



**National Center for HIV, Dermatology and STI
Ministry of Health
Royal Kingdom of Cambodia**

Expanding the Continuum of Care to Children

In collaboration with Dr. Shaffiq Essajee and the
Clinton Foundation HIV/AIDS Initiative Pediatric Initiative



Abbreviations

AHC	Angkor Hospital for Children
ANC	Ante-natal care
CDC	Center for Disease Control
CHAI	Clinton Foundation HIV/AIDS Initiative
GFATM	Global Fund Against HIV/AIDS, TB, Malaria
HBC	Home-based care
MSF	Médecins Sans Frontiers
NCHADS	National Center for HIV, Dermatology and STI
OVC	Orphans and Vulnerable Children
PMTCT	Prevention of Mother-to-Child Transmission
RH	Referral Hospital

Introduction

Current reports place the HIV prevalence rate in Cambodia at 1.9% ¹ of the general population. Although this is small compared with many nations in sub-Saharan Africa, it is the highest sero-prevalence in the South-east Asia region. It is noteworthy that this rate has actually declined over the past five years – which is a testament to the political commitment of the Government of Cambodia and the success of HIV prevention programs that have resulted in almost universal acceptance of condom usage.

Approximately 123,000 Cambodians aged 15-49 are estimated to be living with HIV. An additional 12,000 (approximately 10% of the total) are children under the age of 15. ² The provision of antiretroviral treatment (ART) to people living with HIV/AIDS (PLHA) is a relatively new phenomenon in Cambodia. The National Strategic Response to HIV was, until 2004, primarily focused on HIV prevention through VCCT and health education. But the advent of high level funding from the Global Fund for AIDS, TB and Malaria (GFATM) has drawn attention to the need to expand and support ART services.

In August 2005, there are around 8,000 adults on ART through public and private sector services. In keeping with the global trend, the numbers of children on treatment is small. Although there are 2 - 3,000 children living with AIDS in Cambodia, only 4 - 500 children are thought to be receiving treatment – primarily at 4 sites in the country (National Pediatric Referral Hospital, Mary Knoll Phnom Penh, AHC in Siem Reap and MSF at a variety of MoH locations, particularly Takeo Referral Hospital)

The Cambodian National Strategic Response to HIV/AIDS has a clearly articulated Continuum of Care (CoC) to provide HIV treatment to PLHA. The CoC has a particularly strong community component within it, but children with HIV are not currently encompassed within this structure. The Clinton Foundation HIV/AIDS Initiative is committed to supporting the government of Cambodia to expand pediatric HIV/AIDS care in Cambodia as outlined in the Memorandum of Understanding between CHAI and the Ministry of Health. This concept paper is a first step to try and achieve that goal.

The general and specific objectives of this concept paper were:

General Objectives:

- To examine current status of Pediatric Care and Treatment.
- To draft a concept paper with key findings and suggestions for treatment scale-up.

Specific Objectives

- To assess ways to incorporate pediatric care and treatment into the existing CoC framework.
- To assist in development of the national training curriculum for Pediatric treatment and counseling.

¹ Cambodian National Documents

² Cambodian National Documents

The findings of this report were generated from literature review, information from the Ministry of Health and other organizations and site visits and meetings with key players in the arena of pediatric HIV care in Cambodia. We hope to offer ideas and suggestions that will improve the lives of children living with HIV/AIDS in Cambodia. The results are presented in the following format:

- Key problems identified
- Integration of children into the Continuum of Care
- Programmatic suggestions/solutions
- Summary

Key Problems Identified

- Without access to care, HIV infected infants have very high mortality (>50% in the first 2 years).³ Many of these children die before they are recognized as HIV infected or exposed, indeed their deaths may not be registered into National statistics. As a result, the numbers of infected children may exceed the estimated 10% of all PHA in Cambodia.
- In Cambodia, a relatively small proportion of pregnant women (between 36-45%)⁴ attend public ante-natal clinics prior to delivery. In addition, approximately 45% of women give birth at home without a medically trained “skilled assistant”.⁵ This results in a high maternal mortality rate, relatively low uptake of prevention of mother-to-child HIV transmission (pMTCT) services, and a large number of preventable pediatric infections. MTCT of HIV is thought to account for approximately 30% of all new HIV infections in Cambodia.⁶
- In the current Continuum of Care, pMTCT is considered a vertical program linked with VCCT services, rather than HIV care services. This means that with some exceptions, few establishments have a robust referral mechanism in place to enable HIV-positive mothers and their infants to access further life-saving care interventions.
- Few providers have currently been trained in pediatric HIV treatment and care.
- At present there is a relative shortage of pediatric ARVs in Cambodia. However, the budget for round 4 of the GFATM – which will be granted in early 2005 – has a sizeable allocation for pediatric drugs that will accommodate in excess of 1,500 children by the end of 2007. Although it is unlikely that any of these drugs will be available in the country before July 2006, there is a need to scale up pediatric treatment now, in order to save children’s lives and establish a vibrant National Pediatric Treatment Program in readiness for the rapid influx of pediatric ARVs by mid 2006.
- There are inadequate facilities for pediatric CD4 testing in Cambodia. Overall, few sites have capacity for CD4 testing, and those that do utilize either the Partec CyFlow instrument (which is highly user dependent and has a poor QA record) or the BD FACSCOUNT instrument (which is not ideal for monitoring HIV-infected children under the age of 6).
- For HIV exposed infants under the age of 18 months, a virologic test is needed to confirm an HIV diagnosis. This is not available in Cambodia. Although the Cambodian National Pediatric HIV Guidelines do offer recommendations for treatment of HIV exposed infants without confirmation of HIV status, in practice these are difficult to use and even the most experienced clinicians are hesitant to treat children based on these recommendations. For example, the National Pediatric Hospital, has only 2 infants on treatment out of a total of 95 children.

³ Newell et al.

⁴ Cambodian National STats

⁵ Cambodian National Stats

⁶ UNAIDS and other stats – check existing docs on Cambodia

- There are a number of NGOs – AHC, French Red Cross, Maryknoll, MSF and others - that are providing ART to the children of Cambodia. Some of these offer innovative community-based care programs that are very much in the spirit of the CoC, and could be instructive for the Cambodian National Program.
- With about 18,000 deaths related to AIDS per year, the issue of AIDS orphans is also a serious concern; this is compounded by poverty and the fact that Cambodian society is still in a state of recovery from devastating decades of conflict. Although a number of organizations are providing orphan care, institutional care is not a solution that can accommodate the extent of the problem. The CoC offers a framework that could be used to tackle this challenge.

Integrating children into the Continuum of Care

A. Defining better child linkages within the CoC.

- The current CoC model has three elements arranged in an interdependent continuum – the community, home and the referral hospital. The needs of children are not clearly articulated in this structure.
- All three levels of care within the continuum can be sources for pediatric clients. The primary entry points for children are:
 - through pMTCT
 - from the pediatric OPD of the RH or health center well-child follow-up and immunization service
 - the pediatric in-patient ward of the RH
 - the TB ward of the RH
 - through improved case finding by community and home based care teams health care workers and PLHA support groups
- several simple programmatic approaches can increase the numbers of HIV-infected children entering care.

1. Educating healthcare workers (HCWs) in pMTCT programs or in ANC services to refer HIV-positive mothers and their children.

- HCWs in pMTCT programs should know *where* their nearest referral base is located and have a concrete referral mechanism
- One way to do this would be to create a booklet of referral resources. This would provide information on available VCCT/pMTCT/adult, family and pediatric care services in each geographic region. The booklet would also have contact information for identified point persons for referral at each of those referral sites.

2. Educating HCWs in well-child/immunization services at Health Centers to enable them to recognize pediatric HIV and refer for VCCT.

- International Management of Childhood Illness (IMCI) guidelines already provide criteria for suspected HIV bases on signs and symptoms⁷
- Clear information presented in large poster format at the point of care would make it easier for HCWs to understand these signs/symptoms and make the relevant referrals.
- HCWs should have the means to “flag” an immunization record if they believe the child is high risk. This could be done by means of a small sticker that a HCW could put on a “yellow card” in order to mark that as a possibly infected patient. This would ensure that even if a patient does not respond to the HCW’s first recommendation for testing, there would be a means to follow up the patient and re-enforce the need for testing at subsequent visits.

⁷ IMCI guidelines website?

3. Use existing human resources to facilitate referral.

- Referral facilitators would be located in pMTCT services, ANC and health centers
- Home-based care and peer support is known to be a highly effective way of ensuring that HIV-positive pregnant women come for follow-up services after pMTCT.
- The MMM may be an ideal resource for these additional referral facilitators. Many MMM members are highly motivated advocates and some are on ART themselves, thus they would not only serve as physical conduits for referral but also as lay counselors for referred patients.

4. Education of HCWs in TB programs including DOTS at health centers to recognize that children with TB are at very high risk of HIV co-infection.

- All patients with TB should be counseled for HIV testing.
- Although the diagnosis of TB in children is difficult and subjective, the high risk of HIV, and the consequences for TB treatment if there is HIV co-infection make it especially important to counsel for VCCT⁸

5. A high-impact public education program within PLHA communities to raise *Treatment Literacy*

- There is a prevalent perception in Cambodia that ART for children is not available and that children cannot benefit from ART
- Home-based care teams and PLHA support groups, should be educated about the fact that children respond very well to ART and tend to have fewer side effects than adults, especially during MMM meetings.
- HIV-positive parents should be encouraged by home-based care teams, peer support groups *and* HCWs at all levels of the health care system to bring their children for HIV testing.
- HIV-positive parents should know that ART for children is available.
- The BCC (Behaviour, Change, and Communication) unit at NCHADS should be tasked with the duty of creating a treatment literacy campaign to address both adult *and* pediatric treatment through IEC materials and mass media.

⁸ In addition to the traditional testing model of VCCT, many health programs are now encouraging the concept of DCT (Diagnostic counselling and testing) especially in clinical care environments (in-patient ward, TB clinic) where a large proportion of the patients are likely infected

B. Creating a Family based initiative in the CoC

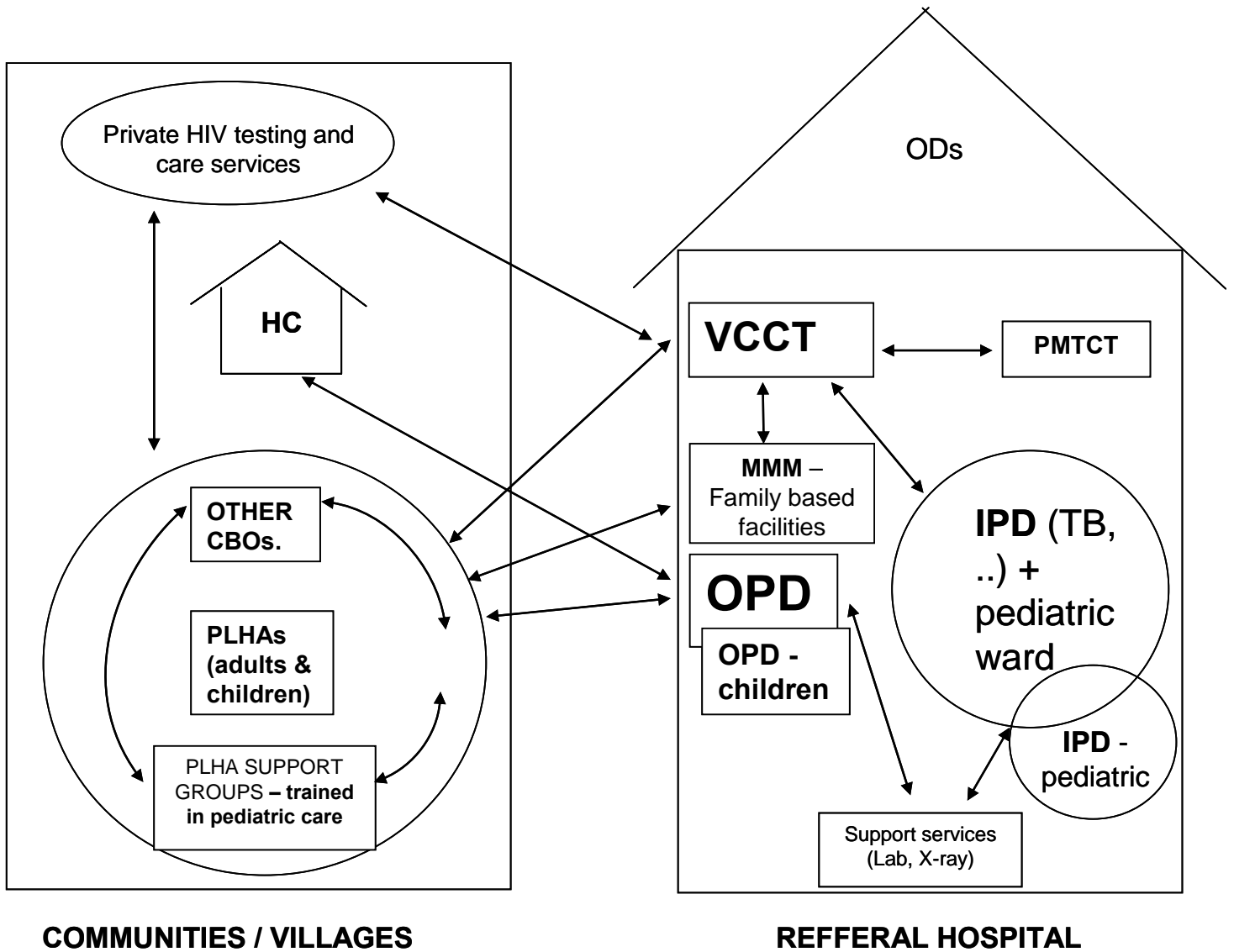
- The majority of children currently on treatment are receiving care within specialized pediatric programs. Although this model ensures high quality services, and is necessary to develop National centers for excellence in training and referral, beyond Phnom Penh and the large provincial centers, there are not enough pediatricians to sustain this approach.
 - Family centered care is well suited to the Cambodian CoC. The CoC has a vital community element that is led by PLHA groups which can extend family centered care from the hospital into the home through home-based care teams and peer support groups trained in pediatric care.⁹
 - There are more than 100 PLHA support groups, and many PLHA are parents themselves, and therefore the strongest advocates for care for their infected children.
 - PLHA support groups could be key partners with the MoH to create family-based care programs. In addition family centered care also recognizes the issues of both HIV- infected and HIV-affected members of the family.
 - Experience in other settings has shown that family-based care improves treatment adherence for *both* caregiver and child.
 - In settings where travel to the clinic is a significant impediment to obtaining services, it might be useful to be able to offer care to both parents and children at the same clinic visit.

C. Strengthening Orphan care within the CoC

- PLHA home based care teams and peer support groups should be encouraged to expand community and home-based care activities to OVC affected by HIV/AIDS.
- Organizations that care for OVC affected by HIV/AIDS should also be encouraged to present orphans for VCCT
- Communities and extended families that provide care for OVC should be assisted with resources and services, and empowered with skills to enable them to cope with the added burden of orphan care.
- These community initiatives should be supported by legislation to ensure that orphans are not denied access to education, and that inherited property is protected until orphans reach the age of maturity.

⁹ Family based care references

The expanded Continuum of Care (including children)



In communities:

- CBO
- Community leaders
- Religious leaders
- Village Health volunteers
- Local NGOs
- Hospices

Programmatic Suggestions/Solutions

i. Amendments to the Pediatric Guidelines

- Although NCHADS already has an excellent set of concise pediatric guidelines, WHO pediatric classifications should be revised in light of newer recommendations which link pediatric HIV classification more closely with IMCI guidelines. (*Annex 1*).
- Pediatric dosing would be more easily understood if the dosing approach was simplified, based on weight bands, rather than body surface area. Many providers in Cambodia, including MSF use weight bands to treat children. A well-accepted weight band regimen has been developed by the US CDC, in collaboration with Columbia and Baylor University (*Annex 2*).
- The choice of antiretroviral drugs in the national pediatric guidelines is appropriate and in line with WHO recommendations, however, clinicians should be aware that zidovudine is of particular benefit to HIV-infected children as it crosses the blood-brain barrier and can improve HIV-associated encephalopathy and developmental delay.¹⁰ This benefit must be balanced against the risk of zidovudine-associated anemia.
- The guidelines focus on pediatric ART, but a comprehensive pediatric HIV care approach needs to stress other elements of routine care which are important.
 - Anemia secondary to malaria, hookworm, nutritional deficiency, ART and HIV, is a key factor. Screening for and treatment of anemia is essential to healthy growth and cognitive development.¹¹
 - Routine 6 monthly treatments with mebendazole is a highly cost-effective intervention especially for children in rural areas which are endemic for parasite infections.¹²
 - Adequate nutrition is a critical element of pediatric ART.
 - HIV-infected children may benefit from an expanded array of immunizations, including 3 doses of conjugated pneumococcal and conjugated hemophilus B vaccines. These are safe in immune-compromised children and should be given at 2 month intervals as soon as HIV infection is confirmed.¹³

ii. Training and Development of Curriculum

- The Cambodian pediatric training curriculum is currently under development. While this curriculum must be developed by Cambodian pediatric providers, there are several

¹⁰ Zidovudine refernece

¹¹ Anemia reference

¹² Bentwich etc

¹³ Immunization with expanded immunizations in HIV-infected kids

established curricula that may be of use. A listing of these curricula and URLs where they may be found on the web is given in *Annex 3*.

- Pediatric counseling presents unique challenges that are often overlooked.
 - *Annex 4* provides some specific directives on pediatric counseling, including counseling for disclosure of HIV status to children and counseling for the family.
 - Several sites in Cambodia have valuable expertise in the area of pediatric counseling in the Cambodian setting. These sites (Mary Knoll and Angkor Children’s Hospital) should be encouraged to contribute to the development of the pediatric curriculum in this specific area.

- “Bedside” or clinical training is more effective than didactic training alone. The facilities of the Angkor Children’s Hospital in Siem Reap and the National Pediatric Referral Hospital in Phnom Penh are excellent sites for clinical pediatric HIV training, but are in heavy demand.

- International training – especially within the South-east Asia region will be necessary to build the capacity of treatment sites. As an initial plan, 10 pediatricians from sites around the country (inc. Battambang, Pursat, Svay Rieng and National Paediatric Hospital) will be trained in pediatric HIV in Thailand at Chiang Mai University with the support of FHI. Such trainings should be expanded to include physicians working with both NGO and MoH groups.

- The training model for adult HIV care provides training over the course of 6 months for 2 weeks per month. This is an excellent design, but requires significant time spent away from clinical care. It might be advisable to *incorporate* pediatric HIV training into the adult training program. This approach emphasizes the fact that in many situations, both adults and children may be treated by the same physicians in a family based care approach.

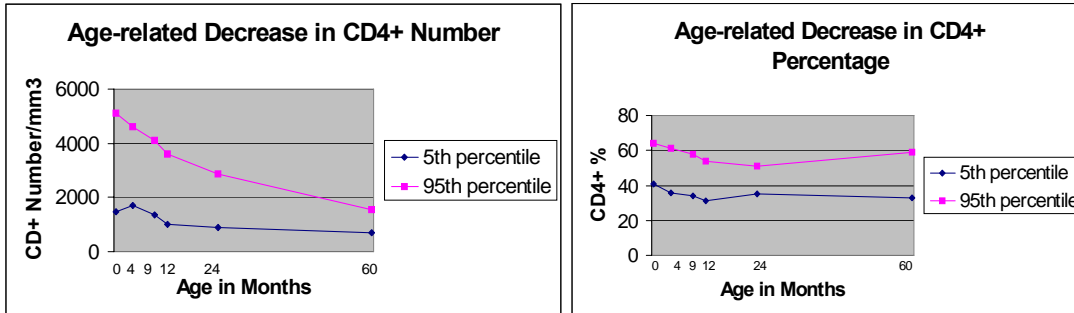
- Emphasis should be placed on training “teams” of doctors, nurses, counselors, pharmacists rather than individuals in isolation.

- The training curriculum should also include a series of pocket sized “aide-memoires” to serve as a quick reference for clinicians providing pediatric care. These should be very condensed and concise. Possible topics could include:
 - antiretroviral drugs and doses
 - Guidelines for prophylaxis
 - Summaries of algorithms for toxicity/failure
 - Monitoring algorithms
 - Interpretation of laboratory tests
 - Referral resources

iii. Improving Laboratory Diagnosis and Monitoring

- The BD FASCCOUNT is the most “user-friendly” CD4 monitoring platform currently available. However, the use of FACSCOUNT poses problems for pediatric monitoring.

- Normal CD4 counts are very high in young children and decline to adult levels by 6 years.
- CD4 percentages remain stable over this period, thus CD4 percentages are used in children to determine ART eligibility criteria and treatment response



- The FACSCOUNT analysis software rejects results that have too high a CD4 count as erroneous, thus the majority of pediatric samples from children under the age of 12 months will fail to be read by FACSCOUNT.
- The ideal solution is to use an instrument such as FACSCaliber which does not have the limitations of FACSCOUNT. However, there is only one FACSCaliber available in the country at present (Institut Pasteur). This instrument is used to analyze samples from Phnom Penh and other provinces, but for logistic reasons, Pasteur limits the number of tests to 5 samples per week per site. This is a significant impediment to pediatric scale up.
- In order to make use of FACSCOUNT instruments, the standard operating procedure (SOP) for FACSCOUNT in children should be modified:
 - For samples from children below 12 months, *dilute* the sample 4-fold with normal saline to obtain a result. The final CD4 count is then calculated by multiplying the test result by a factor of 4.
 - For all samples from children below 6 years, perform a full blood count with automated or manual differential count to obtain the total lymphocyte count. The CD4 percentage can be calculated by dividing the CD4 count by the total lymphocyte count.
- Infant diagnosis requires virologic assays such as DNA PCR. This is not available in Cambodia. There is an instrument for “real-time PCR” at the Institut Pasteur. Real-time PCR shows promise as a cost-effective and sensitive method for infant diagnosis, but at present this is a research test. Recommendations are:
 - To establish DNA PCR at an infant diagnosis reference center in Cambodia – either the National Pediatric Hospital, or the National Institute of Public Health.
 - To use a modified DNA PCR using filter paper dried blood spots (DBS) rather than fresh samples of blood. DBS are stable, safe and much easier to transport than samples of blood. DBS could be sent from the provinces to the reference center for testing.

- Based on current guidelines for HIV-exposed infants (exclusive breast feeding and early weaning at 6 months), DBS would need to be performed twice – at 3 months of age and 7 months of age to rule out HIV infection.
- Ruling out infection would enable early cessation of cotrimoxazole prophylaxis and would permit HCWs to provide definitive information to mothers on the HIV status of their infants.
- Infants found to be infected, could be eligible for initiation of ART, which would have a significant impact on infant mortality.

iv. Strengthening pMTCT

- In the developed world, pediatric HIV infection has been virtually eradicated by improved pMTCT. In Cambodia, this could be achieved by 2 means and should be addressed jointly with the Directors of the National pMTCT program:
 - Providing ART to all infected pregnant women from the third trimester using non-efavirenz based regimens. [Close hepatic monitoring is necessary for pregnant women with a high CD4 (>500) who are taking nevirapine.]
 - Using a combination of zidovudine from 28 weeks gestation with single-dose nevirapine around labor to the mother and single dose nevirapine with zidovudine to the infant for one week (Lallemant et al. NEJM 2004 *Annex 5*). This approach has become national policy in Thailand and could be implemented in Cambodia.
- Improved education in the community and among HCWs about the effectiveness of pMTCT interventions.
- Outreach to TBA to encourage pregnant women to attend for VCCT and pMTCT program.

v. Integrating Pediatric Care into existing home-based care activities

- There at least two successful pediatric HBC scenarios in Cambodia
 - At the Mary Knoll clinic, trained part-time non-medical personnel visit each child on treatment twice a day to deliver the ART doses and observe that drugs are taken.
 - Angkor Children’s Hospital operates a rural equivalent of this model by providing home visits each week to children on ART
 - These scenarios are intensive, but cost-effective since they maximize adherence and enable HBC workers to detect side effects very early and monitor for weight increases that require dose modification. (Mary Knoll provides treatment to 225 children and has not noted a single case of primary treatment failure in patients who were previously treatment naïve).
 - As part of the CoC, HBC activities should focus not just on the adult PLHA needs but on the child and the whole family

- Learning from the experiences of the Maryknoll and AHC models, pediatric care should be integrated into the existing HBC activities as part of the CoC framework in Cambodia
- This should also be part of PLHA support groups for improving the role of the community in supporting children affected by HIV/AIDS.

vi. Improving Quality of Care in the Pediatric/Family-based HIV Treatment Clinic

- Improved management of systems to increase work efficiency and minimize duplication of services
 - Examine work flow and ensure that providers each know their respective roles and duties.
 - Most hospital based pediatric clinics and programs are focused on the management of acute illnesses. Quality HIV care depends on being able to provide chronic health maintenance. This necessitates a change in the way in which programs are managed to put greater emphasis on a multidisciplinary approach.
- Record keeping – what tools have been developed to facilitate good record and data management?
 - NPH has some well designed HIV patient charts and records. These should be adopted as part of a national program of scale up
 - In addition, there are patient tools that have been developed by FHI for health record keeping. Similar tools should be developed for children.
- Continuity of providers is a very important element of care. Providers should be supported to stay in the same location and not be transferred from one location/department to another. This ensures that the best trained individuals are delivering the highest quality of care
- Improving patient satisfaction
 - peer review of records
 - a patient suggestion box
 - clinic notices re-enforcing the need to provide professional, respectful, courteous and compassionate care at all times.
 - Use of PLHA in the clinic as patient advocates to minimize stigma and discrimination in the health care setting.

vii. Maximizing Access to Resources

- The international momentum to scale up global pediatric HIV treatment is building with a number of agencies focusing greater attention on children, resulting in greater resource allocation for pediatric HIV.

- CHAI has recently launched a global pediatric treatment program that could bring donated pediatric ARVs into Cambodia urgently to clear the current bottleneck in the availability of pediatric formulations.
 - UNICEF is supporting training for 12 pediatricians to attend a pediatric treatment course in Thailand
 - UNICEF has undertaken the support pediatric treatment services at several sites where there is an existing pMTCT program.
- o The AIDS Care Unit of NCHADS has a vital role to play in this arena
 - The unit will be in charge of ensuring communication, coordination and cooperation between NCHADS and *all* sites providing pediatric care – both MoH and NGO.
 - In the addition, the unit would work with other NCHADS units and the Ministry of Health to create linkages between related departments such as pMTCT, maternal-child health, TB/HIV, the NAA and the MoH CDC.
 - For NCHADS, improved collaboration with the NGOs could result in a better understanding of how to create a standardized model of pediatric HIV care as well as bring access to more sites for clinical training of providers.
 - For collaborating partners, a stronger relationship with NCHADS could result in lower costs for diagnostics, free pediatric ARVs and improved access to National Programs of training, monitoring and evaluation.

viii. Integrating Children affected by HIV/AIDS into MMM activities

- o Create some activities to support and entertain children while their parents attend MMM meetings.
- o

Summary

Problem	Action Item
<p>Lack of children accessing care</p>	<p>Establishing Better child linkages within the CoC</p> <ul style="list-style-type: none"> - Education for HCWs in pMTCT sites and health center immunization services to refer children for HIV testing and care - Creating a confidential system to “flag” infant yellow cards if a HCW thinks that infant is at high risk - Public Treatment Literacy Campaign aimed at raising awareness among PLHA of the utility of adult <i>and</i> pediatric treatment - Providing a referral resource handbook to all facilities that lists the HIV services available in their region. - Use existing human resources and MMM volunteers to act as referral facilitators from pMTCT services <p>Creation of a family based care model into the CoC</p> <ul style="list-style-type: none"> - Concept of “one-stop” services for mothers and children to receive care and treatment at a single visit - Allows for localization of resources, e.g. for lab/social support/home based care in one place to serve the needs of the whole family - Recognizes that pediatric specialists are often not available outside of large urban centers <p>Strengthening care for orphans OVC</p> <ul style="list-style-type: none"> - Community based care for OVC with PLHA support groups - OVC activities should be supported by access to resources for education, health and legal protection
<p>Pediatric Training Materials</p>	<p>Amendments to Pediatric guidelines, inc latest classification and weight range based dosing</p> <p>Addition of elements of non-ART comprehensive HIV care</p> <p>Development of training curriculum and training models</p> <ul style="list-style-type: none"> - Emphasis on “clinical” training, not only didactics - Link pediatric training to adult training and present the concept of taking an inclusive approach to care of the whole the family

Laboratory support for pediatrics	CD4 Testing <ul style="list-style-type: none"> - Modified SOP for pediatric specimens run on FACSCOUNT using total lymphocyte count to determine CD4 percentage - Modified SOP for infant samples to enable reading on FACSCOUNT Infant Diagnosis <ul style="list-style-type: none"> - Establishment of a national infant DNA PCR testing program
Strengthening pMTCT	Improved outreach to TBA and education to the community to increase uptake of ANC services, and VCCT during pregnancy Use of enhanced regimens for pMTCT
Integrating pediatric care into existing home-based care activities	Use of trained PLHA to support family centered home based care activities Integrate care and support activities for OVC into routine activities for HBC teams
Improving quality of care	Review of clinic work practices to ensure efficient work flow and minimize patient waiting time Ensuring all providers know their roles to avoid duplication or omission of key elements of care Improved systems of record keeping and data management to facilitate provision of chronic health maintenance Peer review of records and patient suggestion box to continuously improve patient satisfaction Stress importance of continuity of care by the same providers Minimize stigma in the workplace by using PLHA as patient advocates
Maximizing Access to Resources	The AIDS care unit at NCHADS should: <ul style="list-style-type: none"> - strengthen linkages between government and NGO sector - better manage and access resources of UNICEF, FHI, CHAI pediatric initiative and other donors with an interest in supporting pediatric HIV care and treatment

Annex 1

PROPOSED WHO CLINICAL STAGING OF HIV INFECTION FOR ADULTS AND ADOLESCENTS

(For use in those 15 years of age or more with positive HIV antibody test or other laboratory evidence of HIV infection)

PRIMARY HIV INFECTION
Unrecognized Acute retroviral syndrome ¹⁴
CLINICAL STAGE 1
Asymptomatic Persistent generalized lymphadenopathy (PGL)
CLINICAL STAGE 2
Moderate unexplained weight loss (<10% of presumed or measured body weight) Recurrent upper respiratory tract infections (sinusitis, bronchitis, otitis media, pharyngitis) Herpes zoster (past or current episodes in last 2 years) Angular cheilitis Recurrent oral ulcerations (2 or more episodes in 6 months) Papular pruritic eruptions Seborrhoeic dermatitis Fungal nail infections of fingers
CLINICAL STAGE 3
Severe weight loss (>10% presumed or measured body weight) Unexplained chronic diarrhoea for longer than one month Unexplained persistent fever (intermittent or constant, for longer than 1 month) Oral candidiasis Oral hairy leukoplakia Pulmonary tuberculosis ¹⁵ (diagnosed in last two years) Severe presumed bacterial infections (e.g. pneumonia, empyema, pyomyositis, bone or joint infection, meningitis, bacteremia) Acute necrotizing ulcerative stomatitis, gingivitis or periodontitis Unexplained Anaemia (<8gm/dl), neutropenia (<1,000/mm ³) or thrombocytopenia (<50,000/ mm ³) for more than 1 month
CLINICAL STAGE 4
<i>Conditions where a presumptive diagnosis can be made using clinical signs or simple investigations:</i> HIV wasting syndrome Pneumocystis pneumonia Recurrent severe or radiological bacterial pneumonia (2 or more episodes within one year) Chronic orolabial, genital, or anorectal Herpes simplex infection (of more 1 month duration) Candidiasis of the oesophagus Extrapulmonary tuberculosis Kaposi's sarcoma CNS toxoplasmosis HIV encephalopathy
<i>Conditions where confirmatory diagnostic testing is necessary:</i> Cryptococcal meningitis or other extrapulmonary disease Disseminated non-tuberculous mycobacteria infection Progressive multifocal leukoencephalopathy (PML) Candida of trachea, bronchi, or lungs Extrapulmonary Cryptococcosis Cryptosporidiosis (diarrhoea more 1 month) Isosporiasis Cytomegalovirus infection (retinitis or of an organ other than liver, spleen, or lymph nodes) Any disseminated mycosis (e.g. Histoplasmosis, Coccidiomycosis, Penicilliosis) Recurrent non-typhoidal salmonella septicaemia (2 or >episodes in one year) Lymphoma (Cerebral or B cell non-Hodgkin's) Invasive cervical carcinoma Leishmaniasis, visceral American trypanosomiasis reactivation
STAGE ON TREATMENT
Above clinical events occurring on ART

¹⁴ Acute febrile illness 2-4 wks post-exposure often with lymphadenopathy and skin manifestations, pharyngitis.

¹⁵ TB may occur at any CD4 count, and this must be considered where available. If CD4 is less than 200 it should be considered as a stage 4 event. Diagnosis and treatment of both pulmonary and extrapulmonary TB should be in line with international and national guidelines.

Explanatory Notes

The clinical staging system for adults and adolescents is designed to:

1. Provide simple guidance to assist clinical care providers in determining when to start, substitute, switch or stop ARV therapy in HIV infected adults and adolescents, and trigger referral as outlined in WHO guidelines for a public health approach. It is also designed to harmonize with HIV and AIDS case surveillance and enable monitoring of trends in the magnitude and severity of HIV related disease.
2. Be used where HIV infection is confirmed by HIV antibody or virological testing.
3. Encourage clinical care providers to consider diagnostic testing for HIV for patients with the clinical conditions suggestive of HIV disease. Stage 2, 3 or 4 events should prompt the offer of HIV diagnostic testing.
4. Classify disease in a progressive sequence from least to most severe, with each higher clinical stage having a poorer prognosis. Once a stage 3 clinical condition has occurred, the prognosis remains that of stage 3 and does not improve, even with resolution of the original condition, or appearance of a new stage 2 clinical event. ARV therapy improves the prognosis. Further evidence is required to determine the significance of staging events once on ARV treatment.
5. Be largely used with reference to CURRENT clinical events, meaning clinical events that have been diagnosed or are being managed at this episode. 'Current clinical event' is taken to include any time from initial assessment and diagnosis through to immediate management and follow-up for the clinical event.
6. Be considered in relation to previous clinical events, such as reported TB, severe pneumonia, PCP or other conditions. This is RETROSPECTIVE clinical staging and requires caution. HIV infected adults reporting stage 2, 3 or 4 clinical events should have the diagnosis reviewed by HIV care providers to enable appropriate clinical care decisions upon eligibility for co-trimoxazole and other prophylaxis including TB, and the need for ARV treatment. Reported history of a stage 3 or 4 diagnosis event should have immediate referral for current clinical staging and assessment by HIV care providers able to initiate ARV treatment.
7. Be used to guide clinicians in assessing the response to ARV treatment, particularly where viral load and or CD4 counts/ or percent are not widely or easily available. Treatment failure may be suggested by new or recurrent stage 4 events, and new or recurrent stage 2 or 3 events may suggest inadequate response to treatment, potentially due to poor adherence. Clinical events in the first 3 months of starting ART may be due to immune restoration disease (IRD) not a poor response to ART. TLC is not currently recommended for monitoring therapy.

Accompanying tables in the annex provide further detail of the current clinical event, and how it may be diagnosed clinically (with basic or no laboratory or radiological capacity) or definitively. Some conditions are not possible to diagnose without some laboratory or radiological investigation, and this is indicated in the table. In some conditions accepted clinical practice may be to make a presumptive clinical diagnosis. CD4 values and their relation to immunological status are provided to assist clinical decision-making and link with monitoring, and surveillance. (Annex 1)

IMMUNOLOGICAL CATEGORIES

Not considered to have significant immunosuppression	>500 mm ³
Evidence of mild immunosuppression	350-499/mm ³
Evidence of advanced immunosuppression	200/mm ³ - 349/mm ³
Evidence of Severe immunosuppression	<200/mm ³

PROPOSED CLINICAL DEFINITIONS

Indications to start ARV therapy

- Stage 4 - urgently
- Stage 3 - CD4 guided where available
- CD4 < 200/mm³ - any clinical stage

SURVEILLANCE DEFINITIONS

Proposed national surveillance point for HIV Infection in Adults and Adolescents

1. Advanced HIV disease for reporting

All clinical Stage 3 or stage 4 disease

Or

Where CD4 is available: any clinical stage and CD4 < 350 /mm³

WHO PAEDIATRIC CLINICAL STAGING

For use in those 14 years or under with confirmed laboratory evidence of HIV infection; HIV Antibody where age >18 months, DNA or RNA virological testing for those age <18 months.

STAGE 1
Asymptomatic Persistent generalized lymphadenopathy (PGL) Hepatosplenomegaly
STAGE 2
Recurrent or chronic upper respiratory tract infections (otitis media, otorrhoea, sinusitis, 2 or more episodes in any 6 month period) Papular pruritic eruptions Herpes zoster (past or current episodes in last 2 years) Recurrent oral ulcerations (2 or more episodes in 6 months) Lineal gingival Erythema (LGE) Angular cheilitis Parotid enlargement Seborrhoeic dermatitis Extensive Human papilloma virus infection or Molluscum infection Fungal nail infections
STAGE 3
Unexplained moderate malnutrition ¹⁶ not adequately responding to standard therapy Unexplained persistent diarrhoea (more than 14 days) Unexplained persistent fever (intermittent or constant, for longer than 1month) Oral candidiasis (outside neonatal period) Oral hairy leukoplakia Pulmonary tuberculosis ¹⁷ Severe recurrent presumed bacterial pneumonia (2 or more episodes in 6 months) Acute necrotizing ulcerative gingivitis/periodontitis Lymphoid interstitial pneumonitis (LIP) ¹⁸ Unexplained Anaemia (<8gm/dl), neutropenia (<1,000/mm ³) or thrombocytopenia (<50,000/ mm ³) for more than 1 month Chronic HIV associated lung disease including brochiectasis HIV related cardiomyopathy or HIV related nephropathy
STAGE 4
<p><i>Conditions where a presumptive diagnosis can be made using clinical signs or simple investigations:</i></p> <ul style="list-style-type: none"> Unexplained severe wasting or severe malnutrition¹⁹ not adequately responding to standard therapy Pneumocystis pneumonia Recurrent severe presumed bacterial infections (2 or > episodes within one year e.g. empyema, pyomyositis, bone or joint infection, meningitis, but excluding pneumonia) Chronic orolabial or cutaneous Herpes simplex infection (of more 1 month duration) Extrapulmonary tuberculosis Kaposi's sarcoma Oesophageal Candida CNS Toxoplasmosis (outside the neonatal period) HIV encephalopathy <p><i>Conditions where confirmatory diagnostic testing is necessary:</i></p> <ul style="list-style-type: none"> Cryptococcal meningitis (or other extrapulmonary disease) Disseminated non-tuberculous mycobacteria infection Progressive multifocal leukoencephalopathy (PML) Candida of trachea, bronchi or lungs Cryptosporidiosis

¹⁶ Defined as very low weight for age - see http://www.who.int/child-adolescent-health/publications/CHILD_HEALTH/WHO_FCH_CAH_00.1.htm or page4 http://www.who.int/nut/documents/manage_severe_malnutrition_eng.pdf

¹⁷ TB may occur at any CD4 count and CD4 % should be considered where available

¹⁸ Definitions available in accompanying notes

¹⁹ Definition :very low weight or visible severe wasting or oedema of both feet Ref: http://www.who.int/child-adolescent-health/publications/CHILD_HEALTH/WHO_FCH_CAH_00.1.htm

<p>CMV infection (CMV retinitis or infection of organ other than liver, spleen, or lymph nodes onset at age 1 month or more)</p> <p>Any disseminated endemic mycosis (e.g. extra-pulmonary Histoplasmosis, Coccidiomycosis, Penicilliosis)</p> <p>Isosporiasis</p> <p>Recurrent non-typhoidal salmonella septicaemia (2 or > episodes in one year)</p> <p>Acquired HIV related recto-vesico fistula</p> <p>Cerebral or B cell non-Hodgkin's Lymphoma</p>

STAGE ON ARV TREATMENT

Clinical events occurring on ART

WHO PAEDIATRIC CLINICAL STAGING

Presumptive diagnosis of clinical Stage 4 HIV infection²⁰ in children less than eighteen months old where virological confirmation of infection is not available

In a HIV seropositive infant less than 18 months symptomatic with 2 or more of following; oral thrush, +/- severe pneumonia, +/- severe wasting/malnutrition, +/- severe sepsis severe immunosuppression should be suspected and ARV treatment is indicated

If CD4 % is available it should be used to guide decision making

Other factors that support the diagnosis of clinical stage 4 HIV infection in an HIV seropositive infant are recent maternal death or advanced HIV disease in mother.

Explanatory Notes

The clinical staging system for children is designed to:

1. Provide simple guidance to assist clinical care providers in determining when to start, substitute, switch or stop ARV therapy in HIV infected children, as outlined in WHO guidelines for a public health approach. It is also designed to harmonize with HIV and AIDS case surveillance and enable monitoring of trends in the magnitude and severity of HIV related disease.
2. Be used where HIV infection is confirmed by HIV antibody or virological testing. In children under 18 months virological diagnostic methods are recommended.
3. Encourage clinical care providers to consider diagnostic testing for HIV for children with Stage 2,3 or 4 clinical events
4. Classify disease in a progressive sequence from least to most severe, with each higher clinical stage having a poorer prognosis. Once a stage 3 clinical condition has occurred, the prognosis remains that of stage 3 and does not improve, even with resolution of the original condition, or appearance of a new stage 2 clinical event. ARV therapy improves the prognosis. Further evidence is required to determine the significance of staging events once on ARV treatment.
5. Be used with reference to CURRENT clinical events, meaning clinical events that have been diagnosed or are being managed at this episode. 'Current clinical event' is taken to include any

²⁰ Presumptive diagnosis of stage 4 disease in seropositive children < 18 months requires confirmation with HIV virological tests as soon as possible or repeat HIV antibody test after 18 months of age.

time from initial assessment and diagnosis through to immediate management and follow-up for the clinical event.

6. Be considered in relation to previous clinical events, such as reported TB, severe pneumonia, PCP or other conditions. This is RETROSPECTIVE clinical staging and requires caution. Children reporting stage 2, 3 or 4 clinical events should have the diagnoses reviewed by HIV care providers to make appropriate clinical care decisions including the need for ARV treatment. Any reported history of a stage 3 or 4 diagnosis should have immediate assessment by or referral to HIV care providers able to initiate ARV treatment.
7. Be used to guide clinicians in assessing the response to ARV treatment, particularly where viral load and or CD4 count/percent are not widely or easily available. Treatment failure may be suggested by new or recurrent stage 4 events, and new or recurrent stage 2 or 3 events may suggest inadequate response to treatment, potentially due to poor adherence. Note that clinical events in the first 3 months of starting ART may be due to immune restoration disease (IRD) not poor response to ART. TLC is not currently recommended for monitoring therapy. IRD is reported to be less common in children.

Accompanying tables in the annex provide further detail of the current clinical event, and how it may be diagnosed clinically or with basic laboratory or radiological capacity, or require more sophisticated investigations. Some conditions are not possible to diagnose without some laboratory or radiological investigation, and this is indicated in the table. Accepted clinical practice may be to make a presumptive clinical diagnosis. HIV infected children with any signs or symptoms of HIV should be given cotrimoxazole prophylaxis. CD4 values and their relation to immunological status are provided to assist clinical decision-making and link with monitoring, and surveillance.

WHO Recommendations upon Antiretroviral therapy (ART) are in '**Scaling up antiretroviral therapy in resource-limited settings: Treatment guidelines for a public health approach**' available at :

http://www.who.int/3by5/publications/documents/arv_guidelines/en/

Revisions to the clinical staging system for children means that that recommendations on **when to start ART** are now replaced by the following:

- Clinical stage 4 disease requires ARV therapy as soon as is possible irrespective of age, CD4 % or TLC
- Clinical stage 3 disease requires urgent consideration of ARV therapy, although CD4 (percent) and age may guide the urgency to start
- A presumptive diagnosis of stage 4 disease in an HIV exposed infant <18 months²¹ requires ARV therapy
- Any clinical stage with; CD4% < 20% if < 12 months; CD4 % < 15% if > 13 months or CD4 < 200/mm³ if 6 years or over
- Further specifications are usually available in National ARV treatment guidelines

²¹ As in footnote 7 above

Note that : Pulmonary TB and many other stage 2 & 3 conditions also occur in the absence of HIV infection

IMMUNOLOGICAL CATEGORIES FOR PAEDIATRIC HIV INFECTION

IMMUNE STATUS	Age less than 12 months	Age 13 months or more	≥ 6 years
Not considered to have significant immunosuppression	≥ 35 %	> 25%	>500 mm ³
Evidence of mild immunosuppression	< 25-34%	20-24%	350-499/mm ³
Evidence of advanced immunosuppression	20-24%	15-19%	200/mm ³ - 349/mm ³
Evidence of Severe immunosuppression	< 20 %	< 15%	<200/mm ³

PROPOSED REVISED CLINICAL DEFINITIONS FOR PAEDIATRIC HIV INFECTION

Indication to start ARV therapy in HIV infected children

Stage 3 and 4 disease

Or

Any clinical stage AND

CD4% < 20% if < 12 months

CD4 % < 15% if > 13 months

CD4 < 200/mm³ if 6 years or over

Indication for cotrimoxazole prophylaxis

HIV infected- clinical stage 2, 3 or 4

HIV exposed until HIV infection definitively ruled out

SURVEILLANCE DEFINITIONS

Proposed surveillance or reporting points

1. Advanced HIV disease

Clinical Stage 3 or stage 4 disease

Or where available

< 12 months - any clinical stage + CD4% < 24%

> 13 months - any clinical stage + CD4 % < 20%

6 years or over any clinical stage + CD4 < 350 /mm³

2. All new confirmed HIV infections in children

With age, clinical stage and CD4 where available

WHO ADULT AND ADOLESCENT CLINICAL STAGING: CLINICAL and DEFINITIVE CRITERIA
For use in adults and adolescents > 13years with laboratory evidence of HIV infection

Clinical EVENT	PRESUMPTIVE DIAGNOSIS	DEFINITIVE DIAGNOSIS
PRIMARY HIV INFECTION		
Unrecognized infection Acute retroviral syndrome	Acute febrile illness 2-4 wks post-exposure often with lymphadenopathy and skin manifestations ,pharyngitis	Detectable core p24 antigen & high blood HIV RNA, profound temporary lymphopenia and other transient blood abnormalities may occur. Not usually HIV antibody positive until after symptoms. Seroconversion from HIV Ab negative to positive
STAGE 1		
Asymptomatic	No symptoms reported and no signs on examination	Not required
Persistent generalized lymphadenopathy (PGL)	Swollen or enlarged lymph nodes >1cm, in two or more non-contiguous sites, in absence of known cause excluding inguinal sites	Not required but confirmed by histology (germinal centre hyperplasia, lymph node structure preserved)
STAGE 2		
Unexplained moderate weight loss (<10% of presumed or measured body weight)	Reported weight loss, but no obvious thinning of face or body	Confirmed by documented weight loss
Papular pruritic eruptions	Papular vesicular lesions that are pruritic. Note scabies and obvious insect bites should be excluded Also common in uninfected adults	Not required
Seborrhoeic dermatitis	Itchy scaly skin condition particularly affecting scalp, face upper trunk and perineum	Not required
Angular cheilitis	Splits or cracks in lips at the angle of the mouth, responds to anti fungal therapy	Not required
Recurrent oral ulcerations, twice or more in 6 months	Apthous ulceration, typically with a halo of inflammation and a yellow-gray pseudo membranous. May be major or minor or herpetiform	Not required
Herpes zoster	Painful rash of small fluid-filled blisters in distribution of a nerve supply, can be haemorrhagic on erythematous background, and does not cross midline. Current or in the past last two years	Not required
Recurrent presumed bacterial upper respiratory tract infections (2 or more in any 6 month period)	Symptom complex; e.g. unilateral face pain with nasal discharge (sinusitis) or painful swollen ear drum (otitis media) cough with purulent sputum,(bronchitis), sore throat (pharyngitis)	Not required but may be confirmed by laboratory studies where available 2 or > documented occurrences of antibiotic responsive URTI
Fungal nail infections	Fungal paronychia (painful, red and swollen nail bed) or onycholysis (separation of the nail from the nail bed) in the nails of the fingers.	Not required but confirmed by culture of nail scrape

	Also common in uninfected adults. Proximal white subungual onychomycosis is uncommon without immunodeficiency	
STAGE 3		
Unexplained severe weight loss (>10% of presumed or measured body weight)	Reported weight loss without trying, and has noticeable thinning of face waist and extremities	Documented loss of 10% body weight
Unexplained chronic diarrhoea for longer than one month	Chronic diarrhoea (loose or frequent bowel opening 3 or > times daily) reported for longer than one month With or without antibiotic treatment	Not required, but confirmed if 2 or > stools observed and documented as unformed, and 2 or more stool tests reveal no pathogens on microscopy & culture and reveal no faecal leukocytes
Unexplained persistent fever (intermittent or constant and for longer than >1month)	Reports of fever or night sweats for greater than one month, either intermittent or constant with reported lack of response to antibiotics or anti malarials. No other obvious foci of disease reported or found on examination. Malaria must be excluded in malarious areas	Not required but confirmed if Documented fever >37.5 C on 3 or more occasions with negative blood culture, routine and AFB, negative malaria slide and normal or unchanged CXR, and no other obvious foci of disease
Oral candidiasis	Creamy white to yellow soft small plaques on red or normal coloured mucosa, often can be scraped off (pseudo membranous), or red patches on tongue, palate or lining of mouth, usually painful or tender (erythematous form), that respond to antifungal treatment. When Candida appears visually to extend into oesophagus, assess for symptoms (stage 4)	Not required
Oral hairy leukoplakia	Fixed fine small lined patches on lateral borders of the tongue generally bilaterally, which don't scrape off	Not required
Pulmonary tuberculosis (current or in last two years)	Chronic (symptoms \geq 3 weeks) productive cough, haemoptysis, shortness of breath, weight loss, fever, night sweats and fatigue, no resolution of symptoms with standard broad spectrum antibiotics, together with response to standard anti TB treatment in 1 month positive sputum culture of MTB, +/-AFB seen on ZN stain of sputum TB diagnosis and treatment should follow national or international guidelines. CD4 should be used where possible to guide therapy; values below 200 require urgent ART.	Not required but confirmed if symptoms, abnormal CXR plus positive sputum culture of MTB, +/- AFB seen on ZN stain of sputum CXR may be consistent with tuberculosis but may be atypical. Specific findings expected on a CXR in patients with typical TB (cavity, upper or middle lobe infiltrates), Not required but confirmed if symptoms, AFB seen on ZN stain of sputum 2-3/3 or 1 in tissue (or fluid from that tissue), and/or positive culture of sputum or tissue (or fluid from that tissue) for <i>mycobacterium tuberculosis</i> Suggest positive sputum smear OR consistent CXR with no response to antibiotics as per current guidelines
Severe presumed bacterial infection (e.g. pneumonia, meningitis, empyema, pyomyositis, bone or joint infection, bacteremia)	Fever accompanied by specific symptoms or signs that localize infection, and response to antibiotics How many episodes Bound to be poorly sensitive if only one episode	Not required, but confirmed by bacteria isolated from appropriate clinical specimens Includes one episode of Non-typhi salmonella

Acute necrotizing ulcerative gingivitis	Severe pain, ulcerated gingival papillae, loosening of teeth, spontaneous bleeding, bad	Not required
STAGE 4		
HIV wasting syndrome (Hb < 10 gm/dl), neutropenia (<1,000/mm ³) or thrombocytopenia (<30,000/ mm ³) for > 1 month	No unexplained weight loss of greater than 10% body weight and visible thinning of face waist, and extremities plus either unexplained chronic diarrhoea (> than 1 month) or unexplained prolonged or intermittent fever for 1 month or more	Confirmed by lab testing and where documented weight loss without conditions, or not responding to standard therapy with haematinics, documented uniform stools as negative for pathogens (including microscopy, modified ZN and parasites, and culture OR documented temperature >37.5 on 3 or more occasions with no obvious foci of disease, negative blood culture; routine and AFB, negative malaria slide and normal or unchanged CXR
Pneumocystis pneumonia	Dry cough, progressive shortness of breath, especially on exertion, with cyanosis, tachypnoea and fever; symptoms for less than <12 weeks response to high dose co-trimoxazole +/- prednisolone CXR shows typical bilateral peri-hilar diffuse infiltrates	Not required but confirmed by: microscopy of induced sputum or BAL or histology of lung tissue
Recurrent severe or radiological bacterial pneumonia (2 or > episodes within one year)	Two episodes of severe fever, cough and sputum production with abnormal chest X-ray and response to antibiotics	Not required but confirmed by: respiratory pathogens seen in Gram stain, isolated by culture or antigen test from appropriate specimen
Chronic orolabial, genital or anorectal herpes simplex virus infection (of more than 1 month or visceral of any duration)	Severe and progressive painful orolabial genital, or anorectal lesions due to recurrent HSV infection reported for > 1 month History of previous episodes Scarring from previous episodes may be evident	Severe and progressive painful orolabial, genital, or anorectal lesions documented for > 1 month Suggestive symptoms of organ damage e.g. bronchitis, pneumonitis, oesophagitis, colitis, encephalitis supported by histology or culture
Candidiasis of the oesophagus	Chest pain and dysphagia (difficulty in swallowing), odynophagia (pain on swallowing food and fluids), or retrosternal pain worse on swallowing (food and fluids) +/- oral Candida, responds to antifungal treatment	Not required but confirmed by macroscopic appearance at endoscopy, microscopy of specimen from tissue or macroscopic appearance at bronchoscopy or histology or cytology/ smear
Extrapulmonary/disseminated tuberculosis	Systemic illness usually with prolonged fever, night sweats weakness and weight loss, often anaemia Clinical features of organs involved ; e.g. focal lymphadenopathy, cold abscess, sterile pyuria, pericarditis, ascites, pleural effusion, meningitis, arthritis, orchitis, lupus vulgaris CXR may reveal diffuse uniformly distributed small miliary shadows, although may be normal Appropriate features that respond to anti TB therapy	Not required but confirmed by : M tuberculosis isolated form blood culture of any specimen except sputum or BAL Histology (e.g. pleural or pericardial biopsy) AFBs seen in microscopy of CSF, effusion, lymph node aspirate, urine CXR; miliary appearance may be absent, CXR may show interstitial infiltrates Lymphocytic CSF with negative CRAG and no bacterial growth,

		typical abnormalities of CSF Lymphocytic serous effusion, culture negative from joint, pleura, peritoneum, pericardium, urine
Kaposi's sarcoma	Typical appearance in skin or oropharynx, of persistent initially flat patches with a pink or blood-bruise colour skin lesions that usually develop into nodules. Can be confused clinically with bacillary angiomatosis, non-Hodgkin lymphoma, and cutaneous fungal or bacterial infections.	Not required but may be confirmed by : - typical red purple lesions seen on bronchoscopy or endoscopy -dense masses in lymph nodes viscera or lungs by palpation or radiology -histology
Cytomegalovirus retinitis (or CMV infection of an organ other than liver, spleen, or lymph nodes)	Progressive 'floaters' in field of vision and light flashes Diagnosed clinically by typical eye lesions on serial fundoscopic examination; discrete patches of retinal whitening with distinct borders, spreading centrifugally, often following blood vessels, associated with retinal vasculitis, haemorrhage and necrosis	Not required for retinitis, but required for other sites. Symptoms and signs of other organ involvement, e.g. pneumonitis, pancreatitis, colitis, Cholecystitis, not responding to Co-trimoxazole or antibiotics, and with histology or CSF PCR in other sites Ophthalmologic exam by ophthalmologist is diagnostic
CNS Toxoplasmosis	Fever, headache, focal neurological signs, convulsions. Rapid (within 10 days) response to high-dose co-trimoxazole or pyrimethamine and sulphadiazine/clindamycin sulfadiazine	Not required but confirmed by CT scan showing single/multiple lesions with mass effect/enhancing with contrast. If LP performed, CSF non-specific or normal. Resolution of findings after treatment, if patient survives.
Cryptococcal meningitis (extrapulmonary Cryptococcus infection)	Meningitis: usually sub acute, fever with increasing severe headache, meningism, confusion, behavioural changes. Responds to anti fungal therapy.	Confirmed by: CSF: microscopy (India Ink or Gram stain) Serum or CSF cryptococcal antigen positive OR culture positive
HIV encephalopathy	Clinical finding of disabling cognitive and/or motor dysfunction interfering with activities of daily living, progressing over weeks or months in the absence of a concurrent illness or condition other than HIV infection that could explain the findings. Lumbar puncture should be conducted to exclude other infectious causes	Recommended to confirm clinical features and exclude of other causes including neurosyphilis; -brain scan (CT or MRI) with -lumbar puncture and examination of CSF
Disseminated non-tuberculous mycobacteria infection	Non-specific symptoms; fever, sweats, headaches, weight loss, diarrhoea often with abdominal pain. Severe anaemia and/or elevated alkaline phosphatase and/or (in case of diarrhoea) persisting AFB in the stool in spite of TB therapy." No presumptive diagnosis	Non specific clinical symptoms inc. progressive weight loss, fever, anaemia, night sweats, fatigue, or diarrhoea plus culture of atypical mycobacteria species from stool, blood, body fluid or other body tissue, excluding lung
Progressive multifocal leukoencephalopathy (PML)	No presumptive diagnosis	Progressive focal neurological signs without headache or fever, cortical blindness, cerebellar signs, dementia, rarely convulsions, confirmed by consistent MRI or CT scan Biopsy and viral PCR for JC virus
Candida of trachea, bronchi lungs	No presumptive diagnosis	Confirmed by symptoms, clinical signs suggestive of organ involvement and or macroscopic

		appearance at bronchoscopy or histology or cytology/ smear , microscopy of specimen from tissue,
Cryptosporidiosis (with diarrhoea > 1 month)	No presumptive diagnosis	Chronic diarrhoea – often profuse and watery, with weight loss, ± abdominal pain, nausea, vomiting, but mild fever confirmed by microscopic examination of stool- Stools observed to be unformed with organism visualized in stool sample
Isosporiasis	No presumptive diagnosis	Watery diarrhea, cramps, and weight loss, symptoms usually indistinguishable from those of cryptosporidiosis. Isosporiasis responds to high does cotrimoxazole
CMV infection of an organ other than liver, spleen, or lymph nodes	No presumptive diagnosis	Confirmed by: Symptoms and signs of organ involvement e.g. typical eye lesions on fundoscopy or pneumonitis, pancreatitis, colitis, Cholecystitis, not responding to Cotrimoxazole or antibiotics Compatible symptoms, plus histology or detection of antigen from affected tissue
Any disseminated endemic mycosis (e.g. Coccidiomycosis, Histoplasmosis, Penicilliosis)	No presumptive diagnosis	Clinical symptoms non specific and specific e.g. Penicilliosis and Histoplasmosis both cause skin rash, or cough, shortness of breath, fever, anaemia, weight loss Confirmed by direct microscopy, Histology; usually granuloma formation Isolation: Antigen detection from affected tissue (Histo) Chest XR: infiltrates or nodules Blood culture positive for <i>Cryptococcus neoformans</i> Skin lesions culture or microscopy positive
Recurrent non-typhoidal salmonella septicaemia (2 or more episodes in last year)	No presumptive diagnosis	Non-specific symptoms; fever, sweats, headaches, weight loss, diarrhoea (not common but can be severe and bloody) and anorexia, without any focal signs (e.g. LRTI or meningitis), confirmed by blood culture
Lymphoma (Cerebral or B-cell non-Hodgkin's)	No presumptive diagnosis	Symptoms consistent with lymphoma: fever, night sweats, weight loss, lymphadenopathy, splenomegaly, pancytopenia, bowel obstruction, ascites, cranial nerve, spinal cord or nerve root lesions, cutaneous, testicular or lung mass lesions; no response clinically to anti-toxoplasma or anti-TB treatment CNS imaging: at least one lesion with mass effect on brain scan; histology Response to cytotoxic chemotherapy

Invasive cervical carcinoma	No presumptive diagnosis	Persistent vaginal discharge, post-coital or inter-menstrual bleeding unresponsive to appropriate anti-bacterial or anti-fungal treatment; cervical lesions visualized. Histology Cytology – but not carcinoma-in-situ
Leishmaniasis, visceral	No presumptive diagnosis	Suggestive symptoms – malaise, chronic fever, hepato-splenomegaly Pancytopenia Amastigotes visualized or cultured from any appropriate clinical specimen except from chronic cutaneous ulcer.
American trypanosomiasis reactivation (meningoencephalitis and/or myocarditis)	No presumptive diagnosis	Documented <i>Trypanosoma cruzi</i> infection with reactivation of Chagas' disease, parasitological diagnosis of body fluids (direct artificial xenodiagnosis or blood culture, biopsy) associated with: - meningoencephalitis: image of cerebral lesion with mass effect (NMR or CT scan with or without injection of contrast medium - ring imaging) - acute myocarditis: arrhythmia and/or heart failure diagnosed by electrocardiography and echocardiography
STAGE ON ARV TREATMENT		
Stage 2 or 3 clinical events	New or recurrent stage 2 or 3 events should alert the provider to the possibility of poor adherence or failing response to treatment.	
Stage 4 clinical events	New or recurrent stage 4 events suggest failure to respond to ARV treatment, this may be due to true failure of the regimen and or poor adherence.	

PAEDIATRIC WHO CLINICAL STAGING: CLINICAL and DEFINITIVE CRITERIA

For use in those under 12 years of age with confirmed laboratory evidence of HIV infection; HIV Antibody where age >18 months, DNA or RNA virological testing for those age <18 months.

Clinical EVENT	CLINICAL DIAGNOSIS	DEFINITIVE DIAGNOSIS
STAGE 1		
Asymptomatic	No symptoms reported and no signs on examination	Not required
Persistent generalized lymphadenopathy (PGL)	Swollen or enlarged lymph nodes >1cm, in two or more non-contiguous sites, in absence of known cause	Not required (Histology; germinal centre hyperplasia, lymph node structure preserved)
Hepatosplenomegaly	Unexplained clinically palpable enlargement of the liver or spleen	Not required (Confirmed by radiological or ultrasound examination)
STAGE 2		
Papular pruritic eruptions	Persistent papular vesicular lesions that are pruritic, note scabies should be excluded	Not required
Seborrhoeic dermatitis	Itchy scaly skin condition particularly affecting scalp, face upper trunk and perineum. Common in uninfected children and in babies	Not required
Fungal nail infections	Fungal paronychia (painful, red and swollen nail bed) or onycholysis, (painless separation of the nail from the nail bed) proximal white subungal onychomycosis is uncommon without immunodeficiency. Common in uninfected children	Culture of nail scrape
Angular cheilitis	Splits or cracks in lips at the angle of the mouth, may be depigmentation, usually respond to anti fungal treatment, but may recur. Also common in nutritional deficiency such as B group vitamins	Not required
Linear gingival Erythema	Erythematous band that follows the contour of the free gingival, may be associated with spontaneous bleeding Uncommon in HIV uninfected children	Not required
Human papilloma virus infection (extensive >5% body area or face or disfiguring)	Characteristic skin lesions; Warts; small, fleshy, grainy bumps, often rough, on sole of feet are flat (Plantar warts) Also very common in uninfected children	Not required
Molluscum infection (extensive more than 5% body area or face or disfiguring)	Characteristic skin lesions -small flesh-coloured pearly or pink dome-shaped or umbilicated growths, may be inflamed or red Also common in uninfected children	Not required
Recurrent oral ulcerations (2 or more in 6 months)	Apthous ulceration, typically with a halo of inflammation and a yellow-gray pseudo	Not required

	membranous. May be major or minor or herpetiform ulceration	
Parotid enlargement	Asymptomatic and bilateral, swelling that may spontaneously resolve and recur, in absence of other known cause , usually painless Uncommon in HIV uninfected children	Not required
Herpes zoster	Painful rash of usually small fluid-filled blisters in distribution of a nerve supply, can be haemorrhagic on erythematous background, and can become large and confluent. Note severe persistent herpes zoster may be a more sever prognosis.	Viral culture, histology EM of lesions fluid
Recurrent upper respiratory tract infections (otitis media, otorrhoea or sinusitis) twice or more in any 6 month period	Symptom complex; e.g. fever with unilateral face pain with nasal discharge (sinusitis) or painful swollen ear drum (otitis media) cough with purulent sputum (bronchitis), sore throat (pharyngitis) and barking croup-like cough with intercostal retraction on breathing . Persistent or recurrent discharge from ear	Not required but may be confirmed by laboratory studies where available
STAGE 3		
Unexplained moderate malnutrition not adequately responding to standard therapy	Reported and unexplained as very low weight for age ²² , or weight loss or lack of growth (1 minus 2 SD score or Z score, low WFH, low WFA) and not adequately responding within two weeks to standard management of malnutrition (national/ international or IMCI guidelines)	Documented loss of body weight , failure to gain weight on standard management and no other cause identified during investigation,
Unexplained persistent diarrhoea (more than 14 days as in IMCI guidelines)	Unexplained persistent diarrhoea (loose or frequent bowel opening 3 or more times daily) reported, not responding to standard management	Not required, but confirmed if Stools observed and documented as unformed, culture and microscopy reveal no pathogens
Unexplained persistent fever (intermittent or constant and for longer than >1month)	Reports of fever or night sweats for greater than one month , either intermittent or constant with reported lack of response to antibiotics or anti malarials No other obvious foci of disease reported or found on examination. Malaria must be excluded in malarious areas	Not required but confirmed if Documented fever >37.5 C on 3 or more occasions with negative blood culture, routine and AFB, negative malaria slide and normal or unchanged CXR, and no other obvious foci of disease
Oral candidiasis (outside neonatal period)	Persistent creamy white to yellow soft small plaques on red or normal coloured mucosa often can be scraped off (pseudo membranous) or red patches on tongue, palate or lining of mouth, usually painful or tender (erythematous form), respond to antifungal treatment. When Candida appears visually to extend into oesophagus, assess for symptoms (stage 4)	Microscopy or culture
Oral hairy leukoplakia	Fixed fine small lined patches on lateral borders of the tongue generally bilaterally, which don't scrape off	Not required
Pulmonary tuberculosis	Nonspecific symptoms such as irregular fever, anorexia, weight loss, or in the older child productive cough, haemoptysis, fever, night sweats, malaise and weight loss, accompanied by response to standard anti TB treatment in 1 month. Diagnosis should be made according to national guidelines TB can occur at any stage of HIV infection and should be considered a stage 4 clinical event where CD4 % is less than 20% in <18months or< 15% in those over 18 months.	Abnormal CXR plus positive sputum smear, or culture Biopsy and direct smear or culture

²² - http://www.who.int/child-adolescent-health/publications/CHILD_HEALTH/WHO_FCH_CAH_00.1.htm or page4
http://www.who.int/nut/documents/manage_severe_malnutrition_eng.pdf

Severe recurrent presumed bacterial pneumonia	Cough with fast breathing, lower chest wall in-drawing, nasal flaring, wheezing, grunting or head nodding. Sometimes accompanied by vomiting, decreased appetite, or chest pain. On examination: fever, flaring of the nostrils, chest wall retraction or sucking in of the skin above and below the rib cage and between the ribs. Crackles on auscultation Responds to course of antibiotics	Not required but confirmed by bacteria isolated from appropriate clinical specimens
Acute necrotizing ulcerative gingivitis stomatitis or necrotizing ulcerative periodontitis	Severe pain, ulcerated gingival papillae, loosening of teeth, spontaneous bleeding, bad odour, and rapid loss of bone and/or soft tissue	Not required
Lymphoid interstitial pneumonitis (LIP)	No presumptive clinical diagnosis	CXR bilateral reticulonodular interstitial pulmonary infiltrates present for > 2 months with no response to antibiotic treatment and no other pathogen found OR, oxygen saturation persistently <90%, development of cor pulmonale, increased exercise induced fatigue. Frequently confused with miliary TB
Unexplained Anaemia (<8gm/dl), neutropenia (<1,000/mm³) or thrombocytopenia (<30,000/mm³) for > 1 month	No presumptive clinical diagnosis	Diagnosed on lab testing and where not explained by other non HIV conditions, or not responding to standard therapy with haematinics, antimalarial or anthelmintic as outlined in IMCI
Chronic HIV associated lung disease (including bronchiectasis)		History of productive cough of copious amounts of purulent sputum, with or without clubbing, halitosis, and clinical signs on chest auscultation of widespread crackles and wheezes and a chest radiograph showing lobar/ diffuse honey-comb appearance (small cysts) and/or persistent areas of opacification and/or widespread lung destruction, with fibrosis and loss of volume. A CT chest may be used to confirm the diagnosis, but is not mandatory.
STAGE 4		
Unexplained severe wasting or severe malnutrition not adequately responding to standard therapy	Visible severe wasting of muscles of shoulder, arms buttocks and thighs, visible rib outlines, with or without oedema of both feet and or severe palmar pallor. Persistent unexplained reported weight loss of greater <70% weight for age or <- 3SD, as defined by WHO IMCI guidelines ,or <5 th percentile on weight for height chart on 2 or more consecutive occasions >1 month apart , Weight loss despite reliable secure supply of food, and no other foci of disease or cause for malnutrition, and not adequately responsive to 2weeks of standard management of malnutrition as outlined in IMCI or other national management guidelines	Documented weight loss without trying PLUS documented unformed stools negative for pathogens (including microscopy, modified ZN and parasites, and culture OR documented temperature >37.5 on 3 or more occasions with no obvious foci of disease , negative blood culture; routine and AFB, negative malaria slide and normal or unchanged CXR
Pneumocystis pneumonia	Dry cough, progressive shortness of breath, cyanosis, tachypnoea and fever; chest in drawing or stridor. May be hyper-expanded chest. Response to high dose co-trimoxazole +/- prednisolone (Severe or very severe pneumonia as in IMCI),	Microscopy of induced sputum or BAL or histology of lung tissue CXR shows typical bilateral peri-hilar diffuse infiltrates
Recurrent severe presumed bacterial infection (2 or >	Fever accompanied by specific symptoms or signs that localize infection, responds to antibiotics	Not required but confirmed by bacteria isolated from appropriate clinical specimens and

episodes within one year) (e.g. meningitis, empyema, pyomyositis, bone or joint infection, bacteremia)		includes recurrent non-typhoidal salmonella septicaemia
Chronic herpes simplex virus infection (of more than 1 month or visceral of any duration)	Severe and progressive painful orolabial or skin lesions due to recurrent HSV reported for > 1 month History of previous episodes Scarring from previous episodes may be evident	Severe and progressive painful orolabial or skin lesions documented for > 1 month Suggestive symptoms of organ damage e.g. bronchitis, pneumonitis, oesophagitis, colitis, encephalitis supported by histology or culture
Candidiasis of the oesophagus	Chest pain and dysphagia (difficulty in swallowing), odynophagia (pain on swallowing food and fluids), or retrosternal pain worse on swallowing (food and fluids) +/- oral Candida, responds to antifungal treatment May be difficult to detect in young children, suspect if oral Candida observed plus refusal or difficulties feeding	Not required but confirmed by macroscopic appearance at endoscopy, microscopy of specimen from tissue or macroscopic appearance at bronchoscopy or histology or cytology/ smear
Extrapulmonary tuberculosis	Tuberculosis not limited to lungs. Systemic illness usually with prolonged fever, night sweats weakness and weight loss, often anaemia, Clinical features of organs involved ; e.g. focal lymphadenopathy, cold abscess, sterile pyuria, pericarditis, ascites, pleural effusion, meningitis, arthritis, orchitis, lupus vulgaris Appropriate features that respond to standard anti TB therapy	M tuberculosis isolated form blood culture of specimen except sputum or BAL Histology (e.g. pleural or pericardial biopsy) AFBs seen in microscopy of CSF, effusion, lymph node aspirate CXR; miliary appearance may be absent Lymphocytic CSF with negative CRAG and no bacterial growth Lymphocytic serous effusion, culture negative from joint, pleura, peritoneum, pericardium
Kaposi's sarcoma	Typical appearance in skin or oropharynx, initially flat patches with a pink or blood-bruise colour that usually develop into nodules	Typical red purple lesions seen on bronchoscopy or endoscopy Biopsy
Cytomegalovirus infection; Onset at age >1 month of organ other than liver, spleen, or lymph nodes	No presumptive clinical diagnosis Clinically disease suspected by typical eye lesions on serial fundoscopic examination; discrete patches of retinal whitening with distinct borders, spreading centrifugally, often following blood vessels, associated with retinal vasculitis, haemorrhage and necrosis	Symptoms and signs of organ involvement e.g. typical eye lesions on fundoscopy or pneumonitis not responding to Co-trimoxazole or antibiotics Compatible symptoms, plus histology or detection of antigen from affected tissue or
CNS Toxoplasmosis	Fever, headache, focal neurological signs, convulsions. Response to high-dose co-trimoxazole or pyrimethamine and sulphadiazine/clindamycin	CT scan showing single/multiple lesions with mass effect/enhancing with contrast. If LP performed, CSF non-specific or normal. Resolution of findings after treatment, if patient survives.
Cryptococcal meningitis	Meningitis: usually sub acute, fever with increasing severe headache, irritability, meningism, confusion, behavioural changes Responds to anti fungal therapy	Confirmed by: CSF: microscopy (India Ink or Gram stain) Serum CRAG positive
HIV encephalopathy	At least one of the following progressing over at least 2 months in the absence of another illness: failure to attain, or loss of, developmental milestones , or loss of intellectual ability or Progressive impaired brain growth demonstrated by stagnation of head circumference measurements or Acquired symmetric motor deficit accompanied by 2 or more of the following paresis, pathologic reflexes ataxia or gait disturbances	Brain scan CT or MRI to exclude other causes

<p>Any disseminated endemic mycosis (e.g. cryptococcosis, Histoplasmosis, Coccidiomycosis, Penicilliosis)</p>	<p>No presumptive clinical diagnosis</p>	<p>Clinical symptoms non specific and specific e.g. Penicilliosis and Histoplasmosis both cause skin rash, or cough, shortness of breath, fever, anaemia, weight loss</p> <p>Confirmed by direct microscopy, Histology; usually gramuloma formation Isolation Antigen detection Chest XR infiltrates or nodules</p>
<p>Candidiasis of the trachea, bronchi, or lungs</p>	<p>No presumptive clinical diagnosis</p>	<p>Macroscopic appearance at endoscopy Microscopy of specimen from tissue</p> <p>Macroscopic appearance at bronchoscopy or histology or cytology/ smear</p>
<p>Disseminated Mycobacteriosis, other than tuberculosis (MOT)</p>	<p>No presumptive clinical diagnosis</p>	<p>Non specific clinical symptoms inc. progressive weight loss, fever, anaemia, night sweats, fatigue, or diarrhoea</p> <p>plus culture of atypical mycobacteria species from stool, blood, body fluid or other body tissue, excluding lung</p>
<p>Cryptosporidiosis or Isosporiasis (with diarrhoea > 1 month)</p>	<p>No presumptive clinical diagnosis</p>	<p>Chronic diarrhoea – often profuse and watery, with weight loss, ± abdominal pain, nausea, vomiting, but usually mild or no fever. Confirmed by microscopic examination</p>
<p>Cerebral or B cell non-Hodgkin's Lymphoma</p>	<p>Presumptive clinical diagnosis not recommended</p>	<p>Symptoms consistent with lymphoma: fever, night sweats, weight loss, lymphadenopathy, splenomegaly, pancytopenia, bowel obstruction, ascites, cranial nerve, spinal cord or nerve root lesions, cutaneous, testicular or lung mass lesions; no response clinically to anti-toxoplasma or anti-TB treatment</p> <p>CNS imaging: at least one lesion with mass effect on brain scan, and no response to anti-toxoplasma and anti-TB treatment</p> <p>Histology Response to cytotoxic chemotherapy</p>
<p>Progressive multifocal leukoencephalopathy (PML)</p>	<p>No presumptive clinical diagnosis</p>	<p>Progressive focal neurological signs without headache or fever, cortical blindness, cerebellar signs, rarely convulsions MRI or CT scan</p>
<p>HIV related nephropathy</p>	<p>No presumptive clinical diagnosis</p>	<p>Symptoms and signs suggestive of renal disease, with no other obvious cause identified. Early morning urine protein/creatinine ratio of >200mg/mmol in the absence of a urinary tract infection and an absence of an axillary temperature of 38.0C</p>
<p>HIV related cardiomyopathy</p>	<p>No presumptive clinical diagnosis</p>	<p>Exclusion of other causes of congestive cardiac failure/large heart. The left ventricle and right ventricle are enlarged. The end-diastolic and end-systolic dimensions of the left or right ventricle are increased (2 SD from the mean for body surface area), with a reduced fractional shortening and ejection fraction (2 SD from the mean)</p>

STAGE ON ARV TREATMENT		
Stage 2 or 3 clinical events	New or recurrent stage 2 or 3 events should alert the provider to the possibility of poor adherence or failing response to treatment.	
Stage 4 clinical events	New or recurrent stage 4 events suggest failure to respond to ARV treatment, this may be due to true failure of the regimen and or poor adherence.	

Annex 2

See attached

Annex 3

Paediatric Training Resources

HIV Curriculum for the Health Professional, Baylor International Paediatric AIDS Initiative

This training curriculum is organized into 12 chapters, each with objectives, key points, lecture notes, student review of key points, questions about hypothetical cases, review questions, and references. The material addresses both adults and paediatrics.

<http://baylorids.org/curriculum/files/complete.pdf>

Handbook on Paediatric AIDS in Africa, ANECCA

This handbook consists of 12 chapters, all of which focus on paediatric AIDS. Each chapter includes a summary, lecture material, and references for additional reading.

<http://www.fhi.org/NR/ronlyres/eyvks26iqr4nk3tk6gru6b66hsuguqk2ljicmwq5xrq6d5mfsez327ag4mkb5aeidqqpkfofkt6a/ANECCA013105.pdf>

The Paediatric Clinical Manual, Columbia University Mailman School of Public Health, International Center for AIDS Programs

This manual includes 8 chapters that provide paediatric care-related information. All chapters include background lecture material. Most also include key points to remember, common clinical scenarios, and frequently asked questions.

http://www.mtctplus.org/intranet/pdf/Paediatric_Clinical_Manual.pdf

The Columbia Clinical Manual, Columbia University Mailman School of Public Health, International Center for AIDS Programs

The Columbia Clinical Manual includes 7 sections that focus on both adults and children with one section devoted entirely to children. The sections contain clearly presented relevant information as well as helpful diagrams and tables.

<http://www.womenchildrenhiv.org/pdf/p03-pi/pi-72-00.pdf>

The PIH Guide to Community-Based Treatment of HIV in Resource Poor Settings, Partners in Health

This comprehensive guide with five dense chapters draws on the PIH experience in Haiti to offer insight into treatment in resource-poor settings. Some information focuses on treating children.

<http://www.go2itech.org/pdf/p06-db/db-50696.pdf>

Building Resilience in Children Affected by HIV/AIDS, Catholic AIDS Action, Namibia

This book is written for adults. It contains information on how children are affected by HIV/AIDS and ideas as to how best to relate to and support children.

<http://www.fhi.org/NR/ronlyres/e5eudagbhigtrlgq6wuvcltmnaiad55yfe3iwwv35ws4s322pu3qu4ffyyfu3h4ndcf6hm6noizaic/CAACompletebook.pdf>

**Always a good resource is the I-TECH online HIV/AIDS clinical training materials database:

<http://www.go2itech.org/>

A brief self-learning manual which is designed for health care workers in the community as well as non-physician staff in the hospital or clinic. Contains both adult and paediatric teaching materials and also offers pre and post tests to determine how effective the training is.

http://www.orhs.org/classes/nursing/HIV2_04

Annex 4

Psychosocial Issues and Support for HIV+ Children And Their Families



i. Child Development

Child development is how children grow and mature. Children develop at their own pace, yet all children thrive when given love, encouragement, guidance and opportunity. The Health Care Provider represents an educational and supportive network for parents and their families. A parent needs the HCP's guidance on child development milestones.

Studies suggest that HIV infected children are at high risk for developmental and behavioral abnormalities. The onset of HIV disease progression in a young child, for example, may increase the risk of neurodevelopmental delays.

The Denver II Developmental Milestones Table (see below) provides the HCP (Health Care Provider) with a way of measuring developmental milestones (gross motor, fine motor, language, and social/emotional) and can be utilized to educate a parent on the expected milestones. Please note the following:

- Underlined milestone should be achieved by 90% of children by this age.
- (O) = By clinicians observation if possible.
- Bold items are abnormal at any age.
- **Please note that each child has a different developmental pace: this list represents when the child 'begins' some of the milestones.**

DEVELOPMENTAL MILESTONES TABLE

Age	Gross Motor	Visual Motor/Problem Solving	Language	Social/Adaptive
2mth	Holds head in midline, Lifts chest off table	Follows object to midline No longer clenches fist tightly	<u>Smiles socially</u> (after being stroked or talked to) (O) Vocalizes	Recognizes parent
6mth	Sits with a little support, <u>no head lag when pulled to sit</u> (O) <u>Bears some</u>	Transfer object from hand to hand Uses raking grasp	Babbles Imitates speech sounds Turns toward	Recognizes strangers Cuddles Avoids eye contact

	<u>weight on legs when held (O)</u> <u>Rolls over</u>		voice	
9mth	<u>Sits without support (O)</u> Pulls to stand, <u>Stands holding on (O)</u> Cruises	Uses pincer (thumb-finger) grasp Throws objects	<u>Says Mama /dada non-specific</u> <u>Waves bye-bye</u> <u>Understands " No"</u> <u>Imitates speech sounds</u>	Starts to explore environment Plays peek-a-boo Responds to name
12mth	<u>Stands alone for 2 seconds</u> Walks with help	Uses mature pincer grasp Bangs two blocks together	Uses mama/dada specifically	Imitates actions, Cooperates with dressing <u>Plays "pat-a-cake" or waves "bye bye" (O)</u> Responds to "No" Avoids eye contact, Concerns child can't hear or "tunes out"
18mth	Runs <u>Walks backwards</u>	Stacks two blocks Scribbles Drinks from a cup	<u>Uses 3 words besides mama, dada</u>	Points to 1-2 body parts (" show me your nose, eyes, etc.") (O) <u>Imitates household chores</u>
24mth	Walks up and down steps without help Kicks ball forward	<u>Removes article of clothing (not hat)</u> Stacks 4 blocks	Combines two words Vocabulary of 20 or more single words Uses own name to refer to self	Points to 6 named body parts (nose, eyes, ears, mouth, hands, feet, tummy, hair) (O) Persistent rocking, hand flapping head banging or toe walking
30mth	Jumps up and down	Puts on article of clothing Stacks 6 blocks	Uses simple sentences Says "NO" often	Shy with strangers Names at least one animal picture
3yr	Can alternate feet when going up steps	Undresses completely Dresses partially	3 word sentences <u>Says what to do when tired, hot, hungry, (1/3) (O)</u>	Names 4 animal pictures Shares toys, Takes turns, Plays well with others
4yr	Hops, skips, alternates feet going down steps <u>Balance on each foot for 2 seconds</u>	Copies a circle (O) Dresses with supervision Catches ball	<u>Says what to do when tired, hot, hungry, (2/3) (O)</u> Asks questions	Plays games with other children <u>Says first and last name when asked (O)</u> Persistent echolalia

5yr	Skips alternating feet Hops on 1 foot 2 or more times Catches a bounced ball	<u>Copies a Cross (O)</u> Dresses without supervision <u>Draws a person 3 parts (O)</u>	Prints first name Asks what a word means <u>Names 4 colors (O)</u>	<u>Puts objects on, under, in front of and behind when asked (O)</u> Likes to help in household task Avoids eye contact
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ii. Building Supportive Relationships with HIV+ Parents/Caregivers

The Paediatric visit

For most parents, the paediatric visit presents both HCP’s and parents/caregivers an opportunity to form a special relationship on behalf of the child. The HCP can promote and monitor the baby’s growth and development, overall health, identify and help to treat problems and help an HIV+ parent feel confident and competent in their (new) role. The paediatric visit is a powerful way the HCP can connect to the parent and a means of building trust and in turn, the family will attend follow-up appointments and seek the care that is offered.

In order to build and promote supportive relationships with parents, the HCP also needs to understand and assess the “behaviors” of parents. A key element in an accurate assessment is for the HCP to assess the parent in a non-judgmental manner. These types of observations will help the HCP to assess and provide support to the parent in a compassionate manner. This means for example, asking ourselves:

- What might this HIV+ father be thinking and how might he be feeling when he yells at his child?
- What might this HIV+ mother’s experience be when she does not respond to her baby’s crying?

In other words, the HCP needs to assess how the parent feels from the “inside” and not just from what the HCP observes from the outside. Also, the HCP needs to assess the external circumstances and their impact on children and families. This means for example, asking ourselves:

- How might this 10 month old baby feel when she is switched from one caregiver to another without any transition time and how does each caregiver react?

The powerful emotions and feelings of parents are the driving force in parenting. The HCP’s awareness, sensitivity and review of the meaning of behaviors and external circumstances of HIV+ parents and families helps to shape appropriate interventions and allows the HCP to become more understanding of the complexity and true meaning behind the parent and/or child’s behavior.

The HCP will also need to reflect on his/her own feelings and behaviors towards each of the family members and their experiences, as this will have an impact on the intervention and reactions of the HCP toward the HIV+ parent and family. An awareness of inner feelings: the parent’s, children’s, and the HCP’s own feelings, allows the HCP not to focus only on outer behavior.

The goal of the HCP is to reduce the HIV+ parent’s feelings of distrust, isolation and secrecy by:

- Listening
- Understanding their stressors
- Not judging
- Fostering a relationship
- Being aware of feelings

Helpful “open-ended” questions

The HCP can ask the parent “open-ended” questions which can help to exhibit a genuine interest and foster a discussion, such as:

- “What has been going on since I last saw you in clinic?”
- “What are your needs today; how might I be able to help you?”

- What not to say might be: “How are you?”

This type of questioning provides the HCP with only a short answer (i.e., “fine”) from the parent, and the response may not be truthful. The lack of further exploration may suggest to the parent, a lack of sincere interest from the HCP.

Tips for Building Relationship’s With Parents/Caregivers (based on the Touchpoints model by Dr. T. Berry Brazelton)

- Value and understand the relationship between you and the parent
- Provide information to a parent at each visit about their child’s development
- Focus on the parent’s experience rather than right or wrong; look for opportunities to support mastery and build parental self-esteem by selecting and admiring success
- Recognize the ‘uniqueness’ of every family; make the mother feel unique and special; acknowledging her strengths
- For the ‘first time’ mother, discuss topics related to mothering and infancy; i.e., infant feelings, breastfeeding, bonding between the mother and infant, maternal issues and feelings, etc.
- Recognize that what a parent needs most from a HCP is their time; and the parent will sense when a HCP is rushed and may not raise important questions or discuss their needs
- Focus on the parents needs; asking what their needs are
- Use the behavior of the child as your language
- Focus on (and observe) the parent child relationship

Helpful hints for the HCP to express and acknowledge with parents when building relationships with them.

- The parent is the expert on his or her child
- All parents have strengths
- All parents want to do well by their child
- All parents have something critical to share at each developmental stage
- All parents have ambivalent feelings
- Parenting is a process built on trial and error

iii. Child Life Skills in a Clinic Setting

Definition – Child Life workers strive to promote optimum development of children, adolescents and families, to maintain normal living patterns and to minimize psychological stress. They employ a variety of therapeutic methods to help children and families cope, adapt, learn and develop with and through their health care experiences and life experiences.

The topics reviewed below are child life assessments, techniques and interventions that Health Care Provider's can use within the clinic setting to help children and their families cope with the varied experiences they may have during the medical visit, and/or within their life experiences.

By using these interventions, the HCP can achieve the primary goal of building an open and trustworthy relationship with the child and family, which in turn, will increase the likelihood that the family will return to the clinic for future appointments.

Managing Children during Medical Procedures

In order to manage children during a medical exam and any medical procedures, HCP's need to:

A. Assess the 3 factors influencing reaction during examination and procedure and find ways to help the children cope:

1. The age and developmental level of a child
2. The child's expectations of the examination and/or procedure
3. The amount of control the child has

B. Find ways to help the child cope:

1. Improve the child's understanding
2. Create positive expectations and outcomes
3. Combat and decrease anxiety

Three factors influencing reaction during examination and procedure:

1. The age and developmental level of a child

Infancy (up to 18 months)

- During this stage of development (attachment stage) it is important to involve the caregiver in the procedure or keep the caregiver in the infant's line of vision or at least a familiar object with the infant.
- Due to "stranger anxiety", have the same HCP perform the procedure (for consistency), and limit the number of strangers in the room.
- During the procedure, the HCP and/or the caregiver can use sensory soothing measures, such as stroking, talking softly and using a pacifier. The HCP can encourage a caregiver to cuddle and hug the child afterwards.
- Due to increased muscle control, older infants may resist procedures, therefore, "positioning-therapeutic hold" can be utilized with the caregiver and child.
- Due to memory experiences in the older infant, crying and resistance may occur at the sight of objects or persons that inflict pain.

Toddler (2 years)

- During this stage of development children see themselves more as individuals who strive for independence.
- Due to the toddlers limited language skills, allow the child to handle, play with and explore the medical equipment. Talk to the child in simple terms he can understand.
- Due to separation anxiety, incorporate the caregiver and utilize distraction techniques.
- Due to the child's limited concept of time, prepare the child immediately; have preparations completed before involving the child in the procedure, and tell the child when the procedure(s) is over.

Preschooler (3 – 6 years)

- During this stage of development a child thinks ‘magically’, mixing reality and fantasy. It is important to address misconceptions.
- As in the toddler stage, continue to use medical play and preparation, with age appropriate words the child can understand and encourage the child to verbalize his feelings and ideas. Due to fears of bodily harm, clarify why all procedures are performed, yet ask the child beforehand what he understands and has questions about. Reassure the child that it’s ok to cry, and that his job is to hold still.
- Procedures and illness are often viewed as punishment, therefore, explanations need to be verbalized and modeled by the HCP.

School Age (7 – 12 years)

- The school age child has mastered logical thinking and reasoning. During this stage of development, the HCP can continue to build a trusting relationship with the child. The explanation of procedures needed and why they need to happen and incorporating coping techniques which have helped the child in previous visits, will help the child to continue to build trust with the HCP.

2. The child’s expectations of the examination and/or procedure

The HCP needs to assess the child’s past experiences. Suggested questions to parents:

“What has the child been told?”

“How has your child reacted in the past?”

“What worked before or didn’t work?”

“Has your child had recent hospitalizations or difficult procedures?”

“Has anything happened to anyone close to your child?”

3. The amount of control the child has

The amount of control the child has will greatly affect how the child is able to cope with the medical experience. Loss of control promotes anxiety and fear and increased withdrawal of the child with the staff. The more control the HCP can give the child, the more cooperative the child is going to be.

B. Ways to help the child cope

Medical preparation and support is essential with children in order to minimize any stress and anxiety and to foster control and understanding. The HCP’s goal is the emotional well-being of the child and family and to prevent dehumanization.

1. Improve the child’s understanding:

- **By explaining the procedures to a child**

During and/or before the medical examination it is crucial that the HCP continue to explain (with language the child can understand at his age level) to the child about what each instrument is and what it will be used for. This will help to reduce the child’s level of anxiety and any misconceptions the child may have. If a younger child is being examined, let the child touch and explore the items. In order to build trust, a caregiver and HCP need to be honest and truthful with the child about any procedures that will occur during the clinic visit.

- **Through the use of play**

Play is “the business of childhood”; it is “the work of children”. It is the major way by which the child educates him/herself about the world. Children will symbolically represent their feelings in play because they do not have the language to “talk out” feelings as adults do. For example, a child may draw, write or play with animals that tell a story since he/she is unable to put the fears into words.

By using medical play (playing with the medical instruments, stethoscope, blood pressure cuff, thermometer, etc.), the HCP can explain their functions and reduce his feelings that every procedure is an inflicted trauma. The child can also express and show the HCP what he/she understands, and what might have happened in the past. By using the play items, the child will feel more comfortable about what to expect and be able to express it (in a non verbal manner). The HCP can ‘model’ the play items and explain to the child what will happen. If the child can be prepared in advance, the HCP can also suggest ways, to the child and parent, on how to cope (by distraction, therapeutic hold, etc., see section on pain control techniques) with the procedure. Advanced verbal explanation, preparation and demonstration are most effective.

2. Create positive expectations and outcomes

The HCP needs to create positive expectations and outcomes by choosing words carefully and avoiding negative suggestions:

What to say: “It is ok to cry, I just really need you to try to hold still”

“You did a great job holding still”

“You were very brave today”

“Sometimes kids need extra help in holding still; so the staff and/or your Mom is going to help you do this by giving you a big hug”

What not to say: “I will stick you with another needle if you don’t hold still”

“Don’t cry, you’re a big boy”

“Stop acting like a baby”

3. Combat and decrease anxiety

(Refer to the pain management techniques section)

- Emotional support – the caregiver is present for support and therapeutic hold
- Deep breathing: which includes blowing bubbles, counting
- **Create a calm environment – tone of voice, singing a song, etc.**
- **Imagery and Distraction – a favorite place, super hero’s, for example:**
- creating the child’s amount of control (see section on pain control techniques)
- Give choices – to look or not look during a blood drawing, or to sit in the caregivers lap or on the exam table, also reminding them that crying is “ok” as long as they “hold still”
- Continue to teach and utilize the coping mechanisms that were helpful with the child at the last visit

Why not restrain a child during a medical procedure?

Experts in controlling pain in children condemn the common practice of restraining children who resist painful treatments. Restraint (i.e., holding the child down with force), only increases a child’s anxiety and fear and the stressful reactions induced by pain, which in turn can complicate and delay recovery. Also, the child will remember the restraint and will continue to be fearful and have increased anxiety towards the HCP and the clinic, in the future.

Studies suggest that a “therapeutic hold”, where the caregiver or HCP helps to hold the child still (for example, by sitting in the parents lap), allowing the child choices (for example, to watch or not watch, choosing the left or right arm for a blood test), in order to foster some control in the child, is less anxiety provoking and may help to decrease anxiety during future appointments.

Guidelines for Interacting with Children and Adolescents in a Health Care Setting

The table enclosed is a list of “What Works” and “What doesn’t Work” when a HCP interacts and communicates with (HIV+) children in a health care setting.

What Works

Get Down at the Child’s Eye Level

How would you feel if someone four times your size loomed over you at a time when you were scared anyway.

Speak Directly to the Child or Adolescent

The youngster is an individual. Talk to him or her, not just the parents

Be Honest

Hiding the truth from children, even with the best of intentions, results in the child losing trust in hospital personnel.

Identify, Allow and Respect Normal Expressions of Emotion

Crying is okay and so is anger. A youngster will feel and cope better if they can let their emotions out.

Give the Child Choices

But only real choices! If the child can choose juice or water to drink with medication, great! But, if he has no choice about taking the medication, so don’t offer one.

Talk to the Child or Adolescent About Things of Interest to Him or Her

All kids have school, friends, pets, and hobbies and would love to share that part of themselves with you.

Support the Relationship Between Child and Parents

All youngsters, even teens, need their parents, and parents are the experts on their own children.

What Doesn’t Work

Avoid Comparing the Child to Others

Nothing makes children madder than “ you should be able to do this. Johnny is younger than you, and he can do it.”

Be Careful When You Touch Children Other Than for Medical Reasons

Touch children only when they indicate readiness to receive physical comfort. Children aren’t pets!

Don’ t Pity

People need supportive caring, not gushy sympathy.

Refrain from Infantilizing the Older Child

Treat kids appropriately for their age. Just because the youngster is under 21, doesn’t mean your voice needs to go up three octaves.

Try Not to Say, “ Be a Big Boy”

Children will do the best they can. Added pressure of embarrassment doesn’t help, and it’s harmful if the child learns to feel negatively about himself.

All Children Are Not Raised the Same

Don’t expect other people to use the same child discipline or child rearing techniques that you use with your children.

Stop Yourself Before you Threaten

Saying, “If you’re not good mommy will have to leave”, may result in temporary good behavior because the child is frozen with fear. But there may be serious psychological consequences later.

iv. Pain Management in Children

Pain is “an unpleasant sensory (ex, needle) and emotional experience (ex, child has been in clinic 3 yrs) associated with actual or potential tissue damage or described in terms of such damage.” Pain is whatever the person experiencing it says it is. Children have the ability to feel pain. Infants feel more pain than do older children and adults because they lack the physiological ability to block the transmission of pain. Pain should be assessed, treated and prevented as much as possible.

Studies suggest that pain is chronically under treated in children. Therefore when a child says he has pain, HCP’s should take it seriously, because as we all know, children don’t like to go to the doctor, so if they come to the clinic, they must be in pain.

For children, as well as adults, physical, emotional, cultural and social factors influence how pain is experienced and how they respond to different methods of pain control.

Barriers to Pain Assessment

1. Some children will not be honest about the pain they are experiencing due to the consequence of receiving an injection.
2. Some children and caregivers think the HCP will ‘just know’ when the child is in pain, and therefore not communicate or describe in detail the symptoms.
3. Some caregivers may think that children will eventually get accustomed to pain and painful procedures.
4. Some caregivers think that the HCP will always know what is best for the child and they will not ask the HCP for additional pain medication or advice because the HCP did not offer it. Again, a detailed description of the pain, from the child and the caregiver is crucial.

How To Assess Pain in Children

There are multiple ways of assessing pain in children. The HCP can assess a child’s pain by using factors that influence the pain experience. These factors include:

- The child’s developmental level
- The previous pain experiences
- Birth order
- Sex
- Cultural background

Studies also suggest that self-report is a helpful indicator of pain; therefore, the HCP needs to interview the caregiver and the child:

1. By Interviewing the Caregiver

The caregiver can be helpful to a HCP, in assessing a child’s pain and for assessing pain in the future. It is important to interview the parent and request that they be as descriptive as possible.

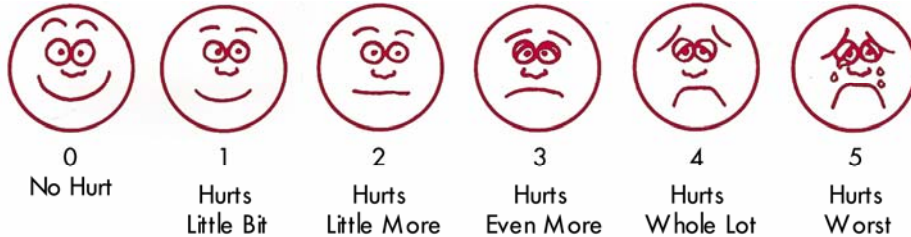
The following signs may mean that the child is in pain:

- Listlessness, body language
- Changes in mood, such as irritability
- Changes in sleep patterns
- Changes in appetite
- Loss of concentration
- Loss of interest in things usually enjoyed
- Lowered activity, loss of playfulness
- Crying, wincing, etc.

2. By Interviewing the Child

The Wong-Baker Faces scale is a poster developed for children to help them communicate how much pain or hurt they feel. It is a poster with pictures of expressive faces. Facial expression is probably one of the easiest scales to use universally. The only word needed to use it is the word pain in the language specific to the child.

The pain assessment scale should be used before the child is in pain.



Wong-Baker FACES Pain Rating Scale:

Brief word instructions: Point to each face using the words to describe the pain intensity. Ask the child to choose the face that best describes his/her own pain and record the appropriate number.

Original instructions: Explain to the child that each face is for a child who feels happy because he has no pain (hurt) or sad because he has some or a lot of pain. Face 0 is very happy because he doesn't hurt at all. Face 1 hurts just a little bit. Face 2 hurts a little more. Face 3 hurts even more. Face 4 hurts a whole lot. Face 5 hurts as much as you can imagine, although you don't have to be crying to feel this bad. Ask the child to choose the face that best describes how he is feeling.

Rating scale is recommended for person's age 3 years and older.

Pain Control in Young Children

Helping children cope with pain gives them a sense of mastery and self-control that they can also apply to other stressful situations, as well as to future health problems involving pain. This is why it is so important for HCP's to help facilitate coping mechanisms for the children and their families while they are in the clinic for medical appointments.

The most effective approaches to helping a child suffer less pain will depend on the child's age. The following examples suggest some of the ways (distraction and relaxation techniques) that work best at different ages:

Age Group

Techniques

Infant

Swaddling
Soothing by touch

	Singing/lullabies Pacifiers Rattles
Toddler (2 years)	Singing Blowing bubbles Therapeutic hold/positioning Tone of voice
Preschooler (3 – 6 years)	Rehearsing the procedure Imagining a super hero Deep breathing Therapeutic hold Holding or squeezing a hand Sitting on parents lap Looking at a book Singing Tone of voice
School age child (7 – 12 years)	(Same as above) Counting by number Describing every detail of the procedure as it occurs 'Story-telling' for distraction Object-name game by alphabet (a – z) Prayer (silent or verbal) Giving choices to foster control: "Watching vs. not watching" Sitting on the table vs. in a chair Choosing the 'site'

Other Factors

1. The HCP needs to encourage the caregiver to participate in helping their children cope with pain and medical procedures. Children will take cues from their caregiver's reactions, therefore, parents need to be aware of, and control their own fears and anxieties, during the child's medical visit and/or procedures.
2. Working as a multi-disciplinary team and viewing the child as one of the experts and members of the team is helpful. Caregivers and HCP's can assist by also reassuring the child that he/she has not done anything wrong to cause the pain. Caregivers often feel responsible for their children's illnesses and may experience guilt. Therefore, caregivers (and family members) can also be encouraged to be part of the team.
3. The 3 stick policy – Some clinics have a policy where after 3 sticks of an unsuccessful blood drawing with a child, the child may go home. This may help the child have less of a traumatic experience and build a trusting relationship with the HCP in knowing the choices and limitations.

v. The Process of Disclosure with Children

One of the most difficult problems that face caregivers is whether to disclose, when to disclose and how to disclose to their child their diagnosis. The HCP is an important source of psychosocial support and guidance for a caregiver in the process of disclosure.

Questions caregivers can consider before talking with their child:

- Do you think your child has an idea about HIV?
- If he/she does know, what do you think it would be like to keep it a secret?
- What do kids need to know?
- What is your main concern about telling your child about his or your HIV infection?
- If he or she did become very upset or angry, how would it show?
- How might talking about the HIV affect your relationship with him?
- How would you respond if he showed signs of being upset?
- At what age do you think he would be ready to be told?
- How would you know he would be ready?
- Would you think it would be better to tell him while he or you are well, or ill?
- Do you think that not raising the subject of HIV might prevent him from asking questions?
- Who do you think would be most relieved when he is told?

Each family is unique therefore an HCP should talk with the parent or caregiver and review the following variables before any decisions or discussions occur:

- The child's age and level of understanding
- The current knowledge the child has
- The family's cultural style and communication style

Once an initial discussion with the caregiver has occurred, the HCP needs to continually (at each clinic visit) discuss and support the many feelings a caregiver may have when they are in the process of deciding when and how to disclose to a child. Discussions relating to the pros and cons of telling and their feelings, anxieties and guilt associated with the illness, can help to foster the process of disclosure. The HCP also needs to reassure the caregiver that confidentiality will be maintained. The HCP's supportive and compassionate manner will strengthen the trust the caregiver will have towards them and empower the parent.

There is no one way to talk to children about HIV or AIDS, and there is no magical age when a caregiver should disclose the facts about the disease.

Disclosure is a continuing process (not a one-time event) that is unique for each family. A HCP needs to reassure a caregiver that conversations at home regarding the illness might evolve within the home, over time and in a nurturing manner, if there is open communication. For example, instead of disclosing everything at once, a child may react better if they learn in an evolving, gradual way. Children will guide a caregiver and/or HCP on when to talk with them based on the questions they begin to ask. For example, when a five year old child begins to ask questions such as, "Why do I take medication?" a response could be, "To keep your body healthy, just like I take vitamins to keep me healthy."

Studies suggest that school age children (approximately 9 – 11 years of age) usually begin to ask and are more curious about why they are visiting the doctor often or taking medications, etc., due to the fact that they see they are different than other children their age (who do not take meds, or are ill, etc.)

Some caregivers may need assistance, guidance and support in telling their child their diagnosis, therefore the HCP can suggest discussing and disclosing the illness during a medical appointment. The HCP needs to discuss with the caregiver beforehand, who they would want in the room at the time, in order to ensure the most supportive environment. Initially, the HCP can begin by asking the child what he/she is thinking. Such questions as:

- "Why do you think you come to the doctor?"
- "What is the blood test for?"
- "Why do you think you take medication?"
- "Do you have any questions you would like to ask me?"

Based on the child's reactions and comments (the child's cues), the HCP can help clarify any misconceptions (or fantasies) the child may have. If the child, for example, changes the subject, this is a cue that the child may not be ready to hear the information. Following the child's 'readiness' (their cues) to hear, can be the HCP's or caregiver's best guide as to how much information should be shared.

Within the home environment, some caregivers fear that they may not have the answer to a question a child has. Reassure them that this is ok, and that they can tell their child that their question is important and to write it down so it can be answered at the next medical appointment (instead of ignoring it, which creates more secrecy and isolation).

Studies have suggested that disclosing to a child is more beneficial for the child's future well-being than not telling. The unknown, i.e., not telling, is always more threatening and fearful than that which is known, i.e., telling. Secrets isolate the child and the child will then feel he/she has no one to talk with. There is an increase in the likelihood that the child will accidentally overhear the information, may hear inaccurate information or fantasize that something else is wrong. They may have increased anxiety, self-blame and depression. The secrecy may also create distrust and/or angry feelings between the child, parent and HCP, which can hinder all future interactions with the child.

Due to the fear some caregivers may have that their child will disclose the diagnosis to others, keeping the diagnosis private (within the family), is an important topic for a caregiver or HCP to explain to the child. A medical team and a family who strive for an atmosphere of honesty and openness regarding the diagnosis, treatment and prognosis of HIV/AIDS will create an atmosphere of trust and unity; which can only benefit the child.

How can an HIV+ parent/caregiver tell their child they are infected?

The HCP needs to help the HIV+ parent/caregiver explore his/her own feelings by providing questions to help consider whether to tell or not. The pros and cons of disclosure (see section on "the process of disclosure with HIV+ adults") also need to be created, discussed and explored with the parent/caregiver. The parent/caregiver needs to take in consideration the child's age and developmental level, the current knowledge the child has and the family's cultural style and communication style (as listed in section 9, number 5).

What are some common feelings and reactions a child may have after disclosure occurs and how to help?

Since children do not usually express their feelings verbally, the HCP can remind the caregiver to watch for any unusual 'signs' or changes in their child. Some changes include:

- Withdrawing from others
- Difficulty sleeping
- An increased need for affection
- Aggression – which may be a sign that they feel angry, frustrated or sad
- A change in their behavior in school

The HCP can suggest to caregivers that they need to continually ask the child if they have any questions, that they will be available to talk with and to let them know they are loved. This will also let the child know that it is safe to discuss and ask questions and that they have someone to talk with. The HCP can remind the family that they are available for continued support at the clinic.

What are some common feelings of the "affected" (uninfected) child?

The 'affected' or uninfected child or sibling is sometimes the 'forgotten' child in the family. Due to other family stressors, a caregiver may forget to address the psychosocial needs of these children.

It is helpful for HCPs to discuss and explore the family dynamics and how the 'affected' child is coping.

The affected child may have questions about the illness, yet may be afraid to ask, due to the secrecy and lack of communication within the home environment. If no one explains things to them, they will make up their own explanations based on incorrect information and sometimes their own explanations may be scarier than the reality. Secrecy may also occur due to the child's desire to not discuss the issue in order to protect the HIV+ parent/caregiver from getting upset.

Young children will sometimes be afraid they caused the illness. They may believe that they ‘wished’ their brother (for example) to be sick. They must be reassured that they did not cause the illness, and that their thoughts or wishes are not real.

Sometimes the affected sibling may become jealous or resentful of their sick brother, for example, due to all the special attention he may receive. And, because a caregiver may spend a great deal of time at medical appointments, a sibling may feel left out and/or confused about what is happening in the family. They may also develop behavioral problems at home or at school (which may be due to the desire to get attention that he/she feels is lacking). The HCP can suggest that the child be brought to the medical appointment so they can see what happens and talk to the staff members.

When an HIV+ parent is ill or has passed away, the older sibling may have to serve as the caretaker of the family. This may cause feelings of anger, depression or resentment. The ‘parentified’ child may also have shame over the sick parent’s appearance.

The HIV+ parent/caregiver needs to think about what they would want to say to their child, based on their age level. At times, a parent feels that not telling will protect the child. If a parent is too secretive, the affected child may decrease the trust he/she has with the parent on other issues. It is important to be honest, as children can sense when something is wrong.

The HCP also needs to encourage an HIV+ parent/caregiver (or favorite aunt, uncle, etc.) to set aside special time with the ‘affected’ child and express to them how much they love them.

vi. Talking to Children About HIV AND AIDS

Why caregivers need to talk to all of their children about HIV and AIDS:

It promotes open communication - Just mentioning the subject lets the child know its okay to talk about HIV, AIDS (and sex) and makes it easier (more comfortable and safe) for him or her to openly ask questions. It can also help clarify any misconceptions or fantasies the child may have.

It creates trust - Children take cues from caregivers, therefore, not responding or the ‘silence’ about the topic, may make the child feel that they cannot talk about it and it must remain a secret. This in turn will create and reinforce the stigma, feelings of confusion, mistrust, isolation and fear of the unknown relating to HIV (or other illnesses). Therefore, talking with a child, will foster trust on this topic, as well as other issues within the family environment.

It educates -The only known “cure” and one of the best methods of prevention for stopping the spread of HIV infection is education. Starting young with children could save their lives. It also prepares the way for more explicit information they will need later. It helps to break the barrier between the child and parent, in order to feel more at ease talking about uncomfortable or embarrassing topics.

Health Care Providers, parents and caretakers are the primary educators and role models for young children.

What are the basic tips a HCP can suggest to caregivers in helping them talk with their children about HIV or any important health topics?

Begin talking with children at a young age. HCP's can suggest to a caregiver to begin by discussing general sex gender issues; for example, naming their body parts, etc., at a young age. A caregiver can also begin by discussing the importance of hand washing; and how germs are spread in different ways. This will create an environment within the home for the child that is open and honest and increase the comfort level of discussing any sex gender issues, in the present moment and 'pave' the way for further discussion's, that are more elaborate in the future.

Answer questions when they come up – don't put them off. The child might not ask again or may be afraid to ask. Remind the caregiver that it is 'ok' not to have all the answers. HCP's can help clarify answers to questions a child may have and be supportive at the clinic visit.

Listen carefully. Be sure to understand and respond directly to the question. Don't be afraid to say that you feel embarrassed. Often just admitting it makes the child feel more comfortable.

Give the amount of information appropriate for your child's age. A 6 year old won't understand as much as a 12 year old. For example:

age 3-4 years – keep it simple, discuss healthy habits (hand-washing, brushing teeth, eating good foods etc.), body parts and what it means to be sick.

age 5-8 years – children are interested in germs and how viruses are spread. Explain that HIV is passed during sex or when sharing needles. Give an example of a cut finger and explain that the disease can enter the body through blood. Try to keep your responses simple and concrete.

age 9-12 years – give a better understanding of the facts and begin to discuss ways to prevent the spread of HIV virus. As the child grows older, give more details so that he or she is well informed by teenage years.

Adolescents – Continue to discuss prevention methods and issues of peer pressure and taking responsibility.

Ask your child questions. A caregiver can ask a child what he or she has heard about or knows about the topic at hand. This will give insight on how to respond and the accurate (or inaccurate) knowledge the child has on the topic. When talking with a child about a topic, make sure the child understands what is being stated by asking questions, and then use correct terms.

Don't stop with one conversation. The topic is so important that you'll need to talk about it several times over the months and years.

vii. Death and Dying Issues for Children

Stages Children Pass Through In Developing An Understanding Of Death and How To Help:

From birth to adolescence, children have distinct stages of development that affect their perception of death.

Intervening to help a child cope with death is successful when these developmental stages are understood and will assist HCP's to minimize the anticipated and actual fears of the child (as well as the sibling or caregiver).

Age 1 – 3 years

Children fear separation from their caregivers at this age range. They are unable to understand the permanent separation that death brings. They equate dying with sleeping and expect people who have died to “wake up”.

How to help the grieving child:

A caregiver needs to keep the daily routine of a toddler as unchanged as possible when a loved one dies, as they need a sense of security. Also, a caregiver needs to make extra time every day to hold, talk to, and comfort the child.

Age 3 – 5 years

Children don't accept death as final. They think of death as a temporary separation from loved ones, for example, sleeping or going away for a while. They do have concern for physical pain and suffering. Death is a departure but not final. They see death as accidental.

With the death of a loved one, they sometimes believe that they somehow caused the death, due to their powerful imaginations, or magical thinking (“I wish my sister would die”), which is normal at this stage. Another example of magical thinking is that they think if they wish hard enough or are good enough, they can bring that person back to life. Also, they may not react to the death of someone they love with grief and sadness, due to the lack of understanding the finality of death.

How to help the grieving child: A caregiver or HCP needs to clearly explain why the person has died. For example, “When people die, lots of boys and girls feel maybe something they did or didn't do had something to do with the death. Actually, grandma died because she had a heart attack and that had nothing to do with anything you did.” Reassurance to the child that they did not cause or hasten the death may be necessary. Many children blame themselves for death because of this egocentric perception of self.

Age 5 – 8 years

Children begin to accept death as final yet have difficulty in thinking that someday they themselves will die. They view it as separation from loved ones, going to heaven. It is important that they are reassured that they will not be abandoned. They may have a greater fear of their HIV+ parent's dying, particularly if they see them as vulnerable. This concern is even greater when they are being raised by a single parent. They may be concerned about death yet associated it with old age.

How to help the grieving child: A caregiver or HCP needs to let a child know that they will not live forever, however, let the child know who is healthy and how bodies can heal and how doctors can help when someone is sick. These comments will help reassure the child that while minor illnesses and injuries are common, they are seldom fatal. A child can be

told that crying is okay for everyone, even boys. Feeling sad, frightened and angry is also appropriate. Also, a child may think he/she is responsible for the death, therefore, a caregiver or HCP needs to be sensitive to and clarify this misconception.

Age 8 – 10 years

Children know someday that they will die yet it is still a distant prospect. They learn that all living things must die. They begin to feel sorrow and loss. Their interest in the mysteries of death continues to grow, and they may ask detailed questions about the biological aspects of dying.

How to help the grieving child: A caregiver or HCP can answer questions as fully as possible and should not discourage normal curiosity about death. Acknowledge the child's feelings and allow the child to cry and to talk about the loss if that is what is expressed.

Age 9 – 11 years

They recognize death as universal and realize someday they will die. They react strongly to death of another. They are interested in the cause of death and in what happens after death. Death is accepted as part of life. When they are confronted with their own death, they may exhibit fear, bitterness and despair.

How to help the grieving child: The HCP can continue to answer questions as fully as possible. The child's feelings should be acknowledged and explored by the HCP, family members and/or friends. Suggested interventions may be: talking about memories, writing daily in a journal to express feelings, drawing pictures of how a child feels, making a photo/picture or collage book of the loss loved one or daily prayer.

Information the HCP can gather from the caregiver before and during the time when the death of a loved one is discussed to a child:

1. What is the child's previous experience of loss, separations and death?
2. What information was given to the child during the course of the illness; in order to determine if the child was somewhat prepared or will be in total shock?
3. Alert the caregivers that children hear things, therefore avoid whispering behind the child's back, as they may feel that there is a secret and they cannot discuss or ask any questions about the death or ill loved one.
4. Children may have fears or misconceptions over what they may have overheard therefore ask them questions in order to clarify misunderstandings.
5. What are the cultural and religious beliefs within the home environment? What is believed about the nature of death, the rituals that surround it and the expectations of afterlife? What formal or informal rituals of grieving will the child be expected to participate in?
6. Remind the caregiver that children will often not bring things up unless someone else does.

Psychosocial Issues and Support For HIV+ Parents/Caregivers



i. Communication Skills

Communication is what makes us human. It is active listening and giving feedback. It is the sharing of ideas and feelings. A patient/caregivers past experiences, physical makeup, cultural background and current psychological state, determines how he/she perceives, interprets, evaluates and organizes perceptions and what actions might be taken in response to them.

Communication is about “messages”: verbal, vocal (tone), and visual. Studies suggest that the factor which carry’s the most ‘believability’ is the visual. The percentage is as follows: 7% verbal, 38% vocal (tone), 55% visual. Therefore, body language (i.e., eye contact, facial expressions, etc.) is the key component for the most effective communication and trust to occur.

The following is a list of ‘approving’ and ‘disapproving’ non-verbal communication that a HCP can assess, when a patient is attending a clinic appointment:

Approving

Smiling
Leaning forward
Relaxed/open body
Stays in eye contact
Even tone of voice

Disapproving

Folded arms, stiff posture, or leaning back
Little eye contact
Squinting eyes
Turning head/body away
Harsh tone, loud voice
Avoidance - writing, not full attention
Frowning
Shaking head no

Three Key Communication Skills

Listed below are three key communication skills that the HCP can use to increase the amount of psychosocial information shared by an HIV+ parent/caregiver:

1. Being a good listener – When questions are asked in an interested tone, not a casual tone of voice, an HIV+ parent/caregiver is more likely to believe the HCP really wants to know the answer. This also includes nonverbal messages which may help to show the patient that the HCP is actively listening; i.e., leaning forward slightly, facing the patient, maintaining eye contact (without staring), and/or touching the patients hand or shoulder (with respectful boundaries).

2. Showing empathy – An HIV+ parent/caregiver appreciates reassurance from the HCP that he is doing the right thing for himself and/or for their child and family. For example, brief statements that acknowledge how difficult it is to manage a baby or toddler can help a parent feel his efforts are appreciated by someone whose opinion matters. Being supportive can be “I understand”, “That sounds like a difficult thing to do but it looks as though you did it well”.

3. Asking questions – An HCP shows he is willing to listen, by asking questions. This eventually creates trust and a willingness to share experiences and concerns between the HIV+ parent/caregiver and HCP.

More Tips for Active Listening

- Stop talking
- Put the patient at ease
- Ask questions and reinforce confidentiality
- Minimize ‘your’ distractions (phone ringing, talking to staff, etc.)
- Show that you want to listen
- Put yourself in the speaker’s place
- Be patient, show compassion

ii. Counseling Techniques and Supportive Strategies

Counseling skills are important for all professionals having contact with HIV-infected patients and families. Utilizing the counseling techniques and supportive strategies listed below are crucial in building relationships between the patient and HCP and providing the best overall quality of care.

1. Awareness

The awareness of ones own values and beliefs is essential for becoming an effective HCP /counselor, and will provide one of the primary goals of making connections with patients; which is a non-judgmental HCP. When a HCP has a strong belief concerning a value which significantly differs from the patient, there may be a negative impact on the clinic visit. Some of the values to be considered are sexuality, HIV/AIDS, people living in poverty and different cultural practices and norms. Attitudes and values are not right or wrong. There will be times when certain situations will “push the HCPs buttons.” It is helpful when the HCP becomes aware of his own conflicts towards the patients attitudes.

Other issues to reflect on include:

- Personal struggles
- Stresses in ones life
- Moral judgments
- Emotional reactions
- Religious beliefs

2. Respect

Effective counselors must demonstrate acceptance of the patient, show empathy, positive regard and respect for the individual. The ability to demonstrate these qualities helps the HCP to connect and relate with the patient, encouraging trust. It allows patients to express all their feelings. It is more important to focus on what is ‘right’ with the patient such as internal resources, survival and coping behaviors and focus less on what is wrong about the patient.

3. Trust

Trust is an integral part of the counseling relationship, specifically because of the stigma surrounding HIV.

It is helpful to explore the patients past experiences with trusting others, considering that if they were betrayed in the past, they will be hesitant to trust the HCP.

Confidentiality is essential. The HCP should discuss the institutional or legal guidelines regarding confidentiality and what its meaning is. The HCP needs to stress the importance and dedication he/she has regarding confidentiality issues with the patients.

If given the chance to explore issues and feelings in a safe, trusting environment, patients can begin to express their feelings, issues and concerns in an honest manner.

4. **Listening Skills**

Counseling requires good listening skill's which include:

Reflection and Listening for Feelings

Reflection focuses on feelings rather than content.

For example:

Patient: "I hate having to wait for my sister. She's always late!"

HCP: "It sounds like you're angry with your sister."

This helps to identify the emotion the person might be experiencing. However, if the patient corrects the HCP, this is ok. It has the same effectiveness, which is the patient's ability to express how he is feeling. If the HCP hears a strong resistance to discussing feelings, then reflecting may not be helpful.

Attending behaviors

Attending behaviors are subtle behaviors that indicate to the patient that the HCP is listening.

For example:

- A nodding of the head to indicate one is listening
- Leaning forward
- Smiling at the patient
- Mirroring: the actions of the patient are mirrored by the HCP; smiling when the patient does, leaning forward when the patient does, etc.
- Voice tone

Restatement

Restatement is repeating back to the patient the content of what they said, using the same words. This shows the patient the HCP is listening and helps to clarify any misunderstanding that the HCP may have when hearing the statement.

Paraphrasing

This technique is similar to reflection.

For Example:

Patient: "Sometimes I just don't know what to do with my son anymore. He's always in trouble at school and failing his classes and I've done everything I could and I just don't have the energy anymore!"

HCP: "There's a lot going on for you right now. It sounds like you're frustrated and feel defeated because you have tried everything you could do to help your son and nothing has worked."

The HCP restates the patient's basic message (both feeling and content) using similar, but fewer words. Paraphrasing is used to clarify feelings and mixed messages. It also encourages the person to continue to explore feelings and issues; and alerts the patient that the HCP is really listening and trying to truly understand the issue.

Use of questioning

Questioning techniques help the patient to: elaborate on certain points, start conversations, obtain specific examples of what is troubling the patient, used to check perceptions of the patient and HCP, clarify thoughts or statements that are vague or conflicting and obtain information in general.

When asking a question to the patient, the question should be open-ended; a question that cannot be answered with a 'yes' or 'no'.

For Example:

"What do you mean when you say you feel like a bad mother?"

"How did you feel when you heard the test results?"

"Could you say more about the incident you had with your son?"

The HCP should not use "why" questions, as the patient may feel judged and offended and may react defensively. Also, such questions as, "How are you?" are not recommended; as the usual response would be 'fine.' Questions such as, "Tell me what has been going on (or how you have been feeling), since I last saw you here", creates a more open-ended discussion for more detailed information. If the patient answers back with a response such as "the same", the HCP may respond with "What does the same mean?"

Listening without judgment

Do not judge the patients feelings or tell the patient the reasons why they may feel a particular way. A HCP needs to show empathy and validate feelings. However, the HCP should not say "I know how you feel". Every patient is unique and only the patient knows how he/she may feel.

5. Constructive Feedback

Providing feedback in a constructive way will help the patient to reflect upon his words or actions. The HCP needs to express positive and negative feedback in a way that is helpful, specific and non-accusatory, in order for the patient not to react defensively and withdraw from the HCP.

For Example:

"I feel concerned when you miss your prenatal appointments because prenatal care will improve you and your baby's health."

"I feel concerned when I hear you are continuing to have sex without using condoms because you are at risk for getting another sexually transmitted disease."

Feedback needs to be gentle and appropriate to the level of involvement the HCP has with the patient.

6. The Environment

The environment or space that the patient discusses HIV or any personal issues should be private and undisturbed (no other people walking in and out). This will help the patient to feel more at ease and discuss any issues or concerns and reassure them that confidentiality is being protected, and not broken.

Understanding Resistance

Why are some patients resistant to counseling and support services?

- It is not easy to trust strangers (the HCP) and be open to them about personal struggles and issues relating to HIV/AIDS
- Needing help is a threat to one's self-esteem, integrity and independence
- It is difficult for the patient to commit to change in their daily life
- It is not easy for patients to confront their underlying issues at first; the process may be too painful.
- Sometimes problems seem too large, too overwhelming, or too unique to share easily with the helper.
- Some cultural traditions prohibit or discourage individuals from receiving help outside the family.

Barriers to the effectiveness of the counselor:

- Unrealistic expectations
- Fear of opening up the 'can of worms'
- Lack of the awareness of attitudes and values which may be in conflict with the clients
- If the HCP has personal conflicts in his own life, he may not be able to listen to the patient
- Burnout
- Self-disclosure by the HCP to the patient: this may not be helpful as HCP's risk losing the opportunity to have the client get in touch with his or her own feelings, it can overwhelm the client hearing the HCP's problems and the client will feel that his/her issues are minimized and unimportant.

Other issues:

Crises

By definition, a crisis is temporary. It is a heightened period of anxiety, fear, confusion and sadness that will improve and diminish over time. A crisis can result in the inability to function in one or more areas of a person's life; for example, a patient that can't get out of bed, is fatigued, can't make decisions or feels completely helpless, hopeless and frightened. The effectiveness of a patient managing a crisis or crises may depend upon the adequacy and awareness of their own coping skills.

Some crisis interventions for the HCP to utilize include:

- Find a quiet safe place to talk, away from all other distractions.
- Listen and do not talk too much.
- Let the patient express their feelings and emotions and allow them (it's ok) to cry.
- Allow for silence. Do not take the opportunity to talk in those moments when the patient pauses or is pensive. Provide emotional support by using reflections to show the patient that you hear how he is feeling. This helps to build trust. For example, "You're really hurting right now," or "You're overwhelmed, you don't know what to do."
- Explore what the patient has done so far, if any, to cope with or change their current situation and how the patient has coped with crises in the past.
- Be directive (if it is possible) in a helpful way (making phone calls, referrals, etc.) and ask the patient what can be done to make it easier to handle.

- Be aware of any underlying issues such as, abuse, suicidal ideations, chronic depression or other mental health problems of the patient. Helping the patient early on after a crises event will help to reduce the danger of suicidal or homicidal impulses.
- Remember that the HCP must not get caught up in having to solve the patient's problems (and may not be able to). HCP's may need to reevaluate their role and expectation of themselves, as well as their patient's expectation.

“If you keep your eyes open and your heart open, you can learn an enormous amount about the human experience.”

iii. Reactions of Patients Newly Diagnosed and How To Help

Intense emotional reactions, along with bouts of denial, may occur after a patient is informed of their HIV or AIDS diagnosis. The stigma of HIV, along with the misconceptions and lack of education on HIV/AIDS can elicit many emotional reactions (such as, feeling alone and isolated) within the HIV+ patient; and greatly affect the patient-provider relationship. Stigma can, for example: prevent people from speaking about and acknowledging HIV as a major cause of illness and death, prevent an HIV+ mother to seek medical and psychosocial care for herself and her children and it can cause the loss of emotional support of family and friends and community organizations.

The following is a list of some reactions:

- Denial – Denial can have positive and negative affects on a newly diagnosed patient. If denial occurs as a means of coping, reducing the feeling of being overwhelmed and enabling the patient to seek care, then it can have a positive effect. However, if the patient's denial affects his reasoning, i.e., he states he feels healthy, therefore, he does not seek medical care, and denial can have a negative affect.
- Fear and anxiety, anger, rage
- Internalized shame
- Struggles with social isolation and depression
- Difficulty talking about the diagnosis, needing to keep it a 'secret', due to the HIV-associated stigma
- Feelings of worthlessness
- Suicidal thoughts
- The prospect of serious medical conditions
- Thoughts of death
- Sadness and grief associated with having a foreshortened future
- Family rejection and fear of abandonment
- Loss of emotional support of family and friends and community organizations
- Feelings of depression associated with lost loved ones
- Anxiety from their sexual relationship and the struggle with disclosing
- Addressing their own mortality and the multiple losses they have encountered in the past
- Hopelessness – the feeling that there is no reason to seek care for what may be considered a terminal illness.
- Physical complaints - The HCP also needs to be aware of and assess the 'physical' complaints of the newly diagnosed HIV+ patient which may be occurring due to emotional stressors; complaints such as a stomachache, headache, etc.

Issues for women

- HIV+ women are more likely to respond to the needs of other family members before they respond to their own medical and psychosocial needs relating to their HIV care.

- HIV+ women report that they suggest using condoms infrequently because they fear violence or rejection from their partners.
- HIV+ women have reported that they have been rejected by family members due to their fear of casual transmission (lack of education).
- HIV+ women expressed their frustration and hopelessness of watching other family members confront anger, hatred and misunderstanding when disclosing to them. These experiences increase a woman's feelings of isolation and shame and reduce social support (all the more necessary under these circumstances).

The HCP needs to reassure the patient that each person reacts in his or her own way and that there is no one 'correct' way to feel or behave; each person is unique and what they are feeling is a natural reaction, after being told their diagnosis.

HCP's need to acknowledge the patients courage and strength, emphasize these strengths and increase the patients (and if possible the families) ability to cope with the crisis at hand.

The impact of HIV on the family

HIV is an illness that affects the whole family and not just the HIV infected individual.

- When there is one person with HIV in a family, often there are others who are not yet diagnosed or choose not to be tested.
- Guilty feelings about the HIV transmission to loved ones may exist
- HIV affects couples as it may suggest that one partner is having sexual relations with an outside partner.
- Physical or verbal abuse may occur when disclosure occurs in the family
- The diagnosis of HIV infection in a child may indicate the disease is in the mother and the father and that the other children may carry the disease
- Siblings of the infected individual may become the 'parentified' child due to an ill adult or death of an adult
- Many children are orphaned
- Families may suffer due to lack of financial support if the HIV infected adult becomes ill and unable to work
- Social supports from extended family members or friends may dissipate due to the stigma of the disease
- Often extended family members, such as grandparents take on the burden of caring for children
- HIV+ women are usually the primary caregivers for their families and may have little support from others when they are ill and will not seek care for themselves

The following is a list of some coping strategies and supportive services

- Explain the importance of maintaining routines and continuing to do things that are normally performed
- Continually reassure the patient that he/she is not alone, as the staff in clinic can be available to talk with, for psychosocial support and education (The HCP is the supportive component, and may be the only source of support).
- Continually acknowledge the patients varied feelings
- Continually educate and assist the patient on practical needs; such as, proper medical follow-up, adequate nutrition, shelter, adequate sleep, management of stress and anxiety and risk reduction practices.
- Suggest that they reach out to family and friends, if possible or to discuss and explore disclosure issues
- Explore the patients coping skills by discussing past traumatic events and how the patient handled the crises

- Continually discuss and review their life experiences and personal worth in a positive way
- Explore the patients spiritual side; utilize visualization, meditation or religious activities as a means of coping
- Offer groups for the patient to join for support or any local community support services

Confidentiality

Confidentiality needs to be addressed and discussed at each visit to reassure the patient that all medical and psychosocial issues will be kept confidential and to establish trust within the patient/professional relationship.

iv. The Process of Disclosure with Adults

In order to provide psychosocial support, in a compassionate manner, to an HIV+ patient who is considering to disclose to another, HCP's need to:

- Begin by exploring their own feelings and anxieties on this topic

One of the first steps in providing help for an HIV+ patient is for the HCP to be aware of and comfortable with the facts about HIV transmission and the psychosocial issues of HIV. If the HCP does not feel comfortable and address these issues and their own varied feelings about HIV, it will be conveyed to the HIV+ patient, who will then be even more isolated.

- Explore the HIV+ patients feelings and anxieties

Disclosure is a highly personal decision based on the HIV+ patients own individual needs, family and social situations and values. The HCP needs to help the patient reflect on and discuss their feelings about disclosure.

Questions to help the HIV+ patient consider when and how to tell:

- What is it like to have a secret?
- What are the pros and cons of telling?
- What family members or friends in your life would be supportive to you?
- **What have you thought about saying?**
- What do you think will happen when you tell?
- What are your beliefs about HIV/AIDS?

Another method to help an HIV+ patient discuss and explore this topic, can be to create a list, with the patient, on the 'pros and cons' of disclosure. Listed below are feelings and thoughts, that have been expressed by a person who is HIV+ or has AIDS, while contemplating whether or not to disclose their status to someone else. Each person is unique, therefore this list is a guide for the staff only.

Why one doesn't tell:

CONS: The guilt, burden and pain of the illness to others

The inability to handle the information shared

The denial/obstacles about the illness

The stigma, discrimination and secrecy

The shame involved in telling someone how it was contracted

The fears involved with discussing death with family, friends and children

The possible withdrawal and rejection of family and friends

The stress involved in "knowing"

The fear and protection of domestic abuse
In order to protect the children

Why one does tell:

PROS: It creates intimacy within a relationship or family
It creates trust within a relationship or family
It creates control over a patient/child's life
It creates relief and open communication
It creates a better quality and appreciation of life
It breaks their child's 'fantasies,' misconceptions
It breaks any confusion, isolation, fears or mistrust
It creates treatment adherence

Disclosure is a continuing process that evolves over time, and is unique to each person. The HCP needs to continue processing the patient's pros and cons and provide support, as many adults will only have the HCP to talk with about these topics. The process is not about getting them to tell, it is about listening and providing support. It is breaking the isolation and silence, not feeling that these issues have to be dealt with alone, and the relief that exists after being able to talk about it. Allowing the patient to have the opportunity to talk about these issues with the HCP will help to facilitate the healing process. The HCP may be the only person with whom the patient can experience some relief and release by discussing the diagnosis, as well as fears that the secret may be discovered. Keep in mind that the adult is not only coping with the traumatic news but also the strain of keeping it a secret (and the stress and welfare of their baby).

Many HIV+ patients express the desire to keep the diagnosis a secret. The HCP can suggest that keeping the diagnosis a secret might be an unrealistic expectation, or fantasy, as eventually the infected adults feelings and behaviors will affect their family and their relationships; loved ones will figure it out on their own and this will again create more secrecy and isolation.

HCP should be conscious of not forcing the disclosure, not telling the infected adult what to do however, just being a good listener. To truly listen to the patient and find out what his/her experiences are with all its contradictions, ambiguities and irrationalities. Listening, as the patient shares their feelings, offers the prospect of easing the burden.

The HCP needs to resist making comments about what a patient may be experiencing.

Only the patient knows themselves and no one else. The HCP needs to resist saying "I know how you feel".

Sometimes, there is a desire for the HCP to express personal stories of their own, when a patient is upset or under stress. The HCP feels this may create a bond with the patient or help to alleviate the pain. This can be detrimental to the relationship and the patient may feel the HCP is uninterested or their story is unimportant and may feel embarrassed to express their feelings in the future.

In the presence of a compassionate, empathetic and caring HCP, the HIV+ patient may have the ability to ventilate over and over again any painful feelings in the security of a non-judgmental environment. This deepens the adult/HCP relationship so that they feel, for example, less isolated (secrecy) and to possibly create new hope (an uninfected baby) and provide the patient with the knowledge to live one day at a time.

Confidentiality needs to be discussed at each visit to ensure trust within the patient/provider relationship.

Once the HIV+ patient discloses, it is important to follow up with:

- Any abuse or neglect
- The HIV+ patients reactions and feelings
- Family interventions – where the HCP can help to: educate the family, identify and respect their own survival strategies and unique resources for healing based on resolved problems and crises in the past and facilitate the expression of love of each family member for the others.

v. Death and Dying Issues for Adults

Elisabeth Kubler-Ross describes 5 stages through which dying patients progress as they come to terms with their illness. These stages are descriptions of differing psychological states, and are not necessarily experienced in the order given and not all patients experience all the stages. It is a framework for understanding the feelings and concerns people/patients have with a terminal illness. It is also described as the coping mechanisms of dying patients (as well as 'crises' in ones life) and also of their families:

Shock and Denial: At this stage, a patient might say, "It can't be" or "This isn't happening to me". There is an absence of feeling, an emotional numbness and denial of the illness. Sometimes denial is helpful in coping at this stage. It can be harmful only when self-destructiveness occurs.

Anger: At this stage, a patient might say, "Why me?" Bitterness and resentment may occur and be directed toward God or HCP's. It may be helpful to have the patient discuss the anger to someone who can listen; family, friends and /or the HCP.

Bargaining: At this stage, a patient may say, "I just want to live until my birthday", "I promise I will..." and strike up a bargain with God, in order to put things off a bit.

Depression: At this stage a patient may say, "Why bother, I'm going to die anyway. Its hopeless". A patient acknowledges the severity of the illness at this stage and the reality of what's happening.

Crying, lethargy, insomnia, and withdrawal from friends and family may occur at this stage. A patient will need someone (family, friends or the HCP) who can listen and who he can cry to.

Acceptance: A patient is coming to terms with what is happening and possibly feels a welcome release. Whether a patient reaches acceptance is neither a good or bad reflection on the patient and is not necessarily a goal. Supportive services by the HCP should continue at this stage and discussions for permanency planning.

vi. Supportive Services for HIV+ Families

Each clinic is unique in the services that they provide. Listed below are ideas for support services. The team needs to review and discuss the services they are capable of providing based on the physical space, staffing capabilities and the needs of the patient:

1. Individual support services: Adult Child (play and art therapy)

Individual counseling can help the patient come to terms with the HIV diagnosis, allow for patient education, facilitate expression of feelings, enhance communication skills, and help to explore how HIV/AIDS will affect (both physically and emotionally) all aspects of the patient's life.

Play/Art modalities with children are tools for self-expression, exploration and education. Children will, for example, symbolically represent their feelings in play, drawing, writing and music because they do not have the language to "talk out" feelings as adults can.

2. Group oriented services:

Young mothers parenting group

Early Learning group (group for mother and children, infancy – 5 years)

Peer or Parent/Caregiver group

Prenatal educational group – (i.e., all topics related to prenatal and a pregnancy calendar, with a celebration/reunion at the end)

Volunteer program – (on site and off site)

Hallway program

Reading program

Siblings group

3. Supportive services within the community:

Outreach services

Church groups

Education and support groups in the schools

Alternative Medicine and (traditional healers)

Assessing cultural barriers

The concept of a support group in which adults share personal experiences may seem inappropriate to this culture; therefore the suggested listings above is a 'subtle' way to bring the families together, discuss familiar issues, generate ideas amongst each other, develop trust, provide support and help to each other and in turn, possibly evolve into a group which feels comfortable discussing topics related to their HIV.

The development of a group

HCP's need to develop trusting relationships with HIV+ parents/caregivers starting from the initial visit; during intake and initial assessment. Establishing close ties with other family members, for example

grandparents, will continue to develop trusting relationships with staff and also help to maintain the family system.

Since the patients may not seek out help, it is suggested that group services be made part of the treatment plan (by appointment), like the medical visit.

HCP's need to recognize the need to work on issues unrelated to HIV disease. For example, childcare, parenting support, nutritional advice, advocacy, offsite support etc., can ease the families burden and help establish the HCP-family relationship. Once the HCP demonstrates their abilities to assist with immediate concerns, the patient and family usually will begin to feel more open to pursuing more difficult psychological issues, disclosure issues and continued visits to the clinic. It would be helpful for the HCP to begin an ongoing list of the needs of the patients and families, by asking them what topics they would like to be educated on if a group was to be created.

In order to further educate the local village and community (once a small core group is created in the clinic and the topic of HIV is discussed), the members can share their knowledge when they return to their home environment. This way of educating may be less threatening to the general public.

The team needs to decide the following before initiating a group:

- **Will it be a structured (topics stated by staff) or unstructured (the group decides the topic for the day) group**
- **Will the group meet weekly, bi-weekly or monthly**
- **Will there be a beginning and an end (for example 12 weeks) or will it be open-ended**

One of the main goals for the success of a group is for the staff to remember: to listen, rather than to provide answers and to hear the issues that concerned HIV+ parents/caregivers have.

Some topics of discussions within a group have included:

- Discussing the role of being a mother, a father, or a single parent trying to play both roles
- Balancing the demands of work and home
- Feeding, sleeping, safety, and developmental issues
- Discussions relating to the groups supports and their lack of supports
- Suggestions and shared stories of successes and failures

The effectiveness of group support with HIV+ parents/caregivers (a 'peer' group) includes:

- The group is seen as a place to help each other cope with emotions and share coping strategies
- The group members learn they are not alone even if they feel lonely
- The group can be a place to share painful or shameful experiences without the fear of rejection or abandonment
- The group is a place to help share feelings about stigma and secrecy and consider how this influences their emotional and physical health
- The group serves as a model for a "healthier and expressive" family because it teaches the members how to express feelings and learn social interactions

Helping the Health Care Professional

i. Stress and Burnout

As a result of caring for HIV+ adults and children who are ill and/or in pain, health care professionals often experience feelings of stress and burnout. HCP's are generally caring people who want to help others. Therefore, when they are constantly dealing with situations which are difficult or impossible to solve, they become stressed and sometimes, over time, less effective.

HCP's that have been caring for HIV+ patients have lost many patients to HIV/AIDS and may begin to suffer due to inadequate time to grieve or deal with their loss. Like their patients, they display many of the symptoms of grief (denial, anger, guilt, bargaining, depression, acceptance).

Environmental factors contribute to the stress of health care professionals. Due to the stigma, they are often unable to talk with family and friends about their work. Also, HCP's must confront their own fears about being HIV-infected as they may encounter patients with similar risk behaviors.

Coping strategies

One way HCP's can help each other, is to create a supportive environment during clinic hours, where each staff member can take time to discuss their own feelings and responses to daily issues and stressors with another member. Expressing these feelings can reduce isolation and normalize the daily experiences.

A weekly staff support group can also provide new ways to cope with the stress of work. The goal can be to express feelings, to see things in a different light and to develop new skills and strategies for coping. Topics of interest that can be explored by each provider may be on how each responds to a difficult situation, to think of new ways to cope and respond to the stressor situation and then to discuss the situation in detail. Another way of coping with stress is humor. Humor, (differing from sarcasm), can help to view difficult situations in a positive or less critical, serious manner and to view painful experiences a part of life.

When working with the HIV population, HCP's may have feelings of personal limitations and powerlessness to 'fix' the situation. It can be helpful in this situation to remember the power they do have:

- to listen
- to be with the adult and/or child when they are struggling
- to provide hope
- to provide humor
- to be a positive support factor in the midst of so many negative ones in their lives
- to provide medical treatments

HCP's need to take a step back and reevaluate how to replenish themselves. Addressing their own personal lives, and any unfulfilled needs may impair their ability to care for others and themselves. Therefore, getting adequate rest, nutrition and exercise are some areas to reevaluate. The HCP needs to shift the focus back to his own life, re-establishing relationships with family and friends, seeking leisure and recreational activities that are enjoyed and increasing the overall quality of life.

Other coping strategies

- Set both short-term and long-term goals for oneself; accomplishing short-term goals brings immediate satisfaction

- To compartmentalize – ones career and home; the need to decompress after leaving for the day
- To develop a stress-hardy outlook – and view stress as a challenge, with a sense of control and optimism that the world is manageable
- Grieve losses that may occur and provide emotional support between each staff member
- Set limits
- Remember what one can and can't handle
- Recognize the signs of stress within oneself (ones warning signs)
- Use various methods of relaxation (visualization, meditation, etc.)
- Improve professional skills; continued education or workshops

Single-Dose Perinatal Nevirapine plus Standard Zidovudine to Prevent Mother-to-Child Transmission of HIV-1 in Thailand

[Original Articles]

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Abstract

Background: Although zidovudine prophylaxis decreases the rate of transmission of the human immunodeficiency virus (HIV) type 1 substantially, a large number of infants still become infected. We hypothesized that the administration, in addition to zidovudine, of a single dose of oral nevirapine to mothers during labor and to neonates would further reduce transmission of HIV.

Methods: We conducted a randomized, double-blind trial of three treatment regimens in Thai women who were receiving zidovudine therapy during the third trimester of pregnancy. In one group, mothers and infants received a single dose of nevirapine (nevirapine-nevirapine regimen); in another, mothers and infants received nevirapine and placebo, respectively (nevirapine-placebo regimen); and in the last, mothers and infants received placebo (placebo-placebo regimen). The infants also received one week of zidovudine therapy and were formula-fed. The end point of the study was infection with HIV in the infants, established by virologic testing.

Results: Between January 15, 2001, and February 28, 2003, a total of 1844 Thai women were enrolled. At the first interim analysis, the independent data monitoring committee stopped enrollment in the placebo-placebo group. Among women who delivered before the interim analysis, the as-randomized Kaplan-Meier estimates of the transmission rates were 1.1 percent (95 percent confidence interval, 0.3 to 2.2) in the nevirapine-nevirapine group and 6.3 percent (95 percent confidence interval, 3.8 to 8.9) in the placebo-placebo group ($P < 0.001$). The final per-protocol transmission rate in the nevirapine-nevirapine group, 1.9 percent (95 percent confidence interval, 0.9 to 3.0), was not significantly inferior to the rate in the nevirapine-placebo group (2.8 percent; 95 percent confidence interval, 1.5 to 4.1). Nevirapine had an effect within subgroups defined by known risk factors such as viral load and CD4 count. No serious adverse effects were associated with nevirapine therapy.

Conclusions: A single dose of nevirapine to the mother, with or without a dose of nevirapine to the infant, added to oral zidovudine prophylaxis starting at 28 weeks' gestation, is highly effective in reducing mother-to-child transmission of HIV. *N Engl J Med* 2004;351: 217-28.