e. the elements are arranged in a sequential fashion with the first illustrating the initial care component that needs to be addressed. Ideally, all components should be provided within each level of the health system.

The core foundation of services in **Scenario I** should be in place before moving to the next level. The achievement of all services within a particular scenario should be a stimulus to move to the next scenario level. The ultimate goal is to obtain the standard of care presented in **Scenario III**.

MONITORING AND EVALUATION

HIV/AIDS comprehensive care programs must include a monitoring and evaluation component to refine, adapt and strengthen existing and new services. Services will only be effective if they are consistently evaluated to measure effectiveness, efficiency, quality, usage and acceptability in the community. Programs should seek to collect, analyze and use data that reflect the extent to which quality care is provided at all levels of the health system, and to identify any problems and potential gaps requiring remedial actions.

The purpose of **monitoring** is to ensure that work is progressing as planned and to anticipate or detect any problems in implementation (adequacy of supplies, appropriateness of training).

Evaluation focuses on determining the degree of progress in meeting set goals or program performance. It involves an assessment of inputs (human and capital resources available for program implementation) and program operation variables (who is to do what, where, when and how). It also involves an assessment of impacts and outcomes that may include changes in knowledge, attitudes, behavior, risk factors, disease and disability.

Appropriate indicators for the above monitoring and evaluation purposes should be selected during the program formulation stage. Indicators need to be established that

The monitoring and evaluation process should answer the following questions:

- ***Appropriateness***: Does the HIV / AIDS comprehensive care system as a whole respond to the main health needs of the target population?
- ***Acceptability***: Are the services provided in a manner that is acceptable to the population and encourages their appropriate utilization?
- ***Accessibility***: Are the services provided so that problems of access (geographical, economic and social barriers) are minimized and equity is promoted?
- ***Effectiveness***: Do the services provide satisfactory outcomes both from the clinicians' point of view and that of the clients and their families?
- ***Efficiency***: Is each service provided so that the maximum output is obtained from the resources expended, and does the mix of services represent the best value for money with regard to the health needs of the target population?
- ***Equity***: Are the health needs of different sectors of the target population met in a fair and just way?

BUILDING BLOCK FRAMEWORK

Scenario I
Scenario II
Scenario III

	Scenario I:	Scenario II:	Scenario III:
TERTIARY LEVEL	• Treatment of toxoplasmosis, PCP & other relevant OIs • Management of complex manifestations of HIV	• Management of anxiety & depression • ARVs for HAART • Antitumoral treatments • Management of chronic pain • Management of anal & proctocolonic syndromes • Parenteral nutrition • Post-exposure prophylaxis (PEP) among health providers	• Use of steroids & other hormones • Elective surgery
SECONDARY LEVEL	• Counseling for secondary prevention • Screening, prophylaxis & treatment of TB • Prophylaxis of PCP • Confirmatory diagnosis of HIV infection & related conditions • ARVs to prevent MTCT • Breast milk substitutes / alternatives to breast-feeding • Vaccination against tetanus & HBV • Access to safe blood & derivatives*	• Screening, prophylaxis & treatment of toxoplasmosis & PCP and other relevant OIs • Nutritional interventions, including anabolic steroids • ARVs for selected patients • Management of sexual functions	• ARVs for HAART
PRIMARY LEVEL	• Voluntary & confidential counseling & testing • Management of pain, malaise & fever • Education on personal & environmental hygiene, universal precautions, safer sex & family planning • Nutritional assessment, counseling & food safety • Syndromic management of STIs • Clinical diagnosis of HIV-related diseases • Vaccination against tetanus	• Prophylaxis / treatment of TB, toxoplasmosis & PCP • Management of HIV-related diseases • Nutritional supplements (vitamins, micronutrients) • Sensitivity-based management of STI • ARVs to prevent MTCT • Breast milk substitutes / alternatives to breast-feeding • Vaccination against HBV	• Clinical & laboratory monitoring of progression of disease • Flu vaccination
COMMUNITY LEVEL	• Emotional support & counseling • Community information, education, communication (IEC) & participation • Personal accompaniment • Support groups • Nutritional assessment, counseling & food safety • Food kitchens & programs • Multidisciplinary health practices (e.g. meditation, reiki) • Condoms & bleach • Access to family planning methods • Advocacy • Assistance to orphaned children	• Financial support • Legal representation • Management of drug banks • Provision of sterile needles • Hospice care • Bereavement and funeral support	• Day care centers
HOME CARE LEVEL	• Universal precautions • Safer sex activities, including family planning • Personal & environmental hygiene practices • Nutrition & food safety measures • Knowledge about when & where to seek additional support	• Adherence to medications & complementary measures	• Formal sharing of experience & networking

SCENARIOS

LEVEL OF HEALTH SYSTEM

* In countries where transfusional services are available at the primary level, this component should be available at the primary level.

measure the quality of care as well as the achievement of program objectives. For example, if one objective of a HIV/AIDS comprehensive care program is to increase the coverage of voluntary and confidential counseling, possible indicators include:

- *Proportion of primary health clinics that offer voluntary and confidential counseling and testing:*
  Number of primary health clinics that offer voluntary and confidential counseling and testing / Number of primary health clinics in a given area

- *Proportion of individuals who accept HIV testing*:
  Number of individuals who accept HIV testing/Number of individuals who receive pre-test counseling and information on HIV testing.

- *Proportion of individuals who return for HIV test results*:
  Number of individuals who return for HIV test results/Number of individuals tested

- *Proportion of individuals who bring in their partner for HIV counseling and testing*:
  Number of individuals who bring in partner for HIV counseling and testing/ Number of individuals who receive pre-test counseling and information on HIV testing

CONCLUSION

As discussed in this document, HIV/AIDS comprehensive care programs consist of a wide range of activities and services that meet the medical, emotional, social and economic needs of **PLHAs**, their family members and caregivers. Comprehensive care programs assist **PLHAs** to live longer and more dignified lives, provide family members and caregivers with invaluable support, and offer society a greater understanding and acceptance of HIV/AIDS. In addition, these programs support and strengthen already established HIV/AIDS prevention programs thereby enhancing the efforts to avert the spread of HIV.

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ANNEX A: Appropriate Services to Meet HIV/AIDS Care Needs

1. Screening and Diagnostic Services

- Laboratory capacity for detection and diagnosis (dependable tests, confirmatory testing)
- Voluntary and confidential counseling and testing (VCCT) services (confidential testing that is undertaken with the informed consent of the individual and ensured access to ongoing counseling)
- Laboratory capacity to identify indicators of progression of infection/immune impairment (CD4 count; viral load, others)
- Capacity to assess the quality level of laboratory results (identify false positive tests, false negative tests)
- Capacity to recognize alerting signs and clinical manifestations (physical, mental, oral) related to HIV infection developed among primary health care providers
- Capacity for providing results and supporting development of individual plans of action in place (support to identify alternatives/options)
- Settings for providing results and counseling in a confidential, private manner available
- Referral services

2. Counseling, Psychological and Social Support

(a) Counseling and Psychological Support

- Psychological interventions for coping with diagnosis
- Counseling to support development of individual plans of action
- Counseling after diagnosis (post-test counseling)
- Secondary prevention (counseling and education to delay onset of clinical manifestations and prevent re-infection)
- Support groups (e. g. peer facilitated groups)
- Professional interventions for coping with severe emotional disturbance

- Adequate (non-judgmental, compassionate) sources of spiritual support
- Multidisciplinary approaches identified (Meditation and other relaxation techniques)

(b) Social Support

- Financial support (insurance, loans, donations, subsidies)
- Home-based care
- Referral systems (for legal, financial, educational, public administration concerns)
- Assistance to orphaned children
- Advocacy and legal representation
- Accompaniment (escorting)
- Food distribution and serving of meals
- Bereavement and funeral support

3. Community Education and Participation

- Information, education and communication (IEC) strategies (e.g. distribution of pamphlets, posters, radio and television announcements, videos in waiting rooms, interactive video games, etc.)
- AIDS education programs (schools, community centers, etc.)
- Education for family members and caregivers (programs and workshops)
- Education for clergy
- Education for personnel officers in private and public sectors (to reduce impact of HIV/AIDS in workplace)
- Development of community support networks
- Information on available services and referral system (i.e. when and where to seek care and support)
- Distribution programs for condoms and bleach
- Provision of sterile needles

4. Prophylaxis and Treatment of Opportunistic Infections and other Infections

- Education and counseling on personal and environmental hygiene practices
- Prophylaxis planned according to local situation (most common health problems, e. g. tuberculosis, diarrhea)
- Expansion of essential drug list
- Treatment guidelines
- Community involvement for implementing DOTS in management of TB

5. Nutritional Interventions

- Nutritional assessment
- Nutritional counseling and education that includes food safety
- Plan of action to prevent weight and muscle mass loss
- Dietary changes to address associated drug reactions (ADRs) and specific symptoms
- Provision of supplements, if needed (vitamins, micronutrients, etc.)
- Use of anabolic steroids

6. Management of Sexually Transmitted Infections

- Syndromic and subsequent etiologic diagnosis
- Treatment guidelines

- STIs among HIV-infected pregnant women
- Monitoring efficacy of treatments among HIV-infected people
- Management of co-infection of HIV and Hepatitis
- Management of Anal and Procto-colonic syndromes

7. Management of HIV in Obstetrical/ Gynecological (Obs/Gyn) Practice

- Diagnosis and management of gynecological manifestations of HIV
- Prevention of mother to child transmission (MTCT) of HIV (e. g. voluntary and confidential counseling and testing, reproductive health counseling, provision of antiretroviral therapy, among others)
- Psychosocial concerns
- Breastfeeding counseling
- Alternatives to breastfeeding (e. g. breastmilk substitutes, heat treated breastmilk, among others)

8. Management of Pain and Palliative Care

- Etiologic diagnosis
- Pharmaceutical management of pain
- Tolerance and addiction to pain killers
- Multidisciplinary approaches in the management of pain (biofeedback, acupuncture, reiki, shiatsu, etc.)
- Chronic pain management (e.g. post-herpetic neuritis)
- Assessment of suicidal risk among patients with chronic pain

9. Antiretroviral Therapy

- Support system to ensure adherence to antiretroviral drugs
- Logistics system to ensure permanent availability of antiretroviral drugs
- Continuous Medical Education to manage appropriate combination schemes
- Laboratory capacity to monitor the effect of ARVs
- Mechanisms to promote and evaluate adherence to treatments
- Surveillance systems to monitor resistance to ARVs
- Evaluation of therapeutic effectiveness
- Drug interactions and secondary effects
- Management of metabolic dysfunctions secondary to ARV therapy

10. Antitumoral Therapy

- Screening for common neoplasms
- Assessing use of chemotherapy and radiotherapy
- Surgical ablation of tumors
- Cancer prevention
- Emotional needs of people with malignancies

11. Neurological and Psychiatric Care

- Pharmaceutical management of anxiety and depression
- Diagnosis and pharmaceutical management of HIV-related neuropathy
- Leucoencephalopathies (demyelination of the central nervous system (CNS))
- Drug-induced neuropathies (lesions/impairments are a result of secondary effects of treatments)

- Diagnosis and management of dementia (paralysis, cognitive impairment, speech problems)
- Management of sequelae of CNS infection/neoplasm
- Severe depression
- HIV infection among psychiatric patients and borderline personalities

12. Management of Addictions

- Assessment of nature of addiction and social environment
- Prevention of re-infection and other important infections (Hepatitis B Virus (HBV), Hepatitis C Virus (HCV), bacteria)
- Counseling on prevention of re-infection and additional infections
- Detoxification approaches

13. Surgical Procedures

- Central lines (intravenous (IV) catheters placed in large veins for maintaining long-term IV infusions)
- Parenteral nutrition (nutrients administered by IV infusion)
- Emergency procedures (e. g. appendicitis)
- Elective surgery (e. g. removal of cysts, hip replacement)
- Cosmetic surgery to manage disfiguring conditions (e. g. Molluscum, warts)

14. Management of Sexual Complaints and Dysfunctions

- Secondary prevention for re-infection
- Loss of sexual desire
- Compulsive sexual behaviors
- Pharmaceutical management of erectile dysfunction
- Guilt, anger and anxiety as obstacles to safe sex practices
- Diagnosis and management of dyspareunia and orgasmic dysfunctions
- Sex counseling and therapy for serodiscordant/seroconcordant couples