

IMPROVING ACCESS TO

ANTI-RETROVIRAL TREATMENT IN CAMBODIA



ANTI-RETRO



Acknowledgements

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The Khmer HIV/AIDS NGO Alliance (KHANA) is a national non-governmental organisation (NGO) that provides financial and technical support to local NGOs and community-based organisations (CBOs) in Cambodia to respond effectively to HIV/AIDS. KHANA was established as a project of the International HIV/AIDS Alliance in 1996 and registered as a NGO in 1999. KHANA's mission is to:

- contribute to a reduction in vulnerability to HIV/STIs and the impact of AIDS by strengthening the capacity of the NGO/CBO sector to develop appropriate, effective and sustainable responses to HIV/AIDS and STIs.

KHANA's NGO partners provide care and support for people with HIV and their families, implement focused HIV prevention activities, and carry out advocacy activities to challenge stigma and improve the lives of people with HIV.

The International HIV/AIDS Alliance (Alliance) is an international NGO that supports community action on HIV/AIDS in developing countries. The Alliance aims to:

- make a significant contribution to HIV/AIDS prevention, care and support to people living with HIV/AIDS and children affected by the epidemic, by working together with communities in developing countries;
- promote the sustainability and scaling-up of effective community AIDS efforts, by building the capacity of CBOs, NGOs and NGO support programmes;
- influence and improve HIV/AIDS policies and programmes of international agencies, donors and the international NGO sector, with particular emphasis on the role of community action.

The International HIV/AIDS Alliance is committed to working with its partners to meet the interim target set in the UN Declaration of Commitment on HIV/AIDS, to ensure that 3 million people in resource limited settings are receiving ARV treatment by 2005.

Table of Contents

Abbreviations	1
Chheng Hong Ky's Story	2
Executive Summary	3
1 Aim of the Assessment	5
2 Methodology	6
3 Policy Environment in Cambodia	7
Generic drug use	7
Essential medicines list	8
Global Fund for HIV/AIDS, Tuberculosis and Malaria	8
4 Access to Health Care in Cambodia	9
5 Current Range of Services	10
Voluntary counselling and testing	10
Laboratory services	11
Prevention of mother to child transmission	11
Tuberculosis	12
Opportunistic infections	13
STI treatment	13
Post-exposure prophylaxis	14
Home-based care	14
Support groups of people with HIV	16
Prevention for/by/with people with HIV	17
6 Anti-retroviral Treatment	19
Current approaches to delivery of ARV treatment	20
Protocols for ARV treatment	22
Knowledge about ARV treatment	23
Issues of access	24
Stigma, discrimination and ARV treatment	26
Barriers to accessing ARV treatment	27
Moving beyond pilot programmes	28
Approaches for delivering ARV treatment	28
7 Conclusion	31
8 Recommendations	32
9 Annexes	35
Annex 1: Key informants	35
Annex 2: Current sources of ARV treatment	36
Annex 3: Fact Sheet: Anti-retroviral drugs	37

Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Clinic
ARV	Anti-retroviral
AZT	Zidovudine
CD4	CD4 T-cell count
CPN+	Cambodian People Living with HIV/AIDS Network
CPU	Cambodia Prostitutes Union
D4T	Stavudine
DDI	Didanosine
DOTS	Directly Observed Treatment - short course
FHI	Family Health International
GFATM	Global Fund to fight AIDS, Tuberculosis, and Malaria
GPO	Government Pharmaceutical Organisation
HBC	Home-Based Care
HIV	Human Immuno-deficiency Virus
IDA	Indra Devi Association
IEC	Information, Education, and Communication
KHANA	Khmer HIV/AIDS NGO Alliance
MDM	Medecins Du Monde
MOH	Ministry of Health
MSF	Medecins Sans Frontieres
MSM	Men who have Sex with Men
NAA	National AIDS Authority
NCHADS	National Centre for HIV/AIDS, Dermatology, and STDs
NGO	Non-Governmental Organisation
NMCHC	National Maternal and Child Health Centre
NRTI	Nucleoside Reverse Transcriptase Inhibitor
OI	Opportunistic Infection
PCP	Pneumocystis Carinii Pneumonia
PEP	Post-Exposure Prophylaxis
PLHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
PSF	Pharmaciens Sans Frontieres
RHAC	Reproductive Health Association of Cambodia
RACHA	Reproductive and Child Health Alliance
TB	Tuberculosis
TLC	Total Lymphocyte Count
TRIPS	Trade Related Intellectual Property Rights
STI	Sexually Transmitted Infection
VC	Vithey Chivit
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

Chheng Hong Ky's Story

Chheng Hong Ky's Story

Chheng Hong Ky is a 46 year-old widow who lives in Takeo province. She has four children aged 24, 17, 14 and 9. Her youngest child is HIV positive. Chheng Hong has sent her youngest child to an orphanage in Phnom Penh in the hope that they will be able to provide care and treatment for the child - care and treatment she cannot afford to provide. Her husband died in an accident in 1998, and soon afterwards she started to become sick. Her brother took her to Kompong Speu province for treatment, where he asked a lab to test her blood for HIV. He did not tell her about her positive test result. Chheng Hong's brother told her to take traditional medicines. She continued to be sick and was unable to work.

Chheng Hong and her children experienced stigma and discrimination from her family and the community. Her nephews and nieces were not allowed to play with her children. Chheng Hong used to make cakes and sell fish in the market, but when people suspected that she had HIV/AIDS, they stopped buying from her. In 1999, Chheng Hong met a woman who was working on HIV/AIDS. This woman encouraged Chheng Hong to meet people working with the Japanese Red Cross in Phnom Penh, where she was referred for an HIV test. She now benefits from home-based care, supported by Partners in Compassion (PC), a KHANA partner NGO in Takeo province. The home care team's visits have helped her family and community to understand more about HIV/AIDS and to reduce some of the stigma and discrimination.

Over a year ago, Chheng Hong began receiving ARV treatment from the MSF-France clinic at Sihanouk and Russian Hospital in Phnom Penh. As she is too poor to pay, Chheng Hong receives free ARV treatment. Every month she travels from her home in a rural area of Takeo province to Phnom Penh for her follow up visit, where she receives her monthly supply of ARVs. She receives an extra day or two's supply in case she is unable to make it to her appointment. Chheng Hong has sold much of her land to meet the costs of her health care, including costs for transportation.

Being on ARV treatment has changed her life. Chheng Hong thinks that ARV treatment is very effective. She is no longer sick all the time and her weight has increased from 33 kg to 45 kg. She feels happier and is able to work better. Chheng Hong takes her medicines twice a day - morning and evening. Her brother and sister have a clock and they remind her to take her medicines on time. She also listens for the time on her radio. The home care team helps her a little with her treatment but they do not have enough knowledge and experience with ARV treatment. Chheng Hong's family knows that she is on ARV treatment but people in the community do not know about it. Chheng Hong says that some people no longer believe she has HIV/AIDS, because she no longer looks sick. Chheng Hong thinks that if she told people in the community about her experience with ARV treatment, it would help to reduce stigma and discrimination because they would see that HIV/AIDS does not necessarily lead to illness and death.

Executive Summary

Executive Summary

Cambodia is often cited as an example of how an effective multi-sectoral response to HIV, with strong political commitment and effective co-operation between government, non-governmental organisations (NGOs), and international organisations, can impact on the spread of infection. Cambodia has an HIV/AIDS prevalence of 2.6% in the adult population (15-49 years). Government data indicates that HIV prevalence rates in some of the populations under surveillance appear to be declining. However, the current data indicates that HIV/AIDS is not uniformly distributed throughout the country and numbers of cases of AIDS and AIDS-related deaths continue to increase¹.

Many of the elements of an effective response to HIV/AIDS are already in place in many areas, and home-based care, voluntary counselling and testing (VCT) services, and management of opportunistic infections (OI) are slowly coming to scale in the provinces. While over 80% of the population are rural, large-scale efforts at prevention and care remain concentrated in Phnom Penh and a few provincial capitals.

Globally, anti-retrovirals (ARVs) have proven to be the most effective treatment for prolonging life and improving the quality of life of people with HIV. Treatment of OIs and ARV treatment, is generally only available in a handful of NGO-supported hospitals, and efforts to scale-up access to care and treatment are in their infancy. Despite the limited provision, awareness of the value of ARVs has increased greatly and the majority of people with HIV in home care groups are now calling for them². This has led to increased numbers of patients buying drugs through the private sector. Lack of regulation in the private sector, high cost of the drugs, and risk of poor quality or fake drugs, suggest that many patients may derive little benefit from this - prejudicing future chances of treatment through development of resistance and impoverishing themselves in the process.

Care of opportunistic infections and use of ARVs have largely been hospital or clinic-based. Home-based care and the increasing activism of people with HIV represent an opportunity for the development of community-based approaches for improving access to ARV treatment. Such systems, along with simplified treatment and follow-up regimes, will help reduce the workload on hospital and clinic staff, and will be essential if treatment is to become available in rural areas and away from specialist centres. People with HIV are not just the passive recipients of treatment and they have an important role to play in the safe and effective delivery and use of ARVs. This depends on having the essential resources of information, knowledge, skills and materials (medicines and diagnostic supplies) that are both available and accessible to meet the needs as they arise.

The increasing recognition of the importance of treatment in the HIV/AIDS response raises the possibility of developing a truly comprehensive approach in Cambodia. Development of comprehensive models of HIV/AIDS care, treatment and prevention may be of particular importance to the future of care for other chronic diseases such as cancer and diabetes. For these goals to be achieved and for public confidence in the health system to increase, it is

¹ National Centre for HIV/AIDS, Dermatology and STDs: HIV Sentinel Surveillance Report, 2002.

² Statement of CPN+ to Secretarial Committee, 2nd National AIDS Conference, Cambodia, October 2002.

vital that financial and political resources mobilised to combat HIV/AIDS are integrated with, and contribute to, a drive for improvements in health care provision generally. Activism (i.e. advocacy, pilot projects etc.) aimed at increasing access to ARVs has resulted in the provision of ARVs in Cambodia becoming more of a reality. The challenge now will be how to make ARV treatment more accessible and to deliver the treatment to people in a safe and effective manner. This will depend on different people doing different things in a co-ordinated way to provide support for individuals and families who are involved in ARV treatment.

It is clear that, in order for the community (including people with HIV) to realise their potential as a valuable resource for ARV treatment, people need information and education, as well as effective clinical care and social support. The development of AIDS-competent and ARV-competent communities in Cambodia requires considerable inputs of training, information and ongoing support to make them effective. Patients and their supporters - for example, families, health care workers and communities - have an active role to play in ARV treatment. If ARV treatment is successful, it will be accepted and used well. If not, people will lose hope and continue to struggle with the already heavy burden of illness, deaths and loss of social and economic support. Safe and effective ARV treatment and community preparedness will form two sides of the same coin of improved health for people affected by HIV in Cambodia.

This report, building on the strengths of KHANA and its partners, focuses on the current and future opportunities for KHANA, and other NGOs, to support access to ARV treatment for people with HIV. Recommendations are given with regard to use of existing sources of ARV, sources for increasing availability of ARV, and models for provision of ARV most likely to bring broad benefits to patients, as well as to prevention efforts, and to the health system in general.

Major recommendations include scaling up care and support and developing new approaches for community preparedness for ARV treatment³ by providing technical and financial support for:

- ongoing information, skills and training on ARV treatment across sectors (including home care teams, other healthcare workers, NGOs, members of the community)
- influencing policy environment to ensure adequate supplies of medicines, diagnostics and other materials
- ensuring meaningful involvement of people with HIV and those on ARV treatment
- involving communities in ARV treatment, supporting and working with a range of different health systems in a co-ordinated manner
- encouraging dialogue and collaboration with a range of partners
- increasing community participation in ARV treatment
- making better use of existing structures and services

³ Community preparedness for ARV treatment includes the following: providing ongoing information, skills and training across sectors, ensuring adequate supplies of medicines, diagnostics and other materials, ensuring involvement of people with HIV and those on ARV treatment, involving communities from the planning stages of ARV treatment programmes, supporting and working with a range of different health systems in a co-ordinated manner, encouraging dialogue and collaboration with a range of partners, increasing community participation and making better use of existing structures and services.

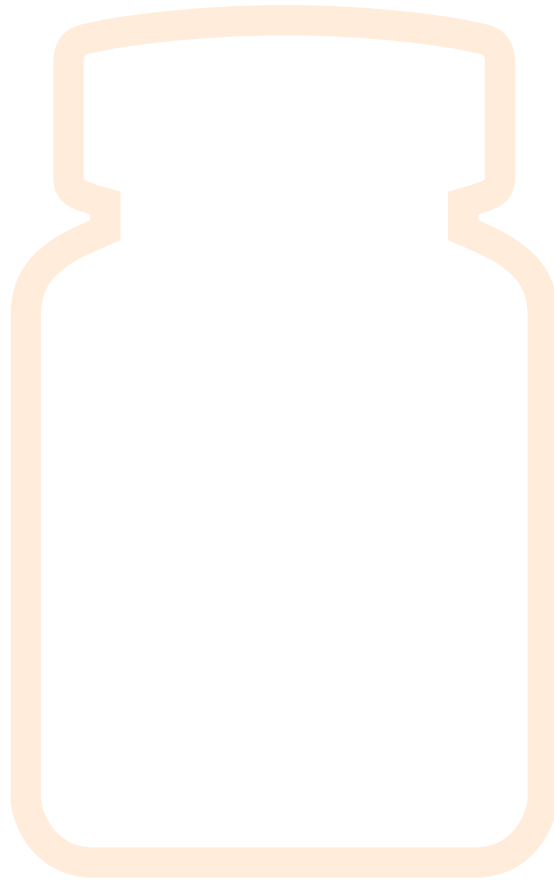
Aim 1 of the Assessment

Aim of the Assessment

The aim of the assessment was to provide the Khmer HIV/AIDS NGO Alliance (KHANA) and the International HIV/AIDS Alliance with guidance on programme and policy for improving access to anti-retroviral (ARV) treatment in Cambodia.

This report attempts to evaluate current and future opportunities for improving access to safe and effective ARV treatment.

The report includes recommendations in the area of improving access to ARV treatment. These recommendations were written specifically for KHANA, but it is also hoped that the assessment will provide guidance to other key stakeholders involved in scaling up access to ARV treatment in Cambodia. Recommendations are given with a view to meeting conditions necessary for people with HIV to support and benefit fully from enhanced access to safe and effective ARV treatment.



Methodology

Methodology

The assessment began at the end of October 2002 and was led by a consultant from the International HIV/AIDS Alliance, in close collaboration with staff from Khmer HIV/AIDS NGO Alliance (KHANA). The consultant was selected on the basis of his experience in providing ARVs in resource-poor settings and prior experience of working in Cambodia. Various activities were carried out, including a literature review of good practice on delivering ARVs in resource-poor settings, in depth interviews with key stakeholders including Government, international and local NGOs, people with HIV and UN agencies, and group discussions amongst self-help groups of people living with HIV.

The findings of the assessment were then presented to over 80 key stakeholders at a meeting in the Sunway Hotel, Phnom Penh on 11 March 2003. This meeting was led by KHANA, with support from the International HIV/AIDS Alliance, and was an important opportunity to discuss current and future opportunities for improving access to safe and effective ARV treatment in Cambodia. Following input and recommendations during this meeting, the Alliance Senior Programme Officer: Care & Support returned to Cambodia in August 2003 to meet with additional stakeholders, build on the initial findings of the assessment, including preparing some specific case studies relating to ARV treatment in Cambodia, and to finalise the report of the assessment.

Policy Environment in Cambodia

3

Policy Environment in Cambodia

For a number of years, Cambodia's Ministry of Health (MOH), with extensive donor support, has put considerable effort into measures to prevent and control the spread of HIV, as well as developing a home-based care and support programme in Phnom Penh and other parts of Cambodia. More recently, a strategy for preventing mother to child transmission (PMTCT) with Nevirapine has been developed⁴. These efforts have been concentrated in Phnom Penh, but increasingly models of prevention and care are being implemented in other provinces of Cambodia. Effective hospital care for OIs, and more recently ARV treatment, has primarily been provided through a few NGOs in Phnom Penh.

The Ministry of Health, through the National Centre for HIV/AIDS, Dermatology and STDs (NCHADS) and the National AIDS Authority (NAA), have developed local guidelines and strategies covering all aspects of HIV and AIDS care and support. Policy, strategy and guidelines for HIV/AIDS testing and counselling were finalised in December 2002. Guidelines for selection of people with HIV for ARV therapy, guidelines for the prophylaxis of OIs in people with HIV and guidelines for the use of ARV therapy in adults and adolescents are in the process of being finalised. Guidelines for the use of ARV drugs⁵ and treatment of OIs have been adapted from WHO treatment guidelines, as have protocols for PMTCT and post-exposure prophylaxis (PEP). The recently introduced National AIDS Law⁶ makes a number of provisions to promote and protect the rights of people with HIV. Despite this, people with HIV report that there remains a great deal of stigma associated with HIV and it is unclear what impact this law will have.

Generic Drug Use

Cambodia will not have to be TRIPS⁷ compliant until 2016. It is nonetheless possible that it may implement TRIPS long before this date. Under TRIPS rules, any generic drug registered in the country will continue to be usable after TRIPS compliance begins. Many ARVs, both patented and generic, are already registered in Cambodia. The registration process has in the past been very rapid and has been facilitated by NGOs such as Medecins Sans Frontieres (MSF), wishing to import generic drugs. Generic forms of all nucleosides⁸ and Nevirapine, as well as AZT/3TC combination tablets, are currently registered. Most ARV generics currently used are produced by Cipla or Ranbaxy in India, or by the Government Pharmaceutical Organisation (GPO) in Thailand. Only some of these generics are WHO pre-qualified⁹, though MSF is using some generic drugs that have been independently pre-qualified with MSF support. Generic triple drug combinations (d4T, 3TC, Nevirapine), while not yet registered, are being used, with government support. Recently, it has been reported that local production of ARVs has begun.

Generic forms of drugs for prophylaxis and treatment of OIs, such as acyclovir and fluconazole, are also available at far cheaper prices than the branded products. Use of generic drugs is currently supported by the Cambodian government and by the Global Fund to fight HIV/AIDS, Tuberculosis and Malaria (GFATM). Use of generic drugs will greatly decrease the cost of ARV treatment (current cheapest options are approximately \$30 per month),

⁴ Cambodia MOH Technical Working Group on PMTCT: Guidelines of the Expansion of PMTCT programme in Cambodia. Final draft, October 2002.

⁵ National AIDS Authority: Guidelines for the use of Anti-retroviral Therapy in Cambodia. 2001

⁶ National Assembly of Kingdom of Cambodia: Law on HIV/AIDS Epidemic Control and Prevention. 2002.

⁷ TRIPS is an abbreviation for Trade Related Intellectual Property Rights Agreement

⁸ Nucleosides are a type of ARV - see fact sheet included in Annex 3

⁹ WHO has a list of approved/pre-qualified drugs and diagnostics. This list is updated regularly and is on the WHO website (www.who.int).

increasing the numbers of people that can be treated, and increasing the likelihood that ARV treatment programmes can be widely implemented.

Essential Medicines List

The advantages of having drugs included on the essential medicines list include improved regulation, inclusion in government drug procurement, political commitment to maintain uninterrupted supplies and standardisation of treatment. ARVs are not yet included on the Cambodia Essential Medicines List¹⁰, though a number of drugs for treating OIs are included. The Cambodian national guidelines on ARV use are largely taken from WHO guidelines for ARV use¹¹ and allow flexibility in choice of medicines, with all likely regimes approved.

Global Fund to fight HIV/AIDS, Tuberculosis and Malaria

The Cambodia application to the Global Fund to fight HIV/AIDS, Tuberculosis and Malaria (GFATM) in the first round was approved. A total of \$16m is pledged, \$6m for the first year, some of this is explicitly allocated for ARV treatment. The ARV treatment component in the first round proposal will focus on strengthening and scaling up some of the existing treatment projects in Phnom Penh, implemented by Medecins Du Monde (MDM) and Centre of Hope (CoH). The funds for this proposal will be disbursed in the near future. The applications in the second and third rounds also contain significant ARV treatment components. The second round proposal has been accepted and the proposal for the third round has recently been submitted. These will focus on scaling up ARV treatment in Phnom Penh and to the provinces within a continuum of care and prevention, training of doctors and pharmacists, and involving people with HIV as peer educators to support adherence and prevention. All three GFATM proposals also call for strengthening and scaling up of VCT, PMTCT and integrated HIV-TB services.

¹⁰ Many ARVs are now included on WHO Model Essential Medicines List.
¹¹ WHO: Scaling up ARV Therapy in Resource Limited Settings. June 2002.

Access to Health Care in Cambodia

4

Access to Health Care in Cambodia

Health care in Cambodia consists of a poorly paid public sector, where unofficial fees are often requested, and a huge and largely unregulated private and informal sector. A number of factors ensure the high use of private rather than public services. Low levels of motivation of poorly paid staff in the public sector, and the lack of regular stocks of essential medicines has led to loss of faith in the public sector. The longer opening hours and closer proximity of pharmacists and private sector care make this a more attractive option. Less than 20% of health care contacts are through the public sector, and pharmacists/drug-sellers are the first contact for 70% of care-seeking episodes. There are over 3700 'pharmacies' in the country, 75% of which are unlicensed. Of 382 private hospitals and clinics, over 70% are unregistered¹². ARVs can be found in most private pharmacies in Phnom Penh.

Standards of care are considered to be poor and in the unregulated private sector, standards of care are thought to be particularly sub-standard. Studies have shown that over 70% of antibiotic therapy was inappropriately prescribed, 22% of tracer medicines tested were counterfeit and 50% of medicines sold enter the country illegally.

The overall effect is the impoverishment of already poor households, paying high prices for inappropriate and ineffective drugs. It is estimated that 46% of land sold by households is sold to fund costs of health care, including the cost of transportation to health services. Effective care for people with HIV is particularly lacking, with many of the problems mentioned above being particularly acute for people with HIV. Stigma and discrimination associated with HIV/AIDS further reduces access to resources, such as information and services, and results in decreasing access to care and support. This also leads to people accessing health care inappropriately, which can be dangerous and lead to further poverty. Amongst those who are aware of treatment and care, poverty and cost is seen as the greatest barrier, and poor experience of hospital care often prevents patients from attending public services for treatment. Private sector, and traditional medicine, as with other illnesses, accounts for the majority of treatment-seeking episodes. Many also concurrently seek treatment from western or allopathic medicine and traditional medicine. Mistrust of the public sector is often deeply entrenched in people's minds, leading to scepticism of care and treatment offered through these services. While the availability of ARVs alone may go some way to dispelling this, without other measures the mistrust may prejudice the overall success of the treatment.



ARVs that are stocked by a pharmacy in Phnom Penh

¹² Ung Phirun: Targeting Improved Access- Cambodia Assessment. <http://www.msh.org/seam/presentations/> (accessed 14/1/03)

Current Range of Services

5

Current Range of Services

In order for ARV treatment to be provided in a safe and effective manner, it must be situated within a continuum of care and prevention. The Government of Cambodia's plans for scaling up ARV treatment also call for strengthening and expansion of related services, including VCT, PMTCT, TB treatment, prophylaxis and treatment of OIs, STI treatment, post-exposure prophylaxis (PEP), home-based care (HBC) and support groups of people with HIV.

Testing and Counselling

Testing and counselling services are a very important entry and access point for care and support and the quality of the first encounter often influences future health and treatment-seeking behaviour. In 1995, the first national HIV testing and counselling policy was developed; it was revised in 2001 to incorporate the use of two different rapid tests for HIV diagnosis.

Cambodia's new AIDS law contains a section on testing and counselling and includes the following:

- the right to voluntary testing
- the right to confidentiality
- banning HIV/AIDS testing as a requirement for employment
- freedom from compulsory testing
- every HIV/AIDS test to be accompanied by pre and post-test counselling
- the need for testing centres to be approved by MOH
- the responsibility of MOH to strengthen and expand HIV/AIDS testing capacity within health facilities

NCHADS reports that there are now 29 VCT centres (government and non-governmental) in Cambodia. The plan is to make HIV/AIDS counselling and testing services available in all provinces by 2004. It is not known how many private testing sites exist and whether or not they provide adequate counselling.

Counselling plays a crucial role in ensuring that people are given appropriate information for prevention and accessing care and support. It should include a discussion of available support, and of ARV treatment, as well as appropriate referral to ensure access to these services. Currently there is no accurate information on successful referral and follow up rates from VCT centres, but it is reported that many do not contact support services. Generally the standard of counselling is said to be poor, with frequent reports of patients receiving no counselling, and others of patients arriving with a positive test result of which they had no knowledge. Overall utilisation of VCT services is said to be low, possibly because people do not know about the services or believe that it is beneficial to know their status.

The availability of ARV drugs can have a great impact on the uptake of VCT services and on follow-up. In Khayelitsha, South Africa, numbers attending VCT services increased from 500 to 14,000 per year, after ARV treatment became available¹³. Similar impact on the uptake of VCT has been reported in other countries where ARV treatment became available.

Lean Srey Luch is 27 years old and the assistant co-ordinator of CPN+. In 1998, both her husband and child became very sick. Her mother suspected that it was HIV-related. Her mother asked a relative who was a nurse to take Leap Srey's blood and have it tested for HIV at a private laboratory. Leap Srey did not know that her blood was being tested for HIV. After getting the result, her mother did not tell Leap Srey about her HIV status. She noticed that her mother had become very sad and cried a lot. Leap Srey guessed that her mother was sad because of her daughter's positive sero-status. Leap Srey asked her mother to tell her about her HIV status. Leap Srey did not receive any counselling, nor did she consent to being tested. Even though she was not sick, she felt hopeless. In 1999, her husband and child died and Leap Srey began getting sick occasionally. In 2000, Leap Srey went to Centre of Hope where she was again tested for HIV, but this time with pre and post-test counselling. She found the counselling and support really helpful. Centre of Hope referred Leap Srey to the MSF clinic at Sihanouk and Russian Hospital where, in 2002, she began receiving ARV treatment. Leap Srey feels much better these days. She has lots of energy and is able to work hard at her job at CPN+. Leap Srey thinks that if people know that they can access ARV treatment, then they would be more willing to find out their HIV status and there would be less stigma and discrimination against people with HIV.

Laboratory Services

Current capacity of laboratory services in terms of skilled personnel and materials, needs to be improved. Facilities for CD4 testing and viral load testing are not readily available, and what is available on a limited scale is found mostly in urban hospitals.

Prevention of Mother To Child Transmission

Approximately 25% of HIV transmission in Cambodia is from mother to child, compared to below 5% in the early 1990's¹⁴. The government finalized its policy on PMTCT¹⁵ in mid 2000. Three pilot projects have been established: Battambang Referral Hospital, the National Maternal and Child Health Center (NMCHC) in Phnom Penh, and Calmette Hospital in Phnom Penh. The PMTCT guidelines¹⁶ include very little discussion of community involvement for increasing utilisation. In discussion with people with HIV, it was clear that knowledge of these programmes was minimal. This could be one of the

factors that contribute to the poor utilisation of PMTCT services. In addition, negative views were expressed by some men living with HIV towards sero-positive women who became

¹³ Eric Goemaere: MSF-Belgium, South Africa. Personal communication.

¹⁴ National Centre for HIV/AIDS, Dermatology and STDs: HIV Sentinel Surveillance Report, 2002.

¹⁵ Policy is based on the use of Nevirapine for PMTCT.

¹⁶ MOH Cambodia: Guidelines for the Expansion of PMTCT Programmes in Cambodia. 2002.

pregnant: "They have been warned not to get pregnant. If they ignore us we will not support them."

Stigma provides a powerful disincentive for pregnant women to accept testing. Many women traditionally prefer to give birth at home. Some of the women who test never return for the PMTCT follow-up. Success of a PMTCT programme will rest heavily on success in demonstrating to women that both they and their child will benefit from it. There is a need to investigate attitudes towards women living with HIV who become pregnant to support uptake of PMTCT services through home care and groups of people with HIV. Barriers to testing and uptake of PMTCT for women (both aware and unaware of their HIV status) also need to be assessed with a specific focus on the impact of stigma.

Antenatal care and PMTCT programmes, like VCT services, may represent a first contact with health services, and measures recommended for VCT to improve counselling and referral should apply to PMTCT as well. Provision of PMTCT+ (where ARV treatment would be provided for the mother and her partner if required) is not currently envisaged. It was, however, agreed at the final meeting on the PMTCT protocol that PEP should also be included in the package, for health care workers in hospitals providing PMTCT.

Tuberculosis

Tuberculosis is by far the most common OI described in Cambodia, with 30-40% of hospitalised AIDS patients presenting with it. Currently almost 10% of TB patients are HIV positive¹⁷. As the epidemic matures and the number of cases of AIDS increases, TB in people with HIV will be increasingly recognised, and the percentage of TB patients having HIV will also increase.

The MOH, with significant donor support, uses directly observed therapy - short course (DOTS) to treat TB in Cambodia. Guidelines for community-based DOTS are being developed. In Phnom Penh, DOTS is administered to inpatients at the National Center for Tuberculosis and Leprosy Control (CENAT), to CENAT outpatients, or through the DOTS Home Delivery Program. The home delivery program has expanded to become the Tuberculosis Expanded Response and Access (TB-ERA) Project; it includes referrals to the home-based care network for TB patients who are also infected with HIV. The home care teams also refer people with HIV to the CENAT afternoon clinic for TB screening and treatment. The provision of transport and free TB screening and treatment means that people with HIV get early screening and treatment of TB, resulting in better access to TB prevention and care.

Standards of support to TB and AIDS patients in hospital vary greatly. Care of TB patients in hospital is often poor, with little attention paid to other health problems, nutrition, counselling, and referral to other support. Where only one of the diseases receives NGO support in a hospital, there may be great contrast in standards of care, and referral between TB and HIV/AIDS can be problematic.

TB services are an important first contact with people with HIV and referral to VCT must be

¹⁷ National Centre for HIV/AIDS, Dermatology and STDs: HIV Sentinel Surveillance Report, 2002.

carefully managed. While there has been increased effort to integrate HIV and TB services, much remains to be done. Improving integration and co-ordination of HIV/AIDS and TB services will ensure effective counselling on both HIV/AIDS and TB, as well as help to prepare delivery and support systems for those on ARVs.

There are some similarities between TB and ARV treatment and lessons learnt from DOTS programmes could be applied to ARV treatment programmes. For example, although direct observation of treatment by the health workers is unlikely to be possible for ARV treatment, support by partners and friends ('buddying' or 'accompagnateur')¹⁸ or by members of a group of people living with HIV/AIDS, might well be feasible.

Opportunistic Infections

Hospital-based treatment of OIs, where available, is generally poor. Patients often have to pay for inappropriate treatment, and many treatments will not be available. The exceptions, where treatment of common OIs such as cryptococcal meningitis, herpes infection, and pneumocystis carinii pneumonia are available free, are NGO supported hospitals, predominantly in Phnom Penh. Availability of drugs for treatment and prevention of OIs is variable in the home care programme. Referral and information sharing between hospitals and community support mechanisms is neither sufficient nor effective. This means that many people living with HIV seen in hospital do not have access to home care, do not belong to established groups of people with HIV, and that home care providers may be unaware of examination results or treatments from hospitals.

There is no provision of cotrimoxazole and isoniazid prophylaxis in public sector facilities. However, some NGOs do provide cotrimoxazole and isoniazid prophylaxis. For example, JICA supports an INH prophylaxis project with Family Health International (FHI) and Gorgas. The government is in the process of finalising guidelines for the provision of prophylaxis of OIs for people with HIV/AIDS. These include guidelines for cotrimoxazole, isoniazid and fluconazole prophylaxis.

STI treatment

Sexually transmitted infections (STIs) are very important in promoting the spread of HIV. In addition, they may cause severe opportunistic infections in AIDS patients. MOH clinics provide STI services in outpatient departments for a small fee. A number of NGOs support provision of these services; NGOs such as Reproductive Health Association of Cambodia (RHAC) and Reproductive and Child Health Alliance (RACHA) provide STI treatment. A core strategy of NCHADS is to improve STI prevention and control through syndromic STI treatment and to increase availability of quality STI services. There may be a need to develop better HIV risk assessment in STI patients and improve training for health care workers in syndromic management of STIs. Drugs for STI treatment are now included in the essential medicines list, and have been purchased by the MOH since 1999. Despite this, the majority of STI treatments are received through the private sector. This may in large part be due to the stigma that is associated with STIs.

¹⁸ This method for supporting adherence to ARV treatment has demonstrated successful treatment outcomes in a rural clinic in Haiti - (Paul Farmer et al. *Community-based approaches to HIV treatment in resource-poor settings. Lancet 2001; 358:404-09*).

Post-Exposure Prophylaxis

While some NGOs, particularly those working in provision of clinical care to people with HIV, offer PEP to hospital staff, the majority of staff working in both public and private hospitals does not have access to PEP. There is currently no provision for support to PEP in the public sector. Protocols for PEP in home care should be adapted from available technical documents (i.e. MSF, WHO, and NMCH hospital). PEP should be offered to anyone providing clinical care to people with HIV or other key populations. Systems (in keeping with UN protocols on PEP) to support ensuring confidentiality should be urgently developed. Most people have little information about PEP - its implementation and implications.

Home-Based Care

KHANA supports 32 home care teams in 6 provinces - Phnom Penh, Battambang, Kompong Cham, Siem Reap, Takeo, and Sihanoukville. Home care teams provide community-based care for people with HIV and other chronic illnesses. All home care teams are based in local health centres. The teams are made up of government health care staff, NGO staff and community volunteers, including people living with HIV/AIDS. Each home care team also provides support to group(s) of people with HIV at community level, which link closely with CPN+. Home care teams provide basic clinical care, psychosocial support and support for referral and follow-up.



A doctor from one of the home care teams provides care and support to patients in Kompong Cham

KHANA supports the majority of home care teams and provided home care to 2676 people living with HIV/AIDS, and a further 2004 children affected by AIDS in 2002. Other home care teams are supported by NGOs such as World Vision, Centre of Hope, Servants, and Maryknoll. The home care teams see 'chronically ill patients', the definition of which can be variable. This is a strategy to reduce stigma associated with HIV/AIDS. Between 85-90% of those receiving home-based care are thought to be living with HIV/AIDS; in Phnom Penh the total number of people with HIV supported by the home care network is around 1,800. Informants indicated that very few sex workers seem to be included in the home care programme. For example, Indra Devi Association (IDA) support 195 clients, of whom only one is known to be a sex worker. Men who have sex with men, the military, and the middle class, are rarely supported by home care. No reliable details exist on numbers who have accessed ARV treatment privately.

Key of Social Health Education Road (KOSHER), a KHANA partner NGO, supports 4 home-based care teams. The home care teams provide medical and psychosocial care and support to chronically ill clients. Team 2B, which serves the Chroy Chanva area in Phnom Penh, provides home-based care to 131 people (61 men and 70 women). 19 of these people are on ARV treatment. In an interview with home care team 2B, members of the home care team said that many of their clients ask them questions about ARVs. Questions asked include:

- Why do ARVs have side effects?
- What are the side effects of ARVs?
- Why do ARVs need to be taken so regularly?
- How many years can ARV treatment prolong your life?
- Do ARVs cure HIV/AIDS?

Members of the home care team 2B said that they are not always able to answer the questions about ARVs and that they would like to have more detailed knowledge about ARV treatment. They think that this is important for them to help their clients properly. When asked where they learned what they know about ARV treatment, they said that they learned from their patients. Some also said that they had learned from participation in workshops, conducted by Centre of Hope and KHANA.

Very little information exists on the health status of those receiving home care. Some groups reported higher numbers of sick patients (Stage 3 and 4 AIDS) than others. Overall, it was thought that 75% of those benefiting from home care were 'sick'. Few records exist of hospital admissions and referrals, or markers of disease progression such as OIs, weight loss, or CD4 counts. While some of these details could be obtained for some home care teams, generally there is very little sharing of information between hospitals and home care teams. Care provision in home care is very variable. Some of the groups have close supervision by doctors, and provide higher level of OI care and treatment than others. The home care guidelines provide for basic palliative care, and until recently did not include cotrimoxazole prophylaxis. The use of cotrimoxazole has been standard in some home care groups for over 2 years (as has use of fluconazole and acyclovir), while others have awaited official government support.

KHANA care and support workshop for home care team members - a session on ARV treatment



Support Groups of People with HIV

Vithey Chivit was the first group of people with HIV in Cambodia. There has been a great increase in the number of PLHA groups in Cambodia, and a general increase in the level of PLHA activism, as a direct result of the evolution of the Cambodian People Living with HIV/AIDS Network (CPN+). The Cambodian government and KHANA have actively promoted CPN+. The network receives funding and support from KHANA, Policy Project and PACT, and provides an umbrella for 11 PLHA groups in Phnom Penh, and 13 in the provinces. In Phnom Penh it represents approximately 2000 people with HIV. The Cambodia Prostitutes Union (CPU) represents 3000 sex workers in Phnom Penh. The BSS data in Cambodia indicates that 15 - 35% of sex workers are HIV-positive. In discussions with people with HIV, it became clear that populations such as sex workers, have little representation in support groups. The role and representation of women within support groups also needs to be strengthened.

20 of 109 Vithey Chivit members are on ARV treatment. The various support groups provide different levels of support to their members, but generally meet once every month for discussion and education led by a team leader. The team leader sometimes brings updates on ARV treatment, but they have not yet had proper training on ARV treatment. The leader of one support group, who was on ARV treatment, had not revealed this to other members of the group. This is said to be generally the case for support group members on ARV treatment. Because of the lack of easy, universal access to ARV treatment and the inequity posed by this, people with HIV on treatment felt revealing that they were on ARV treatment would further increase the stigma around HIV/AIDS.



It is important that people with HIV are not seen as passive recipients of ARV treatment. The long-term success of ARV treatment depends on increasing and supporting the involvement of people with HIV, their family, and their communities, in supporting adherence, prevention and managing health problems. The long-term success of ARV treatment will also depend on regular supplies of affordable drugs. People with HIV and their supporters should be given both the information necessary to understand the treatment, and appropriate involvement in management of treatment. Members of Vithey Chivit provide counselling and support to people with HIV receiving care at MDM-Calmette Hospital. The leader of KOSHER's support group of people with HIV has been involved in the

creation of a support group for patients on ARV treatment at the Sihanouk and Russian hospital. Those involved in home care could also play a vital role in supporting this approach. Support groups of people with HIV will be essential in the dissemination of credible and responsible messages around ARV use to other people with HIV, their families, communities, the health sector and the private sector. They can also play a vital part in monitoring the standards of care provided to their members. The involvement of people with HIV in the selection of patients is important for promoting equity, transparency and accountability in treatment programmes. The involvement of people with HIV in selection of patients is promoted in the (soon to be finalised) national guidelines for the selection of patients for ARV treatment.

Soy Sok Chamreun is 33 years old and a member of Vithey Chivit. He has been on ARV treatment since 2001. His wife is also on ARV treatment. They help each other to take their medicines properly. He has also encouraged her to join a support group of people with HIV.

Soy Sok Chamreun participates in the weekly support group meetings at Vithey Chivit, where many of the members who are on treatment share their stories. He says that he knows that not everyone who is taking ARVs is open about being on treatment. Soy Sok Chamreun thinks that sharing experiences about treatment helps people to take their treatment properly. He also thinks that it is really helpful to hear others' experiences, especially for those who are just starting treatment. Hearing about others' experiences with side effects and how they managed them can support people to deal with their own side effects.

Prevention with/for/by people with HIV

As ARV treatment programmes are scaled up and people with HIV are living longer and healthier lives, there is a heightened need for focused prevention with/for/by people with HIV. The challenge is to implement this within an ethical framework - without putting people with HIV at increased risk of stigma and discrimination and without eroding their human rights¹⁹. People with HIV have always had an essential role to play in preventing new infections. HIV/STI prevention strategies have, however, often failed to address the distinct prevention needs of people with HIV and to acknowledge their significant efforts to avoid infecting others²⁰.

Preventive interventions with positive individuals are likely to have a greater impact on the epidemic, for an equivalent input of cost, time, resources, than preventive interventions focused on negative individuals. A change in the risky behaviour of an HIV positive person will, on average and in almost all affected populations, have a much bigger effect on the spread of the virus than an equivalent change in the behaviour of a negative person²¹.

¹⁹ Positive prevention (draft), Emerging Practice series, International HIV/AIDS Alliance, July 2003.

²⁰ Collins et al, 2000

²¹ King-spooner 1999; Vernazza et al. 1999

Strategies for this type of focused prevention should aim to support people with HIV to protect their sexual health, to avoid new STIs, to delay HIV/AIDS disease progression and to avoid passing their infection on to others. These prevention strategies do not stand alone, but work in combination with one another.

Strategies for this type of focused prevention with/for/by people with HIV include:

- promoting and making available services such as testing and counselling, PMTCT, ARV treatment, peer support groups
- promoting safer sex practices and consistent use of condoms
- conducting focused information campaigns
- providing counselling for sero-discordant couples
- encouraging beneficial disclosure, ethical partner notification²²

²² Opening up the AIDS Epidemic, UNAIDS, 2000.

Anti-retroviral Treatment

6

Anti-retroviral Treatment

The availability of affordable or free ARV treatment effects profound changes on all aspects of HIV care, prevention and impact mitigation.

- It increases the attraction for testing, while at the same time increasing the importance of retaining contact between the client and the health service. Currently few people are getting tested, and fewer still are maintaining contact with the health service or home-based care afterwards. The increased numbers of people presenting for testing may challenge the VCT services, particularly the quality of counselling and referral systems.
- Increased numbers of diagnoses and awareness of treatment options will increase the load on all levels of HIV/AIDS and TB services, perhaps most notably home-based care teams. Availability of ARV treatment may change the perception of AIDS as untreatable (with both positive and negative consequences), while bringing a need for prevention in the context of ARV treatment.
- There are concerns that PMTCT programmes may need to expand to PMTCT+ or avoid using Nevirapine monotherapy, if efficacy of NNRTI²³-based triple therapy is to be retained.
- ARV treatment will help to strengthen fledgling PLHA movements, with people with HIV becoming increasingly involved in supporting and counselling each other. This will be vital if ARV use is to be a success and if home-based care is not to be overwhelmed.

Cambodia is estimated to have 160,000 people with HIV. Of this number, only a small minority, probably less than 10,000 are aware of their status. Of these, the majority live in Phnom Penh, where many benefit from home care and support groups of people with HIV. Over one third of people with HIV will have reached a stage where they may require ARV treatment. NCHADS reports that 2.75% of people with advanced HIV infection are receiving ARV treatment²⁴. NCHADS also reports 70 paediatric cases using ARV treatment. MDM, MSF-France and Centre of Hope treat the majority of these people. Details of current ARV treatment programmes are given in Annex 2. However, there is no data available from private clinics.

With the GFATM funding, the numbers of people who benefit from treatment are likely to increase significantly. Improvements in Cambodia's health infrastructure and changes in the population's health-seeking behaviour will take many years. Ideally these changes would be in place to support effective delivery of ARVs to people with HIV through the public health system. Unfortunately the need for ARVs by the population, increased awareness of the value of treatment within the community of people with HIV, and reductions in price of ARVs,

²³ See Annex 3

²⁴ Cambodian Report on Follow up to the Declaration of Commitment on HIV/AIDS (UNGASS), National AIDS Authority, Kingdom of Cambodia, 2003.

have greatly outpaced these improvements. This has led to increasing availability and use of ARVs through the unregulated private sector, with the result that many people with HIV are buying inappropriate drug regimens, for short periods of time, and impoverishing themselves in the process. The fall in price of the drugs and increased availability of ARVs means that short-term mono- or bi-therapy, though ineffective, is within reach of all but the very poorest people with HIV. It is well established that the incorrect use of these drugs may lead to the rapid development of resistance. This would prejudice the efficacy of future treatment.

This imbalance between public sector provision and demand of people with HIV represents a threat to future ARV programmes, and the greater the delay in the development of effective delivery systems, the greater the threat. From this point of view, scaling-up becomes more urgent and must be considered as a type of 'harm reduction' approach. Free public provision of ARV is then necessary for pragmatic as well as ethical reasons to minimise the harm caused by poorly delivered drugs (treatment failure and impoverishment) and to prevent early appearance of drug resistance.

Current Approaches to Delivery of ARV Treatment

ARV treatment is currently provided in a very limited fashion through a number of hospital-based pilot programmes. This has demonstrated the value of ARV treatment to people

Soung Sarat is a 35 year-old man living in a rural area of Takeo province. He learned he was HIV-positive in 2002. His wife and two children are not sero-positive. Eight months ago, Soung began receiving ARV treatment from MSF-France at Sihanouk and Russian Hospital. Soung has received a great deal of support from the MSF staff on how to take his treatment properly. They have given him information about the drugs, their side effects, how to manage side effects and counselling. He has also been advised to use condoms consistently. He uses the alarm on his mobile phone to remind him when to take his medicines; he also keeps a written record of his treatment. His wife also reminds him to take his medicines. The home care team in his area, supported by Partners in Compassion, also provides him with support. However, the home care team does not seem to have much information about ARV treatment.

Soung Sarat says that ARV treatment is very useful for people with HIV. It helps them to stay strong and healthy. Soung says that ARV treatment should be provided by trained doctors and people should not buy these drugs from private pharmacies - unless they have a prescription from a trained doctor. Soung says that the private pharmacies do not provide any of the information or support that is needed to take these treatments properly. He says that it is important to remember that if ARV treatment is not taken properly, these drugs will not work.

with HIV, who increasingly demand it. If large numbers are to be treated, a more inclusive model for support to ARV delivery is needed. Increasing the capacity of communities and primary health centres to support and follow-up people with HIV on ARV treatment will be vital to their success. Most people with HIV who fail on ARV treatment will fail because of lack of support in the community or family, not because of insufficient hospital contact. This dynamic is equally true for tuberculosis, and many chronic diseases. Better community care has the potential to reduce the workload on hospitals, essential if greater numbers of people turn from the private to public sector.

A major hindrance to developing this support is the 'medicalisation' of HIV/AIDS and HIV/AIDS-related care. While it may be true that chronic diseases can be managed successfully with little recourse to hospital services, this is not the perception held by the medical community or by society in general. Development of non doctor-led approaches that are not over dependent on highly skilled physicians will be essential to significant scaling up of ARV treatment.

For ARV treatment to achieve full therapeutic and social benefit, it is important that patients are highly adherent to it. Taking less than 95% of the medicines prescribed will reduce the efficacy of treatment and speed the onset of resistance. There is very little clear evidence either to predict adherence levels for individuals or for models to support good adherence. Factors that have been shown to have a positive impact include education, counselling and disclosure of status and treatment to family, while poverty and depression have negative consequences on treatment adherence. Community-based structures, such as support groups, have a crucial role to play in supporting ARV treatment, adherence, and prevention. These types of structures should be closely involved in any programme delivering ARV treatment. While it is generally agreed that ARV treatment should be prescribed and monitored under medical supervision, and that medical input is needed to ensure correct selection of patients requiring treatment, this does not necessarily imply that the process should rely solely on, or be led by, medical expertise.

Hospital-based approach to delivery of ARV treatment - MDM, MSF-France, and Centre of Hope, have all adopted essentially the same approach to the provision of ARV treatment. Patients are selected from those attending the hospital HIV clinic, or those admitted to the hospital beds. Generally they are assessed for treatment in the HIV clinics, and selected on the basis of medical criteria by a committee on which hospital doctors play a major role. Doctors put forward the names of patients for selection from those seen in their clinics. The committee may also include social workers, people with HIV and lay people, though it appears that the decision in practice rests with the doctors. Funding for the drugs and associated costs is provided by the NGO supporting the hospital programme. The community, people with HIV and community-based NGOs supporting the patients have little involvement in decision-making regarding treatment.

Clinic-based approach to delivery of ARV treatment - MSF-Belgium in Siem Reap and Takeo select patients from people attending the chronic disease clinic. Patients are screened

for selection and included after discussion by a selection committee. This committee is currently similar to that mentioned above but there is an interest in expanding the involvement of other groups. Funding for treatment is provided through the NGO supporting the clinic. As staff in the clinic predominantly work with patients with chronic illnesses and have no hospital in-patient duties, they are able to focus on long-term support to patients, and are more likely to develop close co-operation with community groups.

Home Care-based approach to delivery of ARV treatment - There are no home care-based programmes delivering ARV treatment in Cambodia, but MSF-Belgium in Bangkok and MSF-France in Surin, Thailand have around 100 people with HIV on ARV treatment through their home care programmes. In Thailand, this approach ensures that staff from the home care group is involved in decision-making around selection of patients. There have been some problems with activists proposing their friends and other activists for treatment, rather than those most closely meeting the defined patient selection criteria. Clinical management is supported by doctors in the hospitals, to which the home care teams are attached.

Protocols for ARV treatment

Current ARV programmes are providing ARV treatment, following similar protocols, in agreement with the national and WHO guidelines²⁵. Treatment is based on triple-therapy, usually with a first-line of 2 nucleosides and 1 non-nucleoside reverse transcriptase inhibitor²⁶. The cheapest treatment (around \$300 annually) currently uses generic Nevirapine, and the simplest regime consists of one tablet of combination of 3TC, d4T, and Nevirapine twice daily. All programmes hold protease inhibitor²⁷ treatment as a second-line. The cost of this second-line therapy is around 10 times that of the first-line, depending on the choice of drug.

People with HIV are eligible for treatment if they have AIDS defining illness or CD4 count of less than 200. Generally those presenting with OIs will first need to have the infections treated before being considered for ARV treatment. Before treatment is started, the patient will need to visit the hospital outpatient clinic for three preparatory appointments during which laboratory tests and counselling will be carried out. Though not a requirement, the MSF-France programme asks patients to attend with a relative or friend who will be their principal support during treatment. This encourages patients to disclose their status to family, which generally predicts better adherence to therapy. MSF social workers provide counselling and support, with involvement from groups of people with HIV, however there is little direct link with the community. Centre of Hope carry out daily observation of treatment early in treatment, though none of the other providers currently do this. Once treatment is started, the patient will usually be given 2 weeks of treatment after which they return for a further appointment and blood tests. At this point, any problems will be discussed and the patient will be given drugs for the next 2-4 weeks. For those without problems on treatment, follow-up will occur at decreasing intervals. There is a good link with the Centre of Hope home-based care group. Most patients currently come from hospital HBC catchment area.

²⁵ Many ARVs are now included on WHO Model Essential Medicines List.

²⁶ Types of ARVs - see Annex 3

²⁷ Types of ARVs - see Annex 3

Anecdotal evidence indicates that where ARVs are provided through private practice or pharmacies, these guidelines are rarely followed.

Knowledge about ARV treatment

The lack of correct knowledge about ARVs leads to inappropriate use of the medicines and contributes to developing drug resistance. In Cambodia, there has been no systematic assessment of knowledge, beliefs, attitudes and experiences about ARV treatment²⁸ amongst people with HIV, their families or those involved in providing the treatment.

Doctors - Those doctors involved in providing HIV/AIDS care through MSF, MDM, and Centre of Hope, are receiving full training on ARV treatment. There is no clear training in the use of ARVs provided elsewhere, either in public or private hospitals, or to those in supervisory positions with the MOH or with NGOs. Despite this, many doctors have been prescribing ARVs in private practice for several years.

Pharmacists - There has been no training in the use of ARVs for pharmacists outside the above programmes. In Phnom Penh a number of pharmacists provide ARVs to people with HIV, the vast majority without providing advice or counselling around use of the drugs. Some training for pharmacists is planned under the GFATM proposals.

Home Care Teams - There is no formal education on ARV treatment provided to home care staff or their supervisors. Some of the home care groups in Phnom Penh have recently begun training on these issues. There is little systematic involvement of home care teams in supporting patients on ARV treatment, except through the Centre of Hope programme.

People with HIV - The leader of CPN+ felt that 80% of members needed ARV treatment, while representatives of Vithey Chivit felt the number was more like 50%. According to home care teams and representatives of people with HIV, the majority of people with HIV who belong to these groups have some awareness of ARV treatment. Generally they are aware that the drugs need to be taken for life and that they prolong life rather than cure the disease. CPN+ felt that over 90% of members were aware of ARV treatment and wanted to be treated. Most knew that they should take three drugs in combination and that monotherapy should never be taken. The leader of Vithey Chivit, however, stated that it would be reasonable for a patient to take ARV monotherapy provided that a doctor had prescribed it. Other home-based care network and CPN+ members disagreed, stating that only triple therapy was acceptable. There has not been any formal education from either CPN+ or from home care groups. As relatively few people have been treated effectively, and those that have often do not disclose the fact that they are receiving treatment (or even that they have HIV), there is little general experience of the value of ARV treatment. It is likely that the above is an over optimistic representation of the level of knowledge amongst PLHA, though the situation is changing extremely fast, and levels of awareness are increasing rapidly, with a strong call for systematic, on-going education on ARV treatment issues from groups of people with HIV. As in Thailand, trained people with HIV could become an invaluable resource as 'peer educators on treatment issues'.

²⁸ Voices from the Community - A report of a Community Consultation on ARV Treatment in Zambia, November 2002. (Community Consultation Guide - in development)

There is clearly a great need for education around ARV treatment, adaptable and relevant to different levels. Guidelines for education on ARV treatment are needed, orientated towards people with HIV using or considering ARV treatment in the private sector or public sector, the communities supporting them, and those involved in provision in all sectors. It is also important to address the education needs among the medical community. Private pharmacies and traditional healers may also be particularly important in some areas.

It has been argued that people with HIV should not be informed of the availability of ARV treatment. One doctor said "there is no point telling patients about ARVs when they cannot afford them. It will just depress them more". In fact, most people with HIV already have some level of awareness about ARV treatment. Dissemination of appropriate key messages will ensure that they do not waste meagre resources on inappropriate treatment, and will enable them to make correct, informed choices where treatment is accessible. The concept that one could be HIV-negative despite a partner being positive can be difficult. Similarly, people with HIV may not accept that while treatment is essential in late disease, it is not necessary in the early stages.

Examples of appropriate key messages for people with HIV:

- you may not require ARV treatment
- treatment with inadequate therapy, though more affordable, is dangerous
- single drug therapy, with Nevirapine in particular, must never be taken (except for PMTCT)
- objective, easy to understand information about ARV treatment
- information on cheapest prices for quality ARVs

Issues of access

HIV/AIDS can contribute to disempowerment by increasing poverty, ill health, and stigma. The availability of home care and more importantly the formation of support groups, represent potent mechanisms for empowering people with HIV through education and social support.

Policies calling for universal access to care and treatment and using objective medical criteria are essential for scaling up access to ARV treatment. Certain groups are more likely to access ARV treatment than others. In general, distribution through the public sector will aim to ensure access is available to all those who need it. Where treatment availability is limited, inequity is inevitable. This should not be a reason to delay starting ARV treatment programmes. Only by starting ARV treatment, can treatment programmes be scaled up to provide universal access to treatment.

ARVs are simplistically viewed by many as representing the difference between life and death. Where availability is limited, those selecting who should be treated and who should

Mrs C is HIV-positive and her husband, a wealthy general in the military, died of AIDS. She was in Siem Reap hospital with terminal AIDS, receiving antibiotics for a chest infection. She had spent over \$6000 on 6 months of ARV treatment, initially triple therapy, then dual therapy with DDI and Nevirapine. She had used all her savings, and sold most of the family land to pay for treatment, and could no longer afford her children's school fees. In hospital she had not revealed her status, and the staff had given no consideration to the possibility of HIV. She had not heard of home-based care, but was keen to receive it, and was unaware that a clinic in the hospital was dispensing free ARVs. She has since been accepted by the clinic to receive ARV treatment, though it is likely that her virus is resistant, limiting treatment options and reducing chances of success.

not, may be seen as holding that choice in their hands. This power can easily be abused, and where it is wielded fairly, those making the choices will still be exposed to great pressures. To mitigate this, it is vital that attention is paid to developing a system that is fair, seen to be fair by people with HIV and is justly and consistently applied.

Currently access to ARVs, in common with access to health care in general, is unequal. In the absence of funding support, only the wealthy can afford correct therapy, often impoverishing themselves in the process.

The availability of free ARV treatment on a limited basis, while ensuring that some poor people with HIV receive ARVs, may not necessarily address problems of equity. Indeed it may increase perceptions of inequity for a number of reasons:

- richer patients may pay bribes
- social factors (education, wealth, job) may increase the likelihood of getting them
- activists or people with HIV supported by certain NGOs may be more likely to get them
- people with HIV living in certain geographic areas may be excluded, or unable to afford travel costs
- certain groups (sex workers - especially Vietnamese sex workers, military, and, paradoxically, in some cases wealthier patients) may be excluded due to low representation in support groups.

It should be noted that where an individual is given treatment, it is important to try to ensure that treatment is available to close relatives who need it. If this is not provided, the individual on treatment may feel pressure to share his or her treatment with HIV-positive relatives, ensuring early treatment failure and appearance of resistance for both.

The limited availability of treatment leads to providers taking different approaches to selecting new patients. These selection processes, while ideally based on medical criteria alone, often have social and random elements to them. Even when appropriate selection criteria are in place, they may be unjustly and inconsistently applied. In discussion with members of groups of people with HIV, a number of criticisms were made of how people were selected for treatment. It was felt that some doctors were not fair in their selection processes. Various anecdotes were shared of people with HIV who had paid bribes to be selected. Bribes of up to \$300 were said to be paid by up to 25% of patients. In some cases bribes were asked for, in others they were provided spontaneously. This was thought to happen despite supervision, though there was unanimous agreement that it would be far worse without this supervision. CPN+ said that treatment had aroused jealousies amongst its members, with accusations that activists received preferential treatment. This had led to people denying being on treatment. Most agreed that people with HIV should be represented on selection committees to ensure that the process was fair and transparent. Many informants stated that these types of problems would be reduced if doctors were better paid.

Stigma, discrimination and ARV treatment

Globally, experience now indicates that increased access to ARV treatment has led to a reduction of stigma and discrimination. Many people with HIV on ARV treatment have given testimonies about how being on ARV treatment has given them hope, broken the synergy between AIDS and death and helped them to become productive members of family life and society.

While there have been great advances in community awareness of the disease, and the recently introduced national AIDS law specifically bans discrimination, it is clear that a great deal of stigma still affects people with HIV. Support group members complained that while staff in HIV/AIDS clinics treated them well, staff in other health facilities would often refuse to look after them if their status was known. While the existence of the AIDS law represents a valuable step, it is unclear what measures might be taken to enforce it and its impact on the lives of people with HIV.

Of note, is the law against knowingly passing on the disease, with harsh penalties described. This could lead to persecution, particularly of traditionally marginalised, excluded populations such as sex workers.

Stigma, along with low levels of awareness of care and support options, continues to contribute to the low uptake of testing and counselling,



Mr X is 35 years old, married with one daughter. He is on ARV treatment but is not open about his status or treatment. He does not want to be open about his HIV status because he thinks that knowledge about HIV/AIDS in the general community is very low and this is one of the reasons for the fear, stigma and discrimination.

Mr X thinks that making ARV treatment more accessible will help to reduce stigma and discrimination. He thinks that much of the fear, hopelessness, stigma and discrimination are because HIV/AIDS is associated with illness and death. Because ARV treatment gives hope, helps one to stay healthy and live longer, it can reduce HIV/AIDS-related fear, stigma and discrimination.

with most people reaching testing arriving either in late stage AIDS, or as a result of a relative disclosing their HIV positive status. ARV treatment has the potential to encourage people to come for testing and to strengthen support networks for people with HIV. However, if only a minority is treated, they may not disclose the fact to their peers, limiting the value of their treatment as a tool to strengthen networks of people with HIV and reduce stigma and discrimination.

Barriers to accessing ARV treatment

Informants reported the following key barriers to accessing ARV treatment:

Financial: The cheapest effective ARV therapy, based on 2 NRTI and Nevirapine, currently costs around \$1/day. This does not include costs of laboratory follow-up and other payments for supportive care. For those requiring protease inhibitors, the cheapest treatment cost rises to between \$3 and \$10 per day. The same treatment may vary in cost hugely, depending on the source of the drugs. Very few people with HIV are able to afford these costs. There are even financial barriers to treatment for those for whom the drugs might be free. Even where services are provided free, people expect that they will have to pay to receive correct treatment. Costs include travel to and from clinics, the cost of laboratory tests etc. For the poorest patients, the monetary value of the ARVs may compel them to sell some or all of their drugs to buy food or pay rent.

Social: Certain groups are unlikely to make use of public health services due to experience of discrimination, either due to their HIV status, or related to their poverty. Sex workers and men who have sex with men appear to make little use of health services. These groups may be excluded from home care and support groups, further limiting their access to ARV treatment.

Physical: Most areas of the country do not have services providing ARV treatment. Those who can afford to travel to areas where ARV treatment is available and accessible may be

refused on the grounds of their location, or may be selected for therapy, only to default due to difficulties of travelling regularly to receive the medication. Both physical and mental illness (depression is particularly common and often unrecognised) associated with HIV/AIDS can prevent people with HIV from accessing health services and limit their ability to continue treatment effectively.

Moving beyond pilot programmes

A pilot treatment programme seeks to treat a few patients in a given area and to provide an example for other programmes to learn from, leading eventually to 'scaling up'. As awareness of ARV availability increases, large numbers of patients may present for treatment. Where the number of patients approaching the programme for treatment greatly outweighs its capacity, the selection of patients becomes increasingly difficult.

Challenges faced by pilot programmes include:

- dissatisfaction amongst those not selected for treatment
- pressure on staff responsible for selection
- perceived or real biases in inclusion
- pressure on people with HIV or providers to share, sell, or inappropriately distribute the drugs

While it may not be possible immediately to treat the majority needing treatment, it should be borne in mind that the fewer patients are treated, the greater these risks may be.

Although risks cannot be avoided completely, a number of measures may reduce them:

- careful education and explanation of reasons for selecting patients for treatment
- transparent and fair selection process with real involvement of people with HIV
- simple clinical and laboratory criteria for inclusion in treatment programme
- minimal use of social selection criteria in choosing patients for treatment
- timely, if not immediate, provision of treatment to all those in need of it
- ensure provision to all people with HIV, and not linked to membership of support groups

Approaches for delivering ARV treatment

A number of scenarios are possible, with differences of site, provider, and varying involvement of community and people with HIV. Two essentially different models for provision are described overleaf: the delivery of ARV treatment through public or NGO-funded hospitals (the current model) with community links, or delivery of ARV treatment through community and organisations of people with HIV with hospital links. While the

cases presented may represent different ends of a spectrum, and the reality will contain elements of both, there is a fundamental difference in the focus of the two approaches.

Hospital focused - Generally, the increase in ARV provision will be through the public health services, with the lead being taken by hospital staff, and selection based in the hands of doctors, using both medical and social criteria. Follow-up will be initially hospital-based, though links with home-based care and support groups of people with HIV may be involved. The advantages of this model are clear, in so far as the medical investigation and care are handled by doctors. Well-trained clinical staff are essential to effective ARV management. In addition, anyone involved in ARV treatment requires training and this is easier to provide to a few staff in specialised hospitals than to large numbers of people in the community.

The challenge of this approach is its high degree of reliance on hospitals, with all the problems these face in Cambodia. Medical staff are under-paid and often reliant on informal payments from patients. Many barriers to access and adherence to ARV treatment are not easily addressed in this scenario. In the worst case, there is minimal involvement of community members and people living with HIV, and only small numbers are put on treatment. With increasing activism by people with HIV, the pressure on the few programmes providing treatment becomes difficult to manage, both for the providing doctors and for the 'lucky' few patients. Corruption may be present in the selection system, damaging perception of the programme, and preventing formation of strong support groups of people with HIV. Lack of community support means that many patients on therapy are poorly adherent and early treatment failure is common. Additionally, the most disadvantaged groups rarely get treatment, as their bargaining at hospital is weak, and the lack of unity amongst people with HIV acts against them. This is the model currently favoured by NCHADS and forms the basis for the planned expansion of services. The alternative described below is similar except for having the health centre (rather than the hospital) at the hub.

Community health centre focused - The focus for this model would either be the health centre, or potentially a community-based HIV/AIDS clinic. Trained people with HIV would be on the staff and closely involved in all levels of support and care. The health centre would provide all care that did not require hospital admission, ideally with a medical doctor providing regular clinic-based consultations for difficult cases. The centre would serve as a focus for referral to and from all other services (laboratory, PMTCT, support group, home care, hospital).

The notion of such a centre as the hub of all activities contrasts with the more hospital-focused approach. People with HIV would be assessed in the clinic for stage of disease and care needs. Those who met basic criteria for ARV treatment would be considered by a treatment selection committee, made up of all stakeholders. Those selected would be prescribed ARVs in the clinic and given counselling and support referrals through the clinic. They would take the prescription to an accredited pharmacist, funded by the NGO or other group paying for treatment. The donors, together with the pharmacist, would ensure quality

of the ARVs and guarantee stocks of most affordable drugs. This pharmacy would provide the drugs either free, subsidised, or at cost price, depending on ability to pay or NGO support for the person with HIV. A supervisory board consisting of various stakeholders would monitor the functioning of the service and arbitrate on problems arising in selection of patients for treatment. The funding for ARVs would be handled through a consortium consisting of MOH, people with HIV and community-based HIV/AIDS NGOs. Criteria for treatment and follow-up would be set by a group comprised of those mentioned above, and hospital doctors, with technical expertise in ARV use and AIDS management.

This model may have several advantages over a hospital-focused delivery system. Foremost, this model addresses the problem of scale and reaching those in rural settings. While the involvement of medical staff is essential to ensure the drugs are used safely and prescribed correctly, it avoids the concentration of power in the hospitals. A transparent community-based system for procuring and delivering treatment, and for selecting the patients, minimises the risk of abuse, and maintains the interest of community and groups of people with HIV in ensuring the treatment programme functions. It reduces the impression that the treatment is only a medical intervention. For most of the life of a person with HIV on treatment, they will be healthy and failure of treatment will relate to failure to adhere to it while in the community. Successful treatment will happen when treatment is incorporated into the lifestyle of a person with HIV. At the moment, the government is not considering this approach.

Conclusion

7

Conclusion

There is now increasing political will and financial commitment to scaling up ARV treatment in Cambodia. The challenge will be how to make ARV treatment more accessible and to deliver the treatment to people in a safe and effective manner. The development of comprehensive models of HIV/AIDS care, treatment and prevention will be critical, as will the development of a public health approach for scaling up ARV treatment. Adopting a public health approach for scaling up ARV treatment will call for simplified first and second line treatment regimens, simplified monitoring and meaningful involvement of a range of stakeholders, including people with HIV and the community.

For these goals to be achieved and for public confidence in the health system to increase, it is vital that financial and political resources to combat HIV/AIDS are integrated with, and contribute to, a drive for improvements in health care provision generally. This will depend on strengthening health services and the interface between these services and the community. It will also mean providing support to communities so that they in turn can provide support for individuals and families who are involved in ARV treatment. It is clear that, in order for the community (including people with HIV) to realise their potential as a valuable resource for ARV treatment, people need information and education, as well as effective clinical care and social support. Patients and those who support them - families, health care workers and communities - have an active role to play in ARV treatment. If ARV treatment is successful, it will be accepted and used well. If not, people will lose hope and continue to struggle with the already heavy burden of illness, deaths and loss of social and economic support.

Safe and effective ARV treatment and community preparedness will form two sides of the same coin of improved health for people affected by HIV in Cambodia. Community preparedness will involve the following: providing ongoing information, skills and training across sectors, ensuring adequate supplies of medicines, diagnostics and other materials, ensuring involvement of people with HIV and those on ARV treatment, involving communities from the planning stages of ARV treatment programmes, supporting and working with a range of different health systems in a co-ordinated manner, encouraging dialogue and collaboration with a range of partners, increasing community participation and making better use of existing structures and services.

Recommendations



Recommendations

Although developed specifically for KHANA, it is hoped that these recommendations also provide guidance to other key stakeholders involved in the provision of care and support and scaling up access to ARV treatment in Cambodia.

Scaling up care and support²⁹

1. Provide technical and financial support to strengthen and expand counselling capacities in home-based care teams and groups of people with HIV. Training for these groups should also cover issues related to testing and counselling, PMTCT, involving communities in testing and counselling and PMTCT etc. All those benefiting from home-based care, their families and people with HIV, could be offered HIV/AIDS counselling on the assumption that supplemental support is required at testing and counselling services.
2. Explore the possibility of involving different groups in training of counsellors.
3. Building on the experience from home-based care, provide technical and financial support to strengthen strategies needed to increase co-operation between home-based care teams, groups of people with HIV, and hospitals. The existence and scaling up of ARV treatment brings an added dimension of urgency to this.
4. Provide technical and financial support to strengthen documentation of the home care provided, including details of investigations, diagnoses, and treatments provided elsewhere.
5. Support interventions to improve rates of referral and follow up from testing and counselling to home-based care and groups of people with HIV. This might include strategies for community mobilisation for testing and counselling that have people with HIV as focal points. This may include placing people with HIV or home care representatives at testing and counselling centres. The advantage of involving people with HIV in testing and counselling services is that this can increase utilisation of testing and counselling services and more people might be screened earlier for treatment.
6. Explore the use of rapid tests for HIV in health centres or home care to decentralise testing. These tests are very easy to use and do not require laboratory services or complex training.
7. Continue to provide technical and financial support to strengthen and expand the integration of HIV/AIDS and TB services. All people with HIV should be able to access TB prevention and care services. Contact through home-based care, community groups, and groups of people with HIV on TB treatment all need to be increased. Home care teams and community volunteers could be more involved both in identifying TB cases, and in providing support to people with HIV on TB treatment. Support to people with HIV on TB therapy should jointly be the responsibility of home-based care teams and DOTS teams. Implementation

²⁹ As a sub-recipient of GFATM funding (1st round), KHANA will be scaling up home-based care by a further 25 teams over the next two years. It is suggested that all recommendations relating to home-based care apply to the existing home-based care teams and the new home based care teams.

of community based DOTS (in accordance with national guidelines) should be supported. Support groups of people with HIV on TB treatment could conduct HIV/AIDS and TB IEC in the community and help to ensure compliance to TB treatment.

8. STI services may represent an important first contact with public services for people with HIV and measures to encourage HIV/AIDS testing and referral (as for TB) should be considered. Supporting the introduction of syndromic management of STIs into home care packages should also be considered as a priority. Encouraging the development of better quality TB and STI treatment and better integration of services is also important.

9. Continue to influence the policy environment for the development and scaling up of PMTCT+ programmes. Continue to advocate for effective counselling and referral at VCT centres and involve people living with HIV in implementation, referral, and monitoring the quality of counselling services.

10. Continue to share experience and influence policy on developing HIV/AIDS workplace and medical benefits policies.

Developing new approaches - ARV Treatment

11. Support a systematic assessment of knowledge, beliefs, attitudes and experiences about ARV treatment amongst people with HIV, their families or those involved in providing the treatment. The assessment should include all the different groups involved in the provision and use of ARV treatment. Based on the results of the assessment, plan systematic, on-going ARV education among different groups, focussing on key messages.

12. Collaborate with Centre of Hope, MSF-France, MSF-Belgium, MDM and Pharmaciens Sans Frontieres to develop comprehensive training on ARV treatment for home-based care teams and people with HIV.

13. Explore and develop opportunities with MDM and Centre of Hope on training of health care workers and scaling up access to ARV treatment through the home care network.

14. Provide technical and financial support to build the capacity of home-based care teams and support groups of people with HIV in community preparedness³⁰ for ARV treatment. This should be done in all sites where KHANA supports/plans to support home-based care and groups of people with HIV. Provide technical and financial support for providing education on ARV treatment for home-based care teams and support groups of people with HIV on all aspects of ARV treatment. This includes supporting people with HIV as peer educators on treatment, home-based care teams and support groups of people with HIV as adherence counsellors for patients placed on ARV treatment. Ensure ARV treatment education and adherence counselling is systematic and ongoing for support groups of people with HIV/AIDS.

³⁰ Community preparedness for ARV treatment includes the following: providing ongoing information, skills and training across sectors, ensuring adequate supplies of medicines, diagnostics and other materials, ensuring involvement of people with HIV and those on ARV treatment, involving communities from the planning stages of ARV treatment programmes, supporting and working with a range of different health systems in a co-ordinated manner, encouraging dialogue and collaboration with a range of partners, increasing community participation and making better use of existing structures and services.

15. Provide technical and financial support to interventions that directly integrate ARV consumer education into counselling at testing and counselling centres and in the community. This could play an important role in encouraging testing and follow-up and have an impact on HIV/AIDS prevention.

16. Provide technical and financial support to facilitate effective referral of TB patients for ARV treatment. Many HIV-positive TB patients will meet criteria for ARV treatment, and should be counselled and referred for ARV treatment as appropriate.

17. Provide technical and financial support for developing and implementing interventions with home-based care teams and groups of people with HIV on prevention for/by/with people with HIV.

18. Explore opportunities for developing the capacity of groups of people with HIV on advocating for their rights to care and treatment.

19. Explore opportunities for promoting the active involvement of under-represented populations (i.e. sex workers, the military, and the middle class) in support groups of people with HIV/networks and ARV treatment programmes.

20. Continue to influence the policy environment for the increased involvement of people with HIV in all aspects of ARV treatment programmes including setting priorities, treatment selection, managing drugs, funds, treatment literacy, etc.

21. Continue to influence the policy environment for ensuring adequate supplies of essential medicines and related commodities, including the use of generic drugs, and support lobbying to ensure trade laws do not prevent access to these sources.

22. Continue to influence the policy environment for GFATM proposals that include ARV treatment components to be in accordance with a community-focused vision of home care and groups of people with HIV.

9 Annexes

Annexes

1 Key informants

National Centre for HIV/AIDS, Dermatology and STDs (NCHADS)
 Ministry of Health
 Cambodian People Living with HIV/AIDS Network (CPN+)
 Vithey Chivit
 People with HIV (Takeo)
 Group of people with HIV/AIDS (Phnom Penh)
 Home Care Network (Phnom Penh)
 Home Care Team (Banteay Srei)
 Home Care Team (Phnom Penh)
 Centre of Hope
 PMTCT Working Group
 VCT centre (National STI clinic, Psar Depou)
 Medecins Du Monde
 Medecins Sans Frontieres - France (Phnom Penh, Bangkok)
 Medecins Sans Frontieres - Belgium (Siem Reap, Takeo)
 Pharmaciens sans Frontieres
 Representative from a private pharmacy (Phnom Penh)
 Key of Social Health Education Road (KOSHER)
 Indra Devi Association (IDA)
 Khmer HIV/AIDS NGO Alliance (KHANA)
 OXFAM
 Cambodian Prostitutes Union
 Care International
 Family Health International
 Caritas
 International HIV/AIDS Alliance
 UNAIDS
 WHO
 UNDP
 GPO pharmacist (Bangkok)

2 Current Sources of ARV Treatment

MSF-France, Sihanouk and Russian Hospital (Phnom Penh)

All medicines, lab tests etc are provided free by MSF. There are approximately 3000 people with HIV in follow-up. The plan is to have 500 people on treatment in 2003.

MDM, Calmette Hospital (Phnom Penh)

MDM provides a free service with some cost recovery, as well as provision of medicines at cost price to those who are able to pay. Patients pay according to ability but are not discriminated against according to their ability to pay. Numbers on treatment will increase significantly when GFATM is received. MDM provides training for one doctor and there is potential to provide more training in the future.

Centre of Hope (Phnom Penh)

They recently started providing free ARV triple therapy. Most patients are on GPOvir triple therapy. They have 300 people with HIV in follow-up. Numbers on treatment will increase significantly when GFATM money is received. There is a plan to scale up provision of training on ARV use.

Private Sector (Phnom Penh)

It is impossible to know how many patients have received or are receiving treatment through the private sector. Many people are on bi-therapy but increasing numbers are on triple therapy. Groups of people with HIV believe significant numbers buy inappropriate therapy from private pharmacies but are not able to quantify this. Very few doctors have undergone accredited training on ARV treatment and many patients are able to buy ARVs directly from private pharmacies.

ESTHER Programme (Phnom Penh, Battambang, and Siem Reap)

ESTHER is a new multi-national programme supported by 4 European countries to develop partnerships between Western and developing country hospitals to increase delivery of care, including ARV treatment. In Cambodia, with French government support, rapid introduction of ARV treatment is planned in a number of areas including Phnom Penh, Battambang, and Siem Reap.

MSF-Belgium, Siem Reap

A chronic disease clinic recently opened within Siem Reap Provincial Hospital. It predominantly provides treatment for HIV, diabetes, and hypertension. The first patients started on ARVs in October, 2003. 10-15 new HIV/AIDS patients are to be included on treatment every month.

MSF-Belgium, Takeo

A chronic disease clinic recently opened within Takeo Provincial Hospital. It predominantly provides treatment for HIV, diabetes, and hypertension. The first patients will start treatment in September 2003. The plan is to include 100 - 200 patients per year for 5 years.

3 Fact Sheet: Anti-retroviral Drugs³¹

What is HIV/AIDS?

HIV (*human immuno-deficiency virus*) is a virus that causes infections in humans. It passes from one person to another through semen, vaginal fluid, blood or breast milk. The most common way to get the infection is through unprotected sexual intercourse. It can also be transmitted through injection needles or blades that have already been used on someone who is HIV-infected. Unborn babies can sometimes get the infection if the mother is HIV-infected.

At first, the infection does not make a person very ill - he or she may remain apparently healthy for some months or years. People usually do not know that they are HIV-infected until they have a special blood test. If the test shows that HIV is present, a person is said to be HIV-positive.

After some time, illnesses may start to appear, especially infections such as TB, herpes (shingles) and other skin or chest infections. The person may lose a lot of weight, start to feel very tired and be unable to do all their usual daily activities. These signs of HIV infection are known as AIDS. They show that the person's body has become unable to repair or defend itself in the usual ways that keep humans healthy. If the person does not get treatment, she or he will gradually become very ill and will eventually die.

People with HIV can get different kinds of treatment, both for the illnesses caused by HIV/AIDS and for fighting the virus itself. The simplest treatment is to make sure an HIV-positive person always gets good food and clean water, and gets good basic care when they are ill. People with HIV need more protein and vitamins in their food than other people. Basic care for illnesses can include simple household or herbal remedies for problems such as skin irritations or mild diarrhoea.

People with HIV also need access to good medical treatment when they get illnesses that are caused by HIV, such as for TB, skin or chest infections. Some of the medicines that are needed are quite cheap and simple to use. They are often provided through home care programmes as well as at clinics and hospitals. Other medicines are more expensive or difficult to use properly, so they might be provided through special clinics and the patient might need special support to use them. For example, TB treatments are often provided through a DOTS scheme in which health care workers or family provide support to the patient to take all their drugs in the right way for as long as treatment is needed (usually 9-12 months).

It is also possible now to treat HIV infection with drugs that attack the HIV virus itself. These drugs did not exist when the HIV epidemic first started but new drugs were invented during the 1990s. Treatment at first was highly expensive, but the drugs were used very successfully in America and Europe. People in those countries are now able to live much longer and healthier lives with HIV than people who do not get the treatment. These drugs are called **anti-retrovirals** or **ARVs**.

³¹ Draft - developed by the International HIV/AIDS Alliance

Anti-retroviral drugs (ARVs)

What can ARVs do?

ARVs can bring a person with AIDS back to good health, and keep an HIV-positive person healthy. They do this by interfering with the ability of the HIV virus to reproduce in the body. This reduces the amount of virus (viral load) in the body and so reducing the ability of the virus to damage the body's defence system (the immune system). This means that the immune system can continue to defend the person against attack by other infections and the person can stay healthy and live longer. But it is important to remember the following:

ARVs do not destroy HIV - but they can reduce its effects and prolong life.

There are three main types of ARV drugs. Each type of drug attacks the virus in a different way. These different types of drugs are used together *as combination treatment* or **HAART** - highly active anti-retroviral therapy. In the special case of preventing mother-to-child HIV transmission (PMTCT), just one or two types of drug may be used for a short time, to protect the baby from becoming infected by its mother's HIV virus during the birth. This does not have any effect on the mother's HIV infection.

Types of ARVs	Generic and Short Chemical Names
Nucleoside analogues (also called Nucleoside Reverse Transcriptase Inhibitors or NRTIs)	Zidovudine (AZT) Didanosine (ddI) Zalcitabine (ddC) Stavudine (d4T) Lamivudine (3TC) Abacavir (ABV)
Nucleotide analogues (also called Nucleotide Reverse Transcriptase Inhibitors)	Tenofovir
Non-nucleoside Reverse Transcriptase Inhibitors (NNRTIs)	Efavirenz (EFV) Nevirapine (NVP) Delavirdine (DLV)
Protease Inhibitors (PIs)	Saquinavir (SQV) Ritonavir (r) Indinavir (IDV) Nelfinavir (NFV) Amprenavir Lopinavir (LPV)

How does my doctor know that I need ARVs?

Treatment usually starts only when HIV has caused obvious damage to the immune system. The doctor can find out what is happening by carefully examining the patient and checking for any illnesses or problems. Special blood tests can also be used. If medical resources are limited, the doctor will depend on basic tests for anaemia and white blood cells. If resources are better, a special CD4 test can be done - this can show how much damage HIV has done to

the immune system and will guide the doctor about when to start treatment. In well-resourced hospitals, a viral load test can be done. This shows how much HIV virus is in the body.

How do I take ARVs?

ARVs are usually in tablets or capsules, or sometimes liquids for taking by mouth. Some have to be taken with an empty stomach, others after first taking some food. They must be taken at specific (accurate) times during each day. This is because the amount of drug in the body must remain at the same level all the time. ARVs do not destroy (cure) HIV infection, so the treatment must continue for the rest of a person's life. This is a big commitment, so the doctor and the patient must help each other to work out which drugs fit in best with the patient's life. They must also make sure that the patient's condition is regularly monitored to make sure the treatment is working and that the patient is not suffering too much from drug side effects.

What are the side effects of ARVs?

All medicines can cause side effects. These are unwanted effects, which vary from causing small inconveniences, such as slight constipation to major problems such as liver damage. Different ARVs cause different side effects and the side effects do not always happen to every patient. Some will last only a short time, soon after starting treatment, then they disappear and treatment can continue without problems. Others can be very serious. They may appear mild at first, but can indicate major problems. So a patient should know before starting treatment what side effects might happen and what to do if anything unusual happens. The doctor may decide to change the treatment to different ARVs if side effects are a problem.

Can I take alcohol, tobacco or other drugs when I am using ARVs?

ARVs and many other substances can affect each other in different ways. It is therefore very important to tell the doctor or pharmacist what else you are taking if you are prescribed ARVs. These substances include alcohol, tobacco, cannabis, narcotics and any prescription drugs or other medicines that you use (such as pain killers, vitamins, cough remedies etc.) Some of these will have no effect on your ARV treatment but others might change the effects of your treatment. Your treatment might have to be changed or you might have to stop using certain medicines or substances that interfere with ARV treatment. This is especially important if the liver is not working well. Remember that excessive use of alcohol can damage the liver, and smoking damages the lungs.

Drug resistance - a problem with ARVs

Another problem of taking ARVs is that the medication can become ineffective, which means that the treatment fails. This is because the HIV virus can change so that a particular drug cannot attack it any more. This means that the viral load increases and the immune system starts to get damaged again. This is called drug resistance. It happens much more easily if a few doses are missed or taken at the wrong time. If treatment fails, the doctor will try to change to a different type of HAART, which might need four or five drugs, but the extra drugs might not be available and the treatment will become more complicated. A person with resistant virus can pass it to another person who will also need special treatment, if it is available.

Sticking to ARV treatment - what is 'adherence'?

Sticking to ARV treatment is called adherence. This means taking the correct doses at the correct times in the correct ways, for as long as prescribed. All medicines require adherence, but most people forget doses or do not always take them at the right time. ARV doses **MUST** be taken faithfully all the time (90-95%) and for the rest of the patient's life in order to work effectively. It is very hard for people to do this if they are isolated, depressed, forgetful or worrying too much about the effects of their medication.

The doctor, pharmacist and support workers should work with the patient to find ways for him or her to take the treatment in the right way. They should make sure the patient knows what to do if side effects occur, since this is a common reason for patients to stop taking their medicines. They should also try to get support from other people to support adherence and coping with side effects. A family member or a community health care worker could give this. A patient might want to keep her or his HIV status and treatment private, but it will help greatly if someone (such as a friend) can be found to share the secret and provide support in a confidential way.



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