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Draft Working Document

**KEY ELEMENTS IN
HIV/AIDS CARE AND SUPPORT**

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Appendix: List of Abbreviations

AFRO:	Regional Office for Africa
AIDS:	Acquired immuno-deficiency syndrome
ARV:	Antiretroviral
CBO:	Community based organisation
DOT:	Directly observed therapy
GIPA:	Greater involvement of people living with AIDS.
HAART:	Highly active antiretroviral therapy
HIV:	Human immuno-deficiency virus
MTCT:	Mother-to-child transmission
NGO:	Non-governmental organisation
OI:	Opportunistic infection
PAHO:	Pan American Health Organization
PLHA:	People living with HIV/AIDS
SEARO:	South East Regional Office
STI:	Sexually transmitted infection
TB:	Tuberculosis
UNAIDS:	Joint United Nations Programme on HIV/AIDS
VCT:	Voluntary counselling and testing
WHO:	World Health Organization

1. INTRODUCTION

Purpose

A lot of publications have been produced on care for people living with HIV/AIDS. This document attempts to bring key issues on HIV/AIDS care in one practical and concise publication. It is intended to provide guidance to all partners in the provision of HIV care and support in resource-constrained settings. The purpose of this document is to identify the key elements and interventions in provision of care and support for PLHA and affected communities. Each element of care is discussed and references for more information on how this element should be implemented are provided as much as possible. These references will be interactive for those documents having an electronic file available in WHO or in UNAIDS Secretariat websites. These references are practical publications useful for the implementation of the key elements of HIV/AIDS care. This document also covers structural elements for service delivery. Finally, it discusses prioritization of the various elements of HIV/AIDS care: these two sections are helpful in the process of prioritization and implementation of HIV/AIDS care interventions listed in this document.

Target audience

The intended audience of this document is policy makers in health care (e.g., senior officials in government ministries, directors of health and medical services, district health officers, National AIDS Control Programme managers) and related sectors such as education, transport and finance. It is also directed to implementers of health policies or care providers (physicians and other clinicians, including nurses, social workers and counsellors), people living with and affected by HIV/AIDS, non-governmental organisations, multi/bilateral aid agencies, UN agencies and other partners working in provision of HIV/AIDS care and support.

Link to other documents

Following the resolution adopted by the WHO Executive Board in January 2000 and by the World Health Assembly in May 2000, WHO is developing a Global Health Sector Strategy

for improving health systems response to HIV/AIDS and Sexually Transmitted Infections¹. This strategy has been developed within the framework of the UNAIDS Global HIV/AIDS Strategy². The present paper represents a contribution toward the discussion surrounding the development of these global strategies, from a care and support perspective, and each country will need to adapt these key elements in HIV/AIDS care and support to its own realities.

2. CARE NEEDS

2.1. Epidemiology and background

At the end of 1999, there were 33.6 million people living with HIV/AIDS. More than 95% of them live in developing countries. The epidemic is continuing to spread globally, with 5.4 million newly infected people in 1999. The cumulative number of deaths due to HIV/AIDS is 18.8 million. 2.8 million deaths due to HIV/AIDS occurred in 1999. HIV/AIDS is the leading cause of death in sub-Saharan Africa where two-thirds of all PLHA are found³. Worldwide, the main burden of disease in PLHA arises from a limited number of common infections - and their complications - to which PLHA are particularly susceptible, namely tuberculosis, pneumonia, diarrhoea and candida infection of the mouth and throat. Tuberculosis is worldwide the single biggest killer of PLHA.

Appreciation and understanding of the care and support needs of PLHA are essential in order to develop relevant and adequate care responses. Studies have revealed that needs of PLHA go beyond clinical care and treatment. PLHA's needs also include, for the most part, social support to alleviate the socio-economic impact of HIV (e.g. basic needs for food, school fees and shelter), psychological support to cope with the implications of having a life-threatening condition, PLHA's right to protection in employment, to confidentiality, to medical care and access to new treatments, counselling, emotional, protection against discrimination and stigma, social support for their orphans left behind after the patients die, etc.

¹ Global Health Sector Strategy for Responding to HIV/AIDS, WHO, 2000 (draft)

² Global HIV/AIDS Strategy Framework, UNAIDS, 2000 (preliminary draft for discussion)

³ Report on the global HIV/AIDS epidemic, UNAIDS, June 2000

2.1.1. The need to strengthen responses

Health systems face increasing challenges in providing care and support for PLHA. When one looks at the impact of HIV/AIDS on the health care system, several observations can be noted: for instance, HIV/AIDS lays additional burdens on the already over-stretched health services and reduces the capacity of health systems to adequately respond to other health challenges. Demand for health services increases due to the increasing numbers of individuals who become ill as a result of HIV infection. This results in increased workload and congestion of health facilities. Hospital bed occupancy rates have increased with over 55% of beds occupied by PLHA in several most affected countries. In addition to demand for hospital beds, consumption of medical supplies and drugs has increased.

HIV infection has given rise to a concurrent epidemic of tuberculosis, which requires additional efforts and resources to address.

The output of health workers in some high prevalence countries can be substantially reduced by HIV/AIDS because of illness and death among health workers; need to care or attend funerals for family members or relatives; burn-out due to overwork; and the fear of perceived risk of occupational transmission of HIV infection.

Some clinical conditions become much more difficult to diagnose and to treat when associated with HIV/AIDS. This and the chronic nature of HIV/AIDS disease translate into increased cost of care to both the service and the users.

Difficulties experienced in resource-constrained settings include:

- low priority for financial support to the health sector nationally and internationally (very small proportion of health budget in most affected countries)
- insufficient remuneration and support for care professionals
- serious managerial weaknesses in health sector at all levels
- irregular and inadequate supplies of drugs, reagents, and equipment,
- lack of investment in buildings infrastructure.
- local production of drugs and other commodities insufficient given the weakness of local pharmaceutical manufacturers and markets and patent protection

Insufficient response to PLHA needs may also be explained by the following factors:

- Within the national and health budgets, HIV care has low priority.
- Sometimes, health reforms and globalisation do not allow for a strong emphasis on HIV care.
- Loss of staff due to burn-out.
- Shortage of relevant HIV information and HIV training opportunities,
- Essential drug lists and drugs procurement not adapted to needs of PLHA.
- Loss of staff due to high HIV-related mortality and morbidity among staff,
- Increasing demand while resources are decreasing.

All these factors lead to inadequate provision of care not only to PLHA but also to other patients.

2.2. Objectives

The **goals** of providing a care and support for PLHA are to:

- reduce HIV-related mortality and morbidity,
- improve the quality of life for PLHA, and
- improve the survival of PLHA.

Specific objectives are:

- to strengthen HIV prevention ,
- to expand greater involvement of PLHA (GIPA),
- to reduce the impact of HIV on the TB and HIV-related diseases,
- to mitigate the socio-economic and psychologic impact of HIV on individuals, families, communities, countries and society at large, and
- to improve HIV care for vulnerable populations such as young people, pregnant mothers, drug users and orphans, whose access to care is limited.

2.3. Rationale for Care and Support

- The consensus about the importance of care highlighted the fact that health care is a **human right**.
- Access to care and support also **contributes to the prevention of HIV infection**. Care provision offers an opportunity to discuss with the client and significant others how they might prevent further spread of the infection, and support them in their choices to do so, e.g. by availing access to interventions that reduce mother to child transmission of HIV, enabling them to increase their safety as a sexual partners through safe sex and condom use, and through use of antiretroviral therapy.
- Care and support for PLHA **decreases the spread of infectious diseases** that are common among HIV-infected people, in particular TB and STIs by early diagnosis and treatment of these conditions.
- By caring openly and compassionately for HIV infected people, their care-givers alleviate the fear of their community for HIV infection, and **alleviate stigma and discrimination**.
- **Social and economic benefits** of care and support for PLHA arise from recognising that when PLHA live longer and healthier, the loss of income for themselves and their families is postponed, and the future of their dependents will be better. And, the economy will benefit through the better performance of its workforce.
- **Care and support for PLHA builds confidence and hope in clients:** if the quality of life of PLHA improves as a result of care and support, **hope** will be instilled to the benefit of the individual and the family, and as a result to the society at large.
- Care and support for **PLHA supports the Greater Involvement of People living with HIV/AIDS (GIPA) in the fight against the epidemic**. Beyond opening the possibility of involving PLHA in policy and decision making, and target action against the epidemic with more precision, GIPA enables the personalization of HIV infection in

provision of health care, prevention, peer counselling, community care and HIV/AIDS advocacy. This makes non-infected people, institutions and policy makers realize that HIV is also their problem, and motivates them to do something about it.

3. PRINCIPLES AND VALUES

To meet the physical, emotional, social and economic needs of PLHA, care and support should be governed by the following principles and values:

- **Respect** for human rights, ethics, confidentiality, informed consent, privacy, and individual dignity. Human rights and ethical practices apply equally to PLHA as to other individuals. Fighting discrimination, enhancing respect of individual autonomy and human dignity, and pursuing informed consent are all relevant to HIV care and support.
- **Equity:** affordable care of acceptable quality should be provided to all people regardless of gender, age, race, ethnicity, sexual identity, income and place of residence. More attention should be given to those groups of the population that have more problems to access care: widows and orphans, pregnant women, children, the elderly, the uneducated and the poor.
- **Quality of care:** care should be of good quality. Interventions and services have maximum benefit if they are of good quality. There ought to be continuous improvement in quality of the services. Quality can be measured in terms of the nature of services provided and in the specific interventions. Measures of quality of services include indicators such as waiting time, attitude of health workers and the type of facilities available. Indicators of specific interventions include compliance with recognized standards in administering the interventions. Quality of services is a strong indicator of how responsive the services are to the expectations of the people.
- **Efficiency and effectiveness:** care should be provided at reasonable societal costs. Resources invested should be result-oriented and there should be corresponding concrete quantifiable results. Efficiency considerations fuel the need to coordinate and integrate health systems so as to ensure the continuity of service delivery among different providers and different levels of care.
- **Accessibility and availability:** all levels of the health system should make care accessible to as many people as possible. The provision of care appropriate to the

resources available and levels of HIV prevalence need to be decided through local consensus building that involves the whole community. This requires regular review with all stakeholders.

- **Sustainability:** initiatives in provision of care and support will remain meaningful – and other principles of care and support will only be viable - where they are embedded in a sustainable programme of provision. This requires taking into account human, logistic and financial resource requirements.

4. KEY INTERVENTIONS FOR HIV/AIDS CARE AND SUPPORT

There exist several cost-effective HIV/AIDS care interventions for which evidence has been documented. Key activities for HIV/AIDS care and support are presented below in Table 1 and are grouped according to their complexity and cost. It should be noted that HIV testing of transfusion blood, the promotion of universal precautions, and health policy activities, such as the regulation of care delivery and the drugs supply, should be undertaken everywhere, and are thus also essential health sector activities.

Table 1 : Care and Support activities, according to need, complexity and cost	
Essential activities	<ul style="list-style-type: none"> • HIV voluntary counselling and testing • Psychosocial support for PLHA and their families • Palliative care and treatment for common OIs : pneumonia, oral thrush, vaginal candidiasis and pulmonary TB (DOTS) • Nutritional care • STI care and family planning services • Cotrimoxazole prophylaxis among HIV-infected people • Recognition and facilitation of community activities that mitigate the impact of HIV infection (including legal structures against stigma and discrimination)
Care and support activities of intermediate complexity and/or cost	<p>ALL THE ABOVE PLUS</p> <ul style="list-style-type: none"> • Active case finding (and treatment) for TB, including for smear negative and disseminated TB, among HIV-infected people • Preventive therapy for TB among HIV-infected people • Systemic antifungals for systemic mycosis (such as cryptococcosis) • Treatment of HIV-associated malignancies : Kaposi's sarcoma, lymphoma and cervical cancer • Treatment of extensive herpes • Prevention of mother to child transmission of HIV • Post exposure prophylaxis of occupational exposure to HIV and for rape • Funding of community efforts that reduce the impact of HIV infection
Care and support activities of high complexity and/or cost	<p>ALL THE ABOVE PLUS</p> <ul style="list-style-type: none"> • Triple antiretroviral therapy • Diagnosis and treatment of opportunistic infections that are difficult to diagnose and/or expensive to treat, such as atypical mycobacterial infections, cytomegalovirus infection, multiresistant TB, toxoplasmosis, etc • Advanced treatment of HIV related malignancies • Specific public services that reduce the economic and social impacts of HIV infection

It is a widespread belief that the majority of health care needs of PLHA can be addressed by ensuring access to medications, in particular antiretroviral therapy. However, this idea falls

short of effectively meeting their complete range of medical, emotional, social and economic needs. PLHA require comprehensive care and support, not just medicines.

For a care and support package for HIV to be comprehensive, it should include elements of voluntary counselling and testing for HIV infection, psychosocial support, home and community-based care, and clinical management (including medical, nursing and counselling care). Many of the activities in each of these areas straddle the divide between care and support, and prevention. This is one of the reasons why care and support to PLHA contribute to prevention. Major elements of care and support of PLHA are described below. Taken as a whole, each contributes to the development of an **enabling environment** which is essential for ensuring adequate levels of care, support, and prevention.

4. 1. Voluntary Counselling and Testing for HIV infection (VCT)

Voluntary counselling and testing (VCT) for HIV infection is an entry point for HIV/AIDS care and prevention. It has several benefits as figure 1 below show. It is therefore important that *voluntary counselling and testing* for HIV infection be made available on a much larger scale than today.

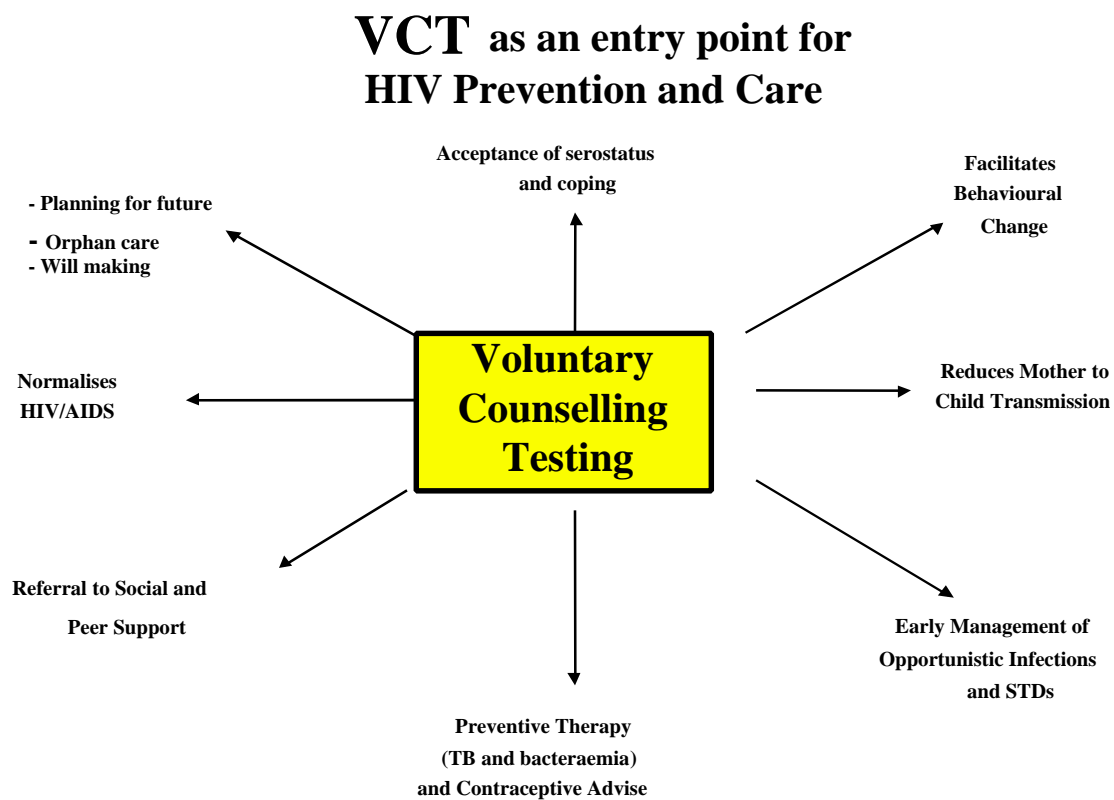
It needs to be emphasised that availability of testing alone is not enough: testing should be voluntary and confidential, and it should be accompanied by counselling. Counselling is important to prepare clients to come to terms of their HIV status: this includes dealing with fear, guilt, stigma, discrimination, care for a chronic condition, the possibility of early death, and to give them an understanding of what they can and should do about HIV infection, should they be HIV-infected. It is also important to help people devise or strengthen ways of staying HIV negative, if they test HIV negative⁴.

In order to be effective, the implementation of VCT services requires many key elements, including community awareness, education and mobilization to ensure those wishing to be tested understand what the test process is and where testing may be undertaken, and to ensure that those who are tested and found infected are not discriminated against and supported with their infection, the training of people (health, educational and other staff and volunteers) in minimum standards of counselling and psychological recognition, acute

⁴ Voluntary Counselling and Testing Technical Update (UNAIDS, 2000)

management and onward referral (and therefore the development of networks of services and resources for taking up onward referrals from counselling); the provision or development of support groups for those affected; the provision of physical facilities suitable for having private, confidential discussions, and monitoring and support for those doing the complex task of counselling^{5, 6}.

Figure 1: VCT is an entry point for HIV prevention and care



⁵ Voluntary counselling and testing for HIV infection in antenatal care: an implementation guide, WHO, 1999.

⁶ Tools for Evaluating Voluntery Counselling and Testing, (UNAIDS, 2000)

4.2 Psychosocial support

A key element in care and support is the provision of psychosocial support. Counselling, spiritual support, support to enable disclosure and risk reduction strategies, medication adherence, and end of life and bereavement support are all part of psychological support. This should be part of the care package at all levels. At its most basic level, this requires the establishment and support of peer-support groups for those found positive, and those affected by HIV. Many good examples of such services – which act as a focus for education, training, and provision of material, basic economic, spiritual and psychosocial support – currently exist in many countries. Those most affected often create such groups through a need for solidarity in the face of broader public stigma and discrimination. The greater involvement of people affected by HIV/AIDS (GIPA) is a vehicle for generation of psychosocial support in communities, and needs to be incorporated and encouraged in designs for care and support.

4.3. Home and community-based care

Home and community-based care means any form of care given to PLHA in their own home and community. It can be care activities that PLHA might do to take care of themselves or the care given by their relatives, friends or health workers within their homes and communities. HIV/AIDS being a chronic condition, it is essential to recognize that PLHA do not always require to be hospitalized and care within their families might be more appropriate at some stage of their disease. Discharging PLHA back to their communities at an early stage or not admitting the person in the first place can be more appropriate provided that the individual's needs can be addressed outside the institution⁷. There will be times that person will need to consult the health professionals for follow up but most of the time, PLHA are well taken care in their homes, their families and communities. Home and community care is thus an essential element of comprehensive care for PLHA in a continuum of care from health institutions to homes and vice versa. For those facing a future of uncertainty and who are fearful of possible consequences of having their status disclosed to others because of stigma and discrimination associated with HIV/AIDS^{8,9}, and for those living far from care and treatment facilities, or without the means to obtain transport to medical and psychosocial support services, provision of care in the home and community

⁷ Sexual Health and Health Care: Care and Support for people with HIV/AIDS in resources poor settings, DFID, 1998

⁸ VCT Outcomes, UNAIDS, 2000

⁹ Opening up the HIV/AIDS Epidemic, UNAIDS, 2000

based care is critically important. Such provision requires community-level organisation, training and support to ensure services are being appropriately implemented and used¹⁰. Nursing care and support to nursing activities in home-based care and elsewhere must be encouraged¹¹.

4.4. Medical management

4.4.1. Diagnosis and treatment of HIV-related diseases

Worldwide, the main burden of disease in PLHA arises from a limited number of common infections – and their complications – to which PLHA are particularly susceptible, namely tuberculosis (TB), pneumonia, diarrhoea, and candida infection of the mouth and throat¹². Diagnosis of these infections is usually possible at health centres and district hospitals, and they are generally amenable to successful treatment with cheap, affordable and effective antibiotics^{13, 14}. Strengthening of the general health services is crucial to ensuring that PLHA have access to care for common HIV-related diseases.

TB is worldwide the single biggest killer of PLHA, yet a course of TB treatment costs as little as US\$20. In addition to strengthening national TB programmes and harnessing community contributions to ensure that every PLHA with TB has access to effective TB care, increased collaboration is necessary between TB and HIV programmes to provide a coherent response to the dual TB/HIV epidemic^{15, 16, 17}.

In addition to these common HIV-related diseases, there is a variety of HIV-related infections and cancers for which treatments are more expensive and, in many parts of the world, not widely available. These HIV-related infections include toxoplasmosis, cryptococcosis, pneumocystis carinii pneumonia, herpes simplex virus, cytomegalovirus and atypical mycobacteria. HIV-related cancers include Kaposi's sarcoma and lymphoma.

¹⁰ AIDS Home Care handbook, WHO/GPA, 1993

¹¹ Nursing Fact sheets in HIV/AIDS, WHO/UNAIDS, 2000

¹² Technical Update on Opportunistic Infections (UNAIDS _____)

¹³ Guidelines on Treatment of Opportunistic Infections (WHO/EDM _____)

¹⁴ WHO model prescribing information on essential drugs used in the treatment of HIV infection and STDs)

¹⁵ TB/HIV: A Clinical Manual (WHO/TB/96.200)

¹⁶ Treatment of Tuberculosis: Guidelines for National Programmes, 2nd Edn, 1997. (WHO/TB/97.220)

¹⁷ TB and HIV: The Dual Epidemic. (UNAIDS PoV_____).

4.4.2. Ensure adequate nutritional advice to PLHA

As denutrition is an important feature of advanced HIV infection, it is important to prevent it. This requires nutritional assessment, nutritional counselling and education that includes food safety, and, if possible, the development of a plan of action to prevent weight and muscle mass loss. With some drugs dietary changes are also needed to prevent side effects and specific symptoms. In some cases provision of nutritional supplements, and the use of anabolic steroids may be useful to prevent or treat wasting. More information on HIV infection and nutrition is found in the UN Secretariat Committee on Nutrition Newsletter, 1998¹⁸.

4.4.3. Palliative care

Palliative care not only includes the management of physical symptoms, such as pain, cough, skin rashes, fever, diarrhoea, but also dealing with depression, suicidal thoughts, and other psychological problems. It also comprises spiritual support, and bereavement counselling, and is inclusive of the client and his environment. It often requires a multidisciplinary approach.

More on palliative care can be found in the UNAIDS Technical Update on Palliative Care¹⁹.

4.4.4. Prevention of HIV-related diseases.

Fortunately, affordable and effective drugs are available to prevent many of the common HIV-related diseases responsible for the main burden of illness and death in high HIV prevalence countries. Isoniazid is effective in preventing reactivation of latent TB²⁰ and cotrimoxazole is effective in protecting against many of the common pathogens (such as pneumococcus and salmonella) responsible for pneumonia and diarrhoea and their complications²¹. The challenge remains to find ways of dramatically increasing access of PLHA to preventive treatments.

4.4.5 Antiretroviral treatment

While antiretroviral therapy is expensive, it should be recognized that it also represents the present gold standard for the treatment of HIV infection. Regardless of whether

¹⁸ UN Secretariat Committee on Nutrition Newsletter, 1998, Volume...

¹⁹ UNAIDS Technical Update on Palliative care,

²⁰ Preventive therapy against tuberculosis in people living with HIV. Policy Statement. Weekly Epidemiological Record 1999; 74: 385-400

²¹ Provisional recommendations on the use of cotrimoxazole in Africa.

governments can afford to subsidize their availability to the general public, there is the need to regulate their use to protect their future usefulness. Also, rather than refusing to deal with these drugs for fear of having to fund them, governments should consider regulating their use and facilitating access to them by supporting human resource development and treatment monitoring infrastructures for antiretroviral therapy, so as to build capacity in the health system to safely and effectively use these drugs^{22, 23}. In countries where resources are more plentiful, there is in addition a strong case to subsidise their use.

4.4.6 Family planning

Family planning is important for PLHA as part of an adjustment strategy that aims to guarantee or improve a future of their family, including their spouses and children. Limiting family size might also enable them to have saved enough to contribute to the cost of their treatment, where such treatment needs to be totally or partly privately funded. It also has a role in the prevention of mother to child transmission²⁴.

4.4.7. Promotion of safe sex and condom use to clients in HIV care and support programmes

In the care of HIV infected people the focus is often on drugs, results of viral load tests and CD4 counts, and possible toxicity of the treatments received. Contacts with health services should be used to support preventive behaviour and to promote safe sex or condom use.

When doctors perform poorly in this area, the services should be organized in such a manner that HIV-infected people get referred to counsellors or services that avail these services to them^{25, 26, 27}.

4.4.8. Diagnosis and treatment of STIs

Diagnosis and treatment of STIs are important not only to prevent HIV but also to prevent complications from STIs. STIs increase HIV transmission, with a factor of 2 to 40. When an STI is treated, this enhancement of HIV transmission disappears. In addition to considerations about the cost-effectiveness of STI intervention, the potential to prevent HIV infection explains why WHO and UNAIDS vigorously promote STI control.

²² Guidance Modules on antiretroviral Treatment , WHO and UNAIDS, 1998

²³ Safe and effective use of antiretroviral in resource-constrained settings, WHO/UNAIDS, 2000.

²⁴ RELEVANT FAMILY PLANNING REFERENCES

²⁵ RELEVANT REFERENCES ON MALE AND FEMALE CONDOM USE

²⁶ Sex and Youth: contextual factors affecting risk for HIV/AIDS, UNAIDS, 1999

²⁷ RELEVANT REFERENCES ON ADOLESCENT HEALTH AND HIV/AIDS

Where STI control is insufficient, it would make sense to strengthen it first in services where known HIV infected people consult. Indeed, targeting PLHA with enhanced STI treatment services has significant benefit beyond that individual: chances of HIV transmission to sexual partners are reduced. Practical information on STI control can be found in various publications^{28, 29, 30, 31, 32}.

4.4.9. Intervention to reduce mother to child transmission of HIV

1.2 million children under the age of 15 years are infected with HIV now, and a cumulative total of 3.6 million children have already died of AIDS since the beginning of the epidemic. Mother to child transmission (MTCT) is responsible for more than 90% of these infections. Strategies to reduce mother to child transmission of HIV infection include primary prevention of HIV infection among women, family planning, antiretroviral therapy, restricted use of invasive obstetric procedures during vaginal delivery, and replacement feeding for the infant.

In the field, pilot programmes on prevention of MTCT are being undertaken. Their monitoring and evaluation will provide many lessons in taking the MTCT experiences to a larger scale. So far, it is known that MTCT prevention has to face many challenges: the weakness of antenatal care infrastructures and services in many developing countries, lack of awareness of HIV transmission and personal HIV infection in many pregnant women, reluctance to engage in VCT for HIV, relatively weak compliance in taking ARV and dilemmas in maintaining infant feeding options.

The UNAIDS technical update on mother to child transmission of HIV provides an overview and strategic guidance for the implementation of interventions to prevent mother to child transmission of HIV³³.

²⁸ Consultation on STD interventions for preventing HIV: what is the evidence?, WHO/UNAIDS, Geneva 2000

²⁹ Management of sexually transmitted diseases, WHO/GPA 1994

³⁰ Guidelines for Sexually Transmitted infections Surveillance, WHO/UNAIDS, 1999.

³¹ The public health approach to STD control, UNAIDS Technical Update, 1998.

³² Sexually transmitted diseases: policies and principles for prevention and care, WHO/UNAIDS, 1997.

³³ CITE REFERENCE

4.4.10. Post exposure prophylaxis of HIV infection for occupational exposure to HIV and for rape victims

Interventions to reduce HIV transmission in the health care setting include the use of universal precautions when handling potentially infected material, e.g. wound care and surgical procedures, and ensuring the safety of blood and blood products. While the use of universal precautions is clearly more cost-effective than that of antiretroviral therapy after an occupational exposure to HIV (or possible exposure to HIV through rape), post-exposure prophylaxis of HIV infection is also among the interventions to be considered here³⁴.

4.5. Behavioral issues in HIV/AIDS care and support

- **Avoid stigma and discriminatory attitudes:** Improving access to HIV/AIDS care and support requires conducive behaviour. Health professionals, relatives and friends should avoid stigma or discrimination against PLHA: stigma and discrimination constitute obstacles to care service development and use, and may jeopardise access to care, openness, adherence to treatment and the whole quality of care.
- **Management of drug addicted people and vulnerable groups:** when present, drug addiction can greatly complicate the clinical management of HIV infection. Continued IV drug use might also put others at risk of becoming infected, in particular when needles are shared or when drug users resort to sex work to finance their habit. For both the individual client and society it is therefore important that care and support services take into account the management of drug addiction in HIV infected clients. Care provision should be an opportunity to explain and recommend to the clients, particularly vulnerable groups (e.g. youth, sex workers, mobile and migrant groups, intravenous drug users, men having sex with men) cost-effective HIV prevention methods that could be used to protect themselves and their entourage.
- **Social and legal support:** community involvement and household assistance to mitigate the impact of HIV/AIDS are examples of social support. Providing food support, volunteers for daily duties, orphan support, PLHA peer support, welfare services, and legal support are also part of social support and should be part of a comprehensive care and support package.

³⁴ 'Title of relevant publication on universal precautions, WHO, 1993'

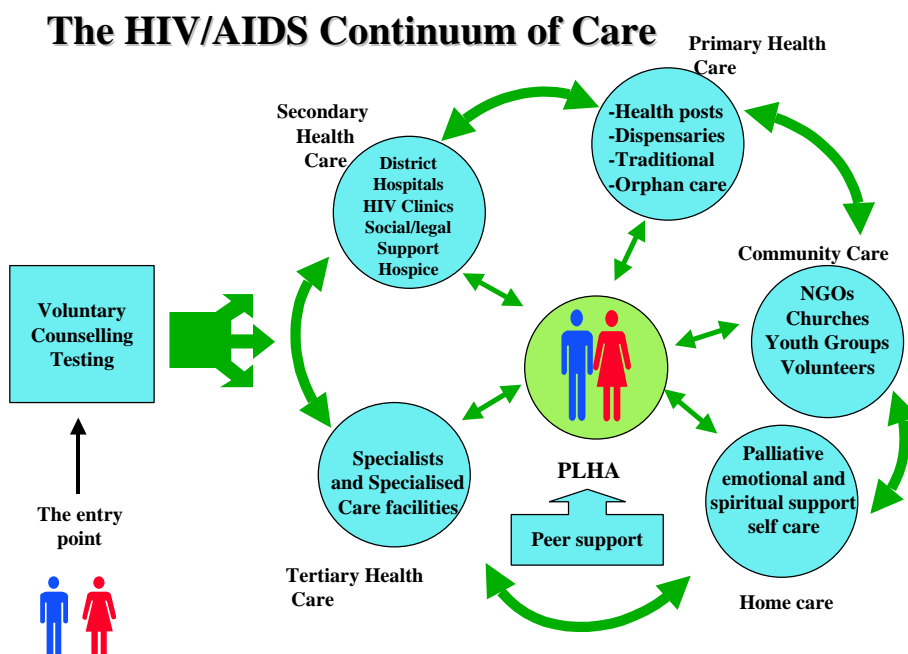
'The safe and effective use of antiretrovirals in resource constrained settings'.

STRUCTURAL ELEMENTS FOR SERVICE DELIVERY

5.1. Identification of actors of comprehensive care and support for PLHA

The provision of comprehensive HIV care and support requires the inputs of many people, ranging from family members to nurses and doctors, and from community workers to psychologists. These people can be grouped according to their affinity with, and access to training in, different care and support activities. There will be people involved more in clinical care, usually the formal health sector where health professionals offer relief of symptoms and diagnosis and treatment of specific diseases and psychosocial problems, and those more obviously involved in social support provided by community based organisations, counsellors or support groups, and social sector organisations.

Figure 2: Care and support continuum



5.2 Human resource development.

The response to HIV/AIDS requires additional skills and approaches that may not have been characteristic of the health system. This includes not only skills for effective clinical management of PLHA but also counselling and psycho-social support skills. These skills are now essential for the response and need to be developed because of the particular PLHA care requirements. There is need to develop human resource management strategies that take into account the impact of the epidemic on the health system as discussed earlier: basic training as well as continuing education will be necessary to produce qualified health personnel in sufficient numbers to cope with the epidemics.

5.3 Guidelines and training.

National guidelines need to be updated or developed on all essential and enhanced elements of comprehensive care. Curriculum revision of existing basic health cadres training from nursing aides to medical specialist training needs to be undertaken. In service training on new interventions such as counselling or ARV management needs to be strengthened. Existing guidance from the global level needs to be widely distributed.

5.4. Strengthening the links among various channels of comprehensive care

To improve the efficiency of service delivery, it is necessary that these people, and the services in which they work, collaborate together, so as to create a continuum service, as depicted in Figure 2. The concept of care across a continuum expresses the need for care through all stages of HIV infection, which should be accessible at several points along a continuum from VCT services, health services (primary health care (PHC), secondary and tertiary health care) and social services to community-based support and home care^{35, 36, 37},

³⁵ HIV/AIDS care and support for persons living with HIV/AIDS, USAID discussion paper, 1999

³⁶ Model of care for patients with HIV/AIDS, Osborne, van Praag and Jakson.

³⁷ The international Newsletter on AIDS prevention and care. AIDS Action. January –March 1999.

³⁸, ³⁹. An important feature of the concept is the explicit recognition that community based activities play a vital role, not only for HIV care and support, but also for HIV prevention, and a formal recognition of the links between care and prevention. Depending on the needs of the patients, they are provided care at PHC level, or secondary or tertiary level of health services. The health services may refer the patients to the community-based care organisations that in their turn refer the patients to health care services when necessary. Thus, the system needs to strengthen the referral system between different levels of health services and between health services and community based care.

5.5 Infrastructure development

Health care services should be established where necessary. VCT services and laboratories need to be established and adequately staffed and equipped. Where advanced ARV treatment is given, there is need for basic facilities to monitor the side effects (toxicity) of the drugs and to measure the efficacy of the treatment by CD cell counts and viral loads.

5.6. Drugs and medical supplies (commodities, condoms, reagents, needles and syringes, surgical equipment and supplies, gloves, etc.): having human resources and infrastructure is not enough to provide good quality health care. Another important ingredient that the government should secure is drugs and medical supplies. Most people living with HIV/AIDS have very limited access to essential medicines. Essential medicines for HIV/AIDS include established essential drugs (for pneumonia, TB, diarrhoea, candida, palliative care, STI treatment), drugs to prevent mother-to-child transmission, and newer high-cost drugs (for opportunistic infections, HIV-related cancers, and highly active antiretroviral therapy – HAART). In order to increase access to drugs and medical supplies, four strategies are suggested⁴⁰:

³⁸ HIV/AIDS care in Uganda, MOH, March 2000.

³⁹ Enhancing care initiative, Harvard School of Public Health, 1999 Report.

⁴⁰ The UN strategy for increasing access to HIV-related drugs, ITT on access to drugs, 2000.

1. **Rational selection and use** - Drugs of choice are identified for specific priority indications based on best evidence on local morbidity patterns and drug efficacy, safety, quality, and cost-effectiveness.
2. **Affordable prices** – “Best prices” for governments, NGOs and people living with AIDS will be sought through better price information, negotiation, competition, and reduction of duties, taxes, and distribution costs.
3. **Sustainable financing** – There will be strong advocacy for reallocation of government resources to HIV/AIDS care (taking from outside health sector, not from HIV prevention or other priority health problems) and expansion of external financing.
4. **Reliable health care services** – Effective use of new HIV-related drugs and prevention of resistance depends on the ability of health care services to diagnose HIV infection, to diagnose associated illnesses and adequately to monitor treatment

5.7. Financing : advocacy programmes to get resources mobilised at national and international levels for care should be developed. Financing of health systems for effective response to HIV/AIDS must achieve two things. First there must be an overall increase in the amount of funds available in health systems. This is because the magnitude of the HIV/AIDS problem requires a lot more resources to deal with than what is available in most countries. HIV/AIDS increases the cost of providing health care. The second goal must be to implement measures that offer protection to people living with HIV/AIDS and their families from financial ruin or reduced access to health services as a result of increased cost of health care.

5.8 Reorganisation of service delivery and partnership: the above-mentioned inputs need to be well planned, equitably distributed and effectively implemented. Supervision, monitoring and evaluation of the services should be ensured. Comprehensive care for PLHA

should be accessible at all levels along a continuum ranging from formal health and social services to community based services and home care. Partnerships between communities and institutions within a catchment area should be developed in such a way that an effective referral system between VCT services, basic hospitals and health centres, and home care services is strengthened. Hospitals, NGOs, and CBOs should ensure complementarity and discharge planning across the continuum. In view of the large number of actors (stakeholders and partners), there is a need for synergy through effective collaboration among different actors or centres on the continuum of care. There is also a need to harmonise the inputs of different partners so that efforts are complementary and relevant to priority PLHA care and support needs. This synergy is essential for improving the effectiveness of different levels and actors within the continuum of care.

5.9. Other factors to take into account in the reorganisation:

- Essential care delivery needs not only trained staff but also a **conducive working environment**. This would include: space, privacy and staff time for VCT in general health services and for particular groups such as young people, antenatal services; operational procedures for patient care, for referrals to home care or enhanced care to ensure a care continuum and for universal precautions, and monitoring of coping capacity and adherence to standards to be put in place.
- **Care for the carers**, including activities to prevent burn-out of staff and access to post exposure prophylaxis at the institutional level, VCT services for health staff, antiretroviral treatment and institutional policies for HIV infected staff.
- **Universal precautions and safe blood supplies**. Institutional policies for infectious disease control should be developed or updated. These include institutional procedures for the rational prescription of blood transfusions. Order and distribution procedures for HIV test kits, gloves, blood collection equipment and sterilisation facilities.

5.10. Facilitating community mobilisation and action

Health services have been traditionally perceived as possessing the knowledge, expertise and means to make people healthy. However, this has often led to complete dependency of people on health services and diminished the autonomy of individuals to safeguard their health. Therefore, when health systems experience difficulties or fail to perform well, health outcomes decline significantly. Therefore the people's responsiveness is as important as the services. Individuals and their behaviour -- sexual relationships, eating habits, substance abuse, or drug compliance -- determine the effectiveness of the intervention.

Health systems ought to aim at empowering individuals and communities to identify health challenges and take measures to promote and protect their health and prevent disease. One way of empowering individuals and communities is by providing appropriate, practical and timely information. The participation of communities and affected individuals is considered essential for a responsive campaign. The more the users participate the more the services may be made more responsive to the expectations of the people. Broader participation also ensures that there is a multiplicity of efforts and skills that are needed for the scale and complexity of the epidemic. Partnerships need to be developed between health services and communities through mutual influences and support.

5.11. Policy development and legislation: several relevant policies and regulations need to be formulated: e.g., HIV testing policies for diagnostic and clinical purposes at national and institutional level, including professional codes need to be reassessed to ensure confidentiality and disclosure policies of HIV testing and result provision, prevention of discrimination and stigma against PLHA in health settings; formalization of counselling as a duty or occupation; formulation of HIV care policies and national standards of essential and

comprehensive HIV care; policies on collaboration between private and public sector and with NGO/CBOs to ensure care provision and referrals across a continuum from institution to home. National drug policies and essential drug lists should be updated to reflect the needs for HIV care. Regulation and standardization of use of relevant HIV treatments (e.g. antiretroviral treatments at accredited sites, for MTCT and post exposure prophylaxis, preventive therapies. Policies to protect the rights of people living with HIV/AIDS need to be developed, promoted and implemented.

5.12. Monitoring and evaluation

HIV/AIDS comprehensive care programs must include a monitoring and evaluation component to refine, adapt and strengthen existing and new services and should be budgeted for and implemented in all HIV/AIDS comprehensive care programs. 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, analyse 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, including participatory assessments and evaluation involving communities.

This implies developing indicators and measurement tools appropriate to compare the quality, extent and coverage of care services at each level with needs, demands and set standards and norms. It also implies that monitoring and evaluation systems must be designed to respond to questions that are relevant for decision-making purposes. More information on HIV/AIDS monitoring and evaluation can be found in the guide to monitoring and evaluation of national AIDS Programme⁴¹.

⁴¹ National AIDS Programmes: A guide to monitoring and evaluation, UNAIDS, WHO, MEASURE, etc. 2000.

6. PRIORITISATION

As resources are never sufficient to satisfy the needs of all, resource allocation is a key activity in public decision making, also in HIV care. WHO and UNAIDS advocate that in care and support resources be allocated taking into account the principles of respect, equity, quality of services, efficiency and effectiveness, accessibility and availability, and sustainability so as to make services available and accessible to as many people as possible. In order to protect the rights of the poor, it is also important to define what services should be considered as first priority and which services of intermediate or high complexity and cost could be considered when more resources are available. Table 1 attempts to do this.

As Table 1 shows, there are three levels of HIV/AIDS care and support interventions on the basis of their complexity and cost. Ideally, all components should be provided within the health system. According to resources available in a setting, the focus might be on the provision of essential (basic) care interventions (Type 1 settings) or on the provision of intermediate cost/complexity care interventions (Type 2 settings) or on the provision of more advanced and highly complex care interventions (Type 3 settings). One might think about a gradual dynamic progress with the ultimate goal of obtaining the standard of care in type 3 settings accessible and available to all PLHA. But in real life of most countries, it is seen that both essential and more complex and costly elements of HIV/AIDS care and support co-exist. For instance antiretroviral drugs (ARVs) are found in most countries, but only for very limited number of patients and in a few clinics in resource-constrained settings. Whenever more resources (human, technical and financial) are available, HIV/AIDS care and support can be scaled up to increase coverage and/or additional elements of care can be considered. The process of enhancing HIV care and support is seen not to be a static “process” but an evolving, dynamic process in which new HIV care elements can be added or integrated depending on the amount of human and financial resources available. Each country may consider a different set of enhanced care elements, that could change over time and place depending on socioeconomic conditions.

While different health sector activities differ in their complexity and cost, it is clear that essential (basic) and complex and high cost services co-exist in all health systems. When essential services don't cover the majority of their target population some would argue that these essential services must be improved before one can even think of public funding or

other public support for more complex and high cost services. It is suggested that the strategic planning approach be used, with the objective to make progress where possible, by choosing from Annex 1 the activities which could be implemented in effective and sustainable way. The process of making the choice and the formulation of a strategic plan⁴² to enhance care and support should involve all stakeholders in HIV care, including NGOs and PLHA groups. The outcome of the exercise should be a community consensus about the future content of the local care and support package, about how service delivery will be optimised, and about how different components will be financed.


WHO/PAHO has also developed a model of prioritisation of care options in relation to resource availability. The advantage of this model is that it covers not only the health sector but also the community and home based care activities⁴³. WHO/SEARO has developed a concept of care which suggests a step-by-step approach in the implementation of HIV/AIDS care activities⁴⁴.

⁴² Guide to strategic planning process for a national response to HIV/AIDS, UNAIDS, 1999.

⁴³ Building Blocks: Guidelines for providing comprehensive care to persons living with HIV/AIDS in the Americas, WHO/PAHO, 1999.

⁴⁴ Planning and implementing HIV/AIDS care programmes: a step-by-step approach, December 1998

Annex 1: Comprehensive HIV/AIDS Care and Support activities by level of service delivery.

 Level of Health System	COMMUNITY LEVEL	<ul style="list-style-type: none"> • Day care centers
		<ul style="list-style-type: none"> • Financial support • Legal representation • Management of drug banks • Provision of sterile needles • Hospice care • Bereavement and funeral support
		<ul style="list-style-type: none"> • Emotional support and counselling • Community information, education, communication (IEC) and participation • Personal accompaniment • Support groups • Nutritional assessment, counseling and food safety • Food kitchens and programs • Multidisciplinary health practices • Condoms and bleach • Access to family planning methods • Advocacy • Assistance to orphaned children
	HOME CARE LEVEL	<ul style="list-style-type: none"> • Formal sharing of experience and networking
		<ul style="list-style-type: none"> • Adherence to medications and complementary measures
		<ul style="list-style-type: none"> • Universal precautions • Safer sex activities, including family planning • Personal and environmental hygiene practices • Nutrition and food safety measures • Knowledge about when and where to seek additional support

Annex 1: Comprehensive HIV/AIDS Care and Support activities by level of service delivery (cont'd)

Level of Health System

TERTIARY LEVEL	<ul style="list-style-type: none"> • Use of steroids and other hormones • Elective surgery • Management of anxiety and depression • ARVs for HAART • Antitumoral treatments • Management of chronic pain • Management of anal and procto-colonic syndromes • Parenteral nutrition • Post-exposure prophylaxis (PEP) among health providers
	<ul style="list-style-type: none"> • Treatment of toxoplasmosis, PCP and other relevant OIs • Management of complex manifestations of HIV
	<ul style="list-style-type: none"> • ARVs for HAART
	<ul style="list-style-type: none"> • Screening, prophylaxis and treatment of toxoplasmosis and PCP • Nutritional interventions, including anabolic steroids • ARVs for selected patients • Management of sexual functions
SECONDARY LEVEL	<ul style="list-style-type: none"> • Counseling for secondary prevention • Screening, prophylaxis and treatment of TB • Prophylaxis of PCP • Confirmatory diagnosis of HIV infection and related conditions • ARVs to prevent MTCT • Breast milk substitutes/alternatives to breast-feeding • Vaccination against tetanus and HBV • Access to safe blood and derivatives*
	<ul style="list-style-type: none"> • Clinical and laboratory monitoring of progression of disease
	<ul style="list-style-type: none"> • Flu vaccination • Prophylaxis/treatment of TB, toxoplasmosis and 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
PRIMARY LEVEL	<ul style="list-style-type: none"> • Voluntary and confidential counseling and testing • Management of pain, malaise and fever • Education on personal and environmental hygiene, universal precautions, safer sex and family planning • Nutritional assessment, counseling and food safety • Syndromic management of STIs • Clinical diagnosis of HIV-related diseases • Vaccination against tetanus

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