# MODULE 3: CLINICAL MANAGEMENT

This module is divided into three sections:

1) Opportunistic Infections

2) Investigations

3) Antiretroviral Therapy: medications, side effects and adherence

4) Nursing care

# A. Opportunistic Infections:

**Goal:** To give an overview of the clinical management of HIV and common opportunistic infections

**Objectives:**

1) Name common opportunistic infections of HIV
2) Describe their signs and symptoms
3) Manage symptoms
4) Prevent complications

**Materials:**

Power point, LCD, index cards, paper, flip chart

**Procedure:**

1) Brainstorm common opportunistic infections and their symptoms
2) Lecture on OIs and management
3) Break groups into groups of three. Each person is assigned a colored index card (use same three colors for all groups)
4) For the first role play assign roles of nurse, patient and observer based on color of index card (eg: all people with pink are the nurse, all people with blue are patient)
5) Conduct role play #1
6) One group demonstrates role play (or if time permits all groups demonstrate role play) and that group's observer reports to entire group
7) Each observer reports their group's activities
8) Switch roles and conduct second role play
9) Repeat steps 6 and 7
10) Debrief

**<u>Opportunistic Infection Role Play #1:</u>**

A 30 year old male is an inpatient on your ward and you are taking care of him. He was admitted 3 days ago with weight loss, fevers and night sweats. He was diagnosed with tuberculosis and started on four drug therapy. The patient is HIV positive but not AIDS defined.

1) What would you teach the patient about what to expect in his clinical course?
2) How would you instruct him to manage his symptoms and medications?
3) What are some community implications?

**Facilitator notes for role play #1**
These points should be brought up by facilitator if they do not arise in the discussion:

1) Side effects of TB medications
2) Treatment duration and adherence
3) Community resources for DOT
4) Teach patient to cover mouth when coughing and to avoid coughing if possible especially around children
5) Educate about protein rich diet
6) Listen to patient, touch the patient and maintain eye contact with patient
7) Discuss HIV status and their feelings about it
8) Discuss HIV disease progression with patient and how TB is an opportunistic infection

## Opportunistic Infection Role Play #2

A 24 year old woman with watery diarrhea for > 1month is admitted to your care with dehydration and low potassium. The patient is AIDS defined. She has two young children at home

1) How can the patient manage her diarrhea?
2) What should she expect in her disease course?
3) What would you teach her about nutrition?

**Facilitator notes for Role Play #2**
These points should be brought up by facilitator if they do not arise in the discussion:

1) Listen to patient, touch the patient and maintain eye contact with patient
2) Make connection that cryptosporidium occurs in late HIV infection and the patient is probably very ill in general
3) Instruct patient to try to remain hydrated
4) Discuss end of life issues including what will happen with her children
5) Her diarrhea will come and go over time
6) Hand washing
7) Disclosure of HIV status
8) Protecting children from infectious diseases (fecal/oral)

**OPPORTUNISITIC INFECTIONS:**

| Opportunistic Infection | Signs and Symptoms | Management |
|---|---|---|
| Tuberculosis – Pulmonary | Night Sweats, Fevers, Productive Cough (often blood tinged), Weight loss<br>Onset: 2-8 weeks | Antibiotics x 6-9 months<br>Isolation<br>Support<br>Directly Observed Therapy |
| Tuberculosis – Extrapulomanry/Disseminated | Night sweats, fever , weight loss, pain in affected area<br>Symptoms vary with affected organ | Antibiotics x 1 year<br>Directly Observed Therapy<br>Support |
| Pneumocystis Carinii Pneumonia | <200 CD4 cells<br>Fever, Shortness of Breath, non productive cough<br>Onset: 2-4 weeks | Antibiotics x 3 weeks<br>Prophylaxis life long<br>Respiratory therapy |
| Recurrent Bacterial Pneumonia | Fever, productive cough, possibly blood tinged sputum, Pleuritic chest pain, shortness of breath<br><br>Onset: acute | Antibiotics<br>Respiratory therapy |
| Cryptococcal Meningitis | <200 CD4 cells<br>Headache, photophobia, neck stiffness, fever | Antifungals:<br>Treatment doses x 8 weeks<br>Maintenance |
| Toxoplasmosis | <100 CD4 cells<br>Headache, neurological changes, fever<br>Onset 2-4 weeks | Antibiotics<br>Treatment doses x 8 weeks<br>Maintenance |
| Oral candidiasis | White patches in mouth – onset is acute<br><br>Difficulty swallowing – Onset 1-2 weeks | Antifungals<br>Nutrition and hydration |
| Cryptosporidiosis | Copious diarrhea<br>Acute onset with waxing and waning course | Support<br>Nutrition<br>Hydration<br>Electrolyte management<br>ART |

# B. Investigations

## Procedures:

1) Lecture discussing the various lab results used in the care of HIV patients
2) Question and answers

**Viral Load testing**: There are several tests available for detecting quantity of virus in a person. These tests are useful for diagnosing acute HIV infection and for therapeutic monitoring. They are measured in log scales. Changes of >50% are considered significant. Factors that increase viral load are: progressive disease, failing antiretroviral therapy, active infections, or recent immunizations. These are generally reported in copies/ml. In an uninfected person or a person who is effectively suppressing viral replication with the use of antiretroviral medications, the value of the viral load should be <400 or <50 copies/ml depending on the assay used.

**CD4 monitoring:** CD4 correlates with patient's immunodeficiency. Generally this test reveals:

- Absolute CD4 count: normal value would be 600-1200 in an adult.
- CD4 percentage: normal value would be 30-60%
- CD8 count: normal value would be 420-660 in an adult.
- CD4:CD8 ratio: normal value would be 1.2-1.9.

-CD4 count <200 is AIDS defining.
-CD4 percentage of <20% indicates serious immunodeficiency and a value of <14% indicates AIDS.

**Complete Blood Count**:

| **Measurement** | **Normal value range** |
|---|---|
| White Blood Cells | 4500-11000/cu mm |
| Red Blood Cells | 4.00-5.20/ cu mm |
| Hemoglobin | 12-15 g/dl |
| Hematocrit | 36-46 % |
| Platelets | 150-350 K /cu mm |
| Lymphocytes | 1100-4800/ cu mm |
| Neutrophils | 1500-7800/cu mm |

A person who is HIV infected will have a lower than normal white blood cell count especially as he/she progresses. In these cases a severely immune compromised patient with a WBC of 11,000 could indicate infection. It is important to follow the trend with each individual.

In the absence of CD4 and viral load testing, a lymphocyte count can be used to determine the effectiveness of HIV medications. If the antiretroviral therapy is effective an increase in lymphocytes will be noted.

**Comprehensive Metabolic Panel**:

| **Measurement** | **Normal value range** |
|---|---|
| Sodium | 135-145 meq/l |
| Potassium | 3.5-5.0 meq/l |
| Chloride | 96-109 meq/l |
| Urea nitrogen | 7-22 mg/dl |
| Glucose | 60-109 mg/dl |
| Creatinine | 0.6-1.3 mg/dl |
| Calcium | 8.4-10.5 mg/dl |
| Total Protein | 6.0-8.2 g/dl |
| Albumin | 3.5-5.3 g/dl |
| Total Bilirubin | 0.1-1.2 mg/dl |
| ALT | 0-40 IU/L |
| AST | 0-37 U/L |
| Alkaline Phosphatase | 30-120 IU/L |
| CO2 | 21-31 meq/l |
| Anion Gap | 11-20 meq/l |

Some common indicators:

Indicators of Renal disease: Elevated potassium, creatinine or urea nitrogen
Indicators of Liver disease: Elevated ALT, AST, Alkaline Phosphatase, total Bilirubin
Indicators of end stage liver disease: lowered albumin and increased protein
Indicators of Diabetes: Elevated glucose
Indicator of lactic acidosis: Lowered CO2
Indicator of Mycobacterial infection: Elevated alkaline phosphatase

# C. Antiretroviral Treatment and Side Effects

**Goal:** To describe the medications used to treat HIV and how to recognize side effects of the medications

**Objectives:**
1) Name antiretroviral medications
2) List side effects
3) Describe the importance of adherence and barriers
4) Teach a client how to take medications

**Materials:**
Power point, index cards

**Procedure:**
1) Lecture presentation of medications, side effects, guidelines and adherence issues
2) Brainstorm interventions that will help a patient to take medications
3) Debrief

## FACILITATOR NOTES:

The following should be addressed:
1) 95% of doses must be taken in order for ARV to be effective therefore if a patient runs short they should not ration nor should a patient share medicines with a friend or family member who is infected.
2) Taking a history from the patient about his/her attitudes about taking medications and their fears about the stigma of taking the medications is critical
3) Patients should be counseled to alert their doctor to ALL medications he/she is taking including ayurvedics due to potential for interaction.
4) Nurse should be sure to give information about side effects, and administration. Support and coaching is also essential.

# ANTIRETROVIRAL TREATMENT

There are many schools of thought regarding guidelines for the treatment of the client with HIV.

THE FOLLOWING ARE THE NACO GUIDELINES FOR TREATING PATIENTS:

The advent of antiretroviral drugs in the late 1980s began a revolution in the management of HIV, which may eventually be seen as analogous to the use of penicillin in the 1940s, for treating bacterial infections. A primary aim of antiretroviral treatment strategies is to suppress viral replication. Successful outcomes on this parameter restores the balance within the immune system, slow or halts disease progression, prevents drug resistance and improves quality of life.

Three groups of ART drugs have been tried, tested and found successful in interrupting viral replication. The use of one or two drug combinations promotes rapid development of resistant strains of HIV and renders the therapy ineffective. Over the past 5-6 years, compelling epidemiological and clinical evidence demonstrates that with strict adherence, the use of three drugs in combination will achieve sustained viral suppression for several years.

## Guidelines for Treatment

WHO recommends adoption of a public health approach to the administration and distribution of antiretroviral therapy. This implies that ART regimens should be standardized, and that only a single first line, and a limited number of second line regimens should be made available through the public sector for large scale use.

Selection of first line regimen should be determined on the basis of a number of considerations like potency, profile of side-effects, ability to keep future treatment options open, ease of adherence, risk during pregnancy, and potential of resistant viral strains. WHO does not recommend any dual drug regimens. The current recommendation in all circumstances is for a triple drug regimen.

Adult Regimens

The overwhelming short term priority is for first-line regimens which will facilitate the scaling up of treatment. Second-line treatment is not a priority in the short-term. The characteristics of an ideal first-line ARV combination are:

- Effective and well tolerated, with minimal side effects
- Potent, even in advanced patients, and robust (favorable resistance profile)
- No interactions or contra-indicators
- Appropriate for use in TB patients and in pregnant or lactating woman
- Available in a fixed dose combination (once or twice a day)
- Stable in tropical conditions
- Not requiring laboratory monitoring
- Affordable

First-line combinations: Today's most available regimen in India (due to low cost generic formulation) is d4T/3TC/NVP, taken as bi-daily (BID) fixed dose combination (FDC)

Advantages: it is well tolerated in most cases, has few contra-indications and is appropriate for use in women of child bearing age. It has proven efficacy under actual field conditions, is affordable, and is easy to take.

Limitations: d4T can have side effects (neuropathy). NVP has suspected negative interaction with rifampicine, has a resistance risk (especially in women receiving NVP–based PPTCT) and can cause hypersensitivity, which requires modifying dosage. It is ineffective on HIV2. NVP recently been determined to be associated with significant hepatotoxicities in women with CD4 counts > 250 and men with CD4 counts>400 and therefore is not recommended for use in persons with high CD4 counts.

**Recommended first-line ART combination regimens in adults and adolescents with documented HIV infection (WHO 2003)**

| ARV Regimen | Usage in women in child bearing age or who are pregnant | Major Potential Toxicities |
|---|---|---|
| D4T/3TC/NVP | • Can be used | • D4T related neuropathy, pancreatitis and lipoatrophy<br>• NVP related |

| | | |
|---|---|---|
| | | hepatotoxicity and severe rash |
| ZDV/3TC/NVP | • Can be used | • ZCV related GI, intolerance, anemia and neutropenia<br>• NVP related hepatotoxicity and severe rash |
| D4T/3TC/EFV | • Should be avoided | • D4T related neuropathy, pancreatitis and lipoatrophy<br>• EFV related CNS toxicity and potential for teratogenicity |
| ZDV/3TC/EFV | • Should be avoided | • ZDV related GI intolerance, anemia and neutropenia<br>• EFV related CNS toxicity and potential for teratogenicity |

In the event of treatment failure, a number of second line regimens have been found to be effective in prolonging the benefits of ART. Here, we need to guard against cross resistance. Ideally, second line regimens should include at least three new drugs. We summarize below, WHOs recommended second line regimens corresponding to each failed first line regimen.

**WHO's recommended second line regimens in adults and adolescents for treatment failure on first line ARV regimen (WHO 2003)**

| First-line regimen | Second-line regimen |
|---|---|
| D4T or ZDV<br>+<br>3TC<br>+<br>NVP or EV | TDF or ABC<br>+<br>ddI [1]<br>+<br>LVP/r or SQV/r [2] |

[1] dose of ddI should be reduced from 400 mg to 250 mg when administered with TDF

[2] LVN/r and SQV/r require secure cold chain. NFV can be considered as an alternative in resource settings without cold chain.

***Criteria for starting ARV therapy in adolescents and adults:***

- Confirmed HIV infection and one of the following conditions:
- WHO clinical state IV(Clinically advanced): HIV disease irrespective of CD4 counts
- WHO clinical stage III: HIV disease with consideration of using CD4 cell counts < 350/mm$^3$
- WHO stage I, II or III disease with CD4 cell count < 200/ mm$^3$

***Criteria for starting ARV therapy in infants and children:***

For HIV sero-positive infants aged 18 months, WHO recommends initiation of ARV therapy, if;

- The infant has virologically proven infection (using HIV DNA PCR, HIV RNA or p24 antigen) and has:
    - WHO Pediatric stage III HIV disease (e.g. clinical AIDS) irrespective of CD4 %, or
    - WHO Pediatric Stage II disease with consideration of using CD4<20% to assist in decision making, or
    - WHO Pediatric stage I (e.g. asymptomatic) and CD4< 20%(to be treated only if CD4 assay available)

- If virologic tests to confirm HIV infection status are not available but CD4 cell assays are available, WHO recommends that ARV therapy can be initiated in HIV-seropositive infants who have WHO stage II or III disease and CD4 percentage <20%. In such cases, HIV antibody testing must be repeated at age 18 months to definitively confirm that the child is HIV infected; only infants with confirmed infection should have ARV therapy continued.

- For HIV seropositive children ≥ 18 months, WHO recommends initiation of ARV therapy if:
    - WHO Pediatric stage III HIV disease(e.g. clinical AIDS) irrespective of CD4%, or
    - WHO Pediatric Stage II disease with consideration of using CD4< 15% to assist in decision making, or
    - WHO Pediatric stage I (e.g. asymptomatic) and CD4< 15%.

The following is generally recommended:

- First-line protocols for pediatric patients should mirror those of adults at all levels of care (Level I,II,III). This is currently difficult because of the lack of appropriate pediatric formulations, particularly for children under 10-15 kilos.
- To facilitate the use of currently available products, the producers and manufacturers need to develop dose ranges that are based on weight. WHO needs to also guide the pediatric attributes of ideal ARV therapy.

***Treating the Pregnant woman***:

Two NRTIs plus:
Nevirapine
Abacavir
Nelfinavir
PI with low dose Ritonavir boosting

Generally, if a woman is pregnant she should not start ART until after her first trimester.

HAART is recommended to prevent perinatal transmission in any woman with a viral load of > 1000 copies/ml. With a viral load < 1000 copies/ml consider AZT monotherapy.

Elective Cesearian section reduces risk of perinatal transmission. However there is no evidence of benefit after onset of labor, after rupture of membranes or with a viral load < 1,000 copies/ml.

## Common Side Effects of HIV Medications:

**NRTIs**;

In general:

1. Most of these medications are well tolerated.
2. Several can cause headaches and abdominal pain.

Specifically:

**Zidovudine**: anemia, headaches, abdominal pain, discoloration of nail beds. Long term can cause lactic acidosis. Should not be used with Stavudine.
**Tenofovir**: renal insufficiency. Must be taken with food.
**Abacavir**: hypersensitivity (rash, myalgias, fevers) generally beginning after 10 days of initiation. This can be fatal if patient is re-challenged on this medication.
**Didanosine:** Numbness and tingling in hands and feet. Must be taken on empty stomach
**Stavudine**: Numbness and tingling in hands and feet. Stavudine long term can cause lactic acidosis and lypoatrophy. Should not be used with Retrovir.

**NNRTIs:**

In general:

1. Can cause a hypersensitivity reaction resulting in rash.
2. Known to cause liver toxicity especially in women.
3. Resistance emerges quickly with poor adherence.

Specifically:

**Efavirenz:** Psychoactive effects such as depression, psychosis in rare occasions, dizziness, drowsiness. Taking this medication with food increases side effects. Should not be used in women of childbearing years.

**PIs:**

In general:

1. Cause nausea, vomiting and diarrhea.
2. Long term use can cause fat redistribution, insulin resistance and high triglycerides.
3. Should be taken with high fat meal to increase absorption and reduce side effects.

Specifically:

**Indinivir**: Can cause kidney stones if a patient does not drink sufficient amounts of water.
**Atazanavir**: Can cause hyperbilirubinemia resulting in jaundice.

## Symptom Management:

One of the major challenges for people living with HIV/AIDS and their care providers is managing symptoms associated with the disease and its treatments. All of the ARV medications have side effects, some more severe than others, causing a variety of symptoms that effect patients ability to adhere to treatment and negatively impacts the quality of their lives. Symptom management is a core domain of nursing requiring the utilization of the nursing functions of assessment, planning, implementation of treatment, and evaluation.

Assessment – to identify symptoms, the patient must be the primary source of information about the symptoms. What is the patient's symptom experience?

Caregivers and health care providers can not correctly identify the symptoms that are impacting the patient's life. Nursing research has found that the provider often misdiagnoses symptoms that are distressful for the patient when input from the patient about his/her symptoms is missing. Such information includes the frequency and intensity of the symptom.

1) Planning: should be done in collaboration with the patient, the family, the caregivers, and the health care providers. Knowledge of potential practices is essential and knowing what's available and accessible locally can aid in managing the symptoms and preventing exacerbation of the condition. If possible, knowing the potential interactions of the products, if products are used, could prevent significant problems.

2) Implementation: After the planning process is completed, which includes an evaluation component, the plan is implemented and the evaluation component is initiated. More then one intervention option may be chosen. The second option should be implemented after evaluation of the first option, particularly if the first option is less then satisfactory.

3) Evaluation – an ongoing assessment should be done to determine if the intervention alleviates the symptom. It may be necessary to change the intervention based upon the outcomes of the management strategy. Has the functional status of the patient improved? Has his/her quality of life improved?
Symptom management interventions can be initiated by the

patient, the caregiver, and/or the health care provider, and are an important component of the continuum of care occurring in all settings.

Opportunistic infections (OIs) also cause symptoms that need to be managed. Patients and family caregivers frequently use "home remedies" (alternate treatments for managing the symptoms). Even in the United States many people living with HIV/AIDS disease use non-prescription medications, such as vitamins and herbs. Research demonstrated that there appears to be less stigma associated with use of traditional medicine and traditional healers. Currently, studies are being conducted by nurse researchers in several southern African countries in collaboration with nurse researchers from the United States to identify non-western medical practices used by people with HIV/AIDS disease to manage their symptoms.

In the United States and other countries with greater resources, symptoms are treated with similar practices as above. In addition, numerous prescribed and over the counter medications to treat and manage the symptoms associated with HIV disease and also those symptoms, such as neuropathy of the feet, that are directly related to taking antiretroviral (ARV) medications. Gastrointestinal discomfort and diarrhea are very common among patients on ARV drug regimens. The importance of using available resources to manage symptoms can not be over emphasized. Knowing if the patient is receiving treatment from the community's traditional healer is also critical to providing the best care possible. Extensive research is lacking in the potential interactions of herbal remedies and most of the prescribed medications used to treat HIV disease. In order to protect patient from harm, the first step is to know what the patient is taking and to be aware and on the alert for drug interactions.

# SAMPLE ADHERENCE QUESTIONS:

Prior to starting medications:

1) Tell me about your daily schedule?
2) What aspects of your life will make it difficult/easy to take medications
3) Do you regularly eat twice per day?
4) Do you have a place to store your medications?
5) Have you ever had to take medications for a long period of time before?
6) Who in your family or community might act as your support?
7) Do you have difficulty swallowing pills?

After starting medications:

1) In the last week have you missed any doses?
2) How have you been feeling?
3) Are you experiencing any side effects?
4) What are you doing about these side effects?
5) How are the side effects affecting your daily life?

# *SAMPLE ASSESSMENT QUESTIONS:*

1) How are you feeling?
2) Can you tell me about your symptoms?
3) How long have you had these symptoms?
4) When did these symptoms start?
5) What makes the symptom better or worse?
6) What do you think is causing the problem?
7) Do you have a history of any opportunistic infections?
8) Are you taking antiretrovirals?
9) When did you start medications?
10) Do you have headache; difficulty swallowing, white patched in your mouth, cough, fever, chest pain, shortness of breath, muscle aches, abdominal pain, nausea, vomiting, diarrhea, fatigue, numbness and tingling in hands or feet, rash, dizziness, changes in vision, changes in appetite, changes in sleep, difficulty walking, changes in body?

## D. NURSING CARE:

**Goal:** On completion of this module the health care workers understand the 'Continuum of Care' approach according to the stages of an HIV infection and can similarly redefine their role as care-providers, which goes beyond medical care during sickness. Furthermore, palliative care and community care as well as individual, family and community support are discussed

**Procedure:**
1. Brainstorm meaning of palliative care and examples
2. Lecture using slides on palliative care and continuum of care
3. Break into four groups and conduct lesson on continuum of care
4. Debrief

# Continuum of Care Approach

**Purpose:**
- To make the participants understand the various needs of People Living with HIV/AIDS (PLHA) and the different stages of the infection.

**Methodology**
The participants are divided into four groups and handed a case scenario along with the questions. The groups will be given 10 mins. to discuss the issue, after which one person from each group has to present possible answers to the questions to the larger group.

**Care Scenario 1**

Anil and Anita have been married since the last four years. They have two children. We met Anil and Anita just as Anil was going for an HIV test. Anil has been positive for 2 years now but has been well for all that time. Last week, however, he has developed a bad chest infection. He has pneumocystis carinii pneumonia, an opportunistic infection of HIV. Anil is very weak, having fever and profuse sweats, he is very breathless and needs help with all activities like moving in bed, getting to the toilet, being washed and helped to eat and drink.
Anita is looking after Anil but she is getting very tired.

Answer the following questions in your groups.

1. What sort of emotional, psychological, spiritual needs might Anil have?

2. What sort of emotional, spiritual and psychological needs might Anita have?
3. What can be done practically at home to help Anil feel more comfortable?
4. Who else might be available to help Anita care for Anil?

**Care Scenario 2**

You have already had the opportunity to discuss what palliative care is. In this scenario you need to consider the care of the person with AIDS who is dying. This includes psychological, emotional, spiritual and physical care of the person and the people close to that person (which may be friend, spouse, family, or partner).
We have met Anil before. He and his wife, Anita, have been through many hard times as he has become sick, battled and survived different illnesses.

Anil has been brought into the government hospital. He has had AIDS for 5 years now. Anita has come to the hospital with Anil and their children are staying with a neighbor. Anil now has bedsores on both hips, he has recently had a severe bout of shingles and he still gets some pain along his chest where the shingles were.
Anil is very thin now, and every movement is painful. Even when he is asleep his face is wrinkled into grimaces of pain. He is sleeping a lot and when he is awake is usually too tired to eat or drink.
Anil is dying. Anita is worried, tired and crying.

You are the doctor on duty. You are going to explain to Anita what is happening. This does not happen very often in real life in hospitals but it does happen all the time in palliative care, so now you can change the way things are done.

1. How would you like to conduct the conversation with Anita?
2. What might some of Anita's concerns be?
3. What are the important points of successful communication in this situation?
4. What do you need to do to make sure Anita gets the opportunities to talk about her concerns?

**Care Scenario 3**

Now, imagine you are the doctor/nurse looking after Anil. He is less and less conscious and sleeps more and more. Anita is still with him. His children have not been to see him. What care do you need to give Anil?

1. What about pain? Is it still a problem? How can you assess this?

2. How can you make Anita feel a valuable part of Anil's care?
3. What about Anil's children? You feel they should come to see him. How can you talk to Anita about this?
4. What about Anil's spiritual care? How can you address this now Anil is too weak to speak for himself?

**Care Scenario 4**

After two weeks in the hospital and a steady deterioration into unconsciousness Anil died in the early hours of this morning with Anita and his children by his side. You are the doctor/nurse on duty.

1. What is your first priority?
2. What might the needs of the family be at this time?
3. What might you other responsibilities be?
4. Because you have taken seriously your responsibility to give good palliative care you have formed a friendly and trusting relationship with Anil and his family. What might your feelings be? What might your needs be?

*CARE AND SUPPORT FOR PEOPLE LIVING WITH HIV/AIDS*

## i Background issues in Care and Support

- Care and support can improve the quality of life for people living with HIV/AIDS
- Care and support can decrease the stigma of having AIDS
- It can strengthen HIV prevention activities as target audiences have contact with people living with the virus
- It may help prevent the spread of AIDS related illnesses that also infect other people
- It can keep people living with HIV/AIDS healthy and able to work as long as possible.

The natural history of HIV is of progressive immune-suppression with the infected individual passing through different stages of disease. Care needs relate to the disease stage, it is useful to consider five stages:

1. Those uninfected but at risk
2. Asymptomatic HIV positive individuals
3. Early HIV disease
4. Late disease or AIDS
5. The terminal stage

Prevention is targeted to those who are uninfected. Asymptomatic individuals will benefit from knowing their HIV status through voluntary counselling and testing. Early disease is characterised by high rates of common virulent infections such as tuberculosis, and bacterial pneumonia. Late disease or IDS occurs when opportunistic infections cause illness.

## ii Different ways to address care and support needs

- Providing counseling and basic information
- Support groups and networks of people with HIV/AIDS
- Home based care
- Community based approaches and community mobilization
- Support for children orphaned by AIDS
- Clinical guidelines for individual patient management
- Improving access to essential drugs
- Specialist hospital based services for HIV/AIDS management
- Palliative and terminal care
- Partnerships with NGOs and private sectors.

## RECOMMENDATIONS TO PROMOTE THE CARE AND SUPPORT AGENDA

- Promote the human rights agenda in HIV/AIDS
- Advocate widely for the care and support agenda
- Set up local and regional networks and databases, which facilitate the spread of practical knowledge and experience in the care and support field.
- Reinforce the fact that HIV/AIDS is now a broad development issue, which needs multi-sectoral responses.

## A. PALLIATIVE CARE AND CARE FOR THE DYING

This is the provision of appropriate relief and support from physical and psychological discomfort in the absence of a cure. Individuals with end stage HIV infection may not benefit from further attempts to treat opportunistic infections.

### i Goals of palliative care

- To provide the patient with as much control over their symptoms as possible
- To keep the patient comfortable
- To assist the person in grieving for and coping with the continuing losses they are experiencing consequent to the impact of HIV infection
- To help the person, their families and care givers organize their lives
- To prepare the person and their loved ones for death.

### ii Palliative care begins

- When medical treatment is no longer effective
- When the person or the relatives decide that they do not want to continue the treatment
- When the body's vital organs begin to fail
- When the relatives opt to have the patient discharged.

## B. TERMINAL DISEASE – CARE AND SUPPORT NEEDS

Most people living with HIV/AIDS will require some form of terminal care. This can either be provided in the hospital, in a terminal care centre or in the community and home with help and assistance. It includes

- Effective analgesia/pain relief
- Management of distressing symptoms
- Spiritual and emotional support for the dying person

- Spiritual and emotional support for the care-giver and family
- Training of the care-giver in basic skills if managed at home
- Assistance with material needs

## C. SIGNS OF IMMINENT DEATH

The friends and family frequently ask caregivers when a person they are caring for is going to die. There are some signs which indicate death may be imminent, but these are general and will not apply to all people and in some cases death is not expected at the time it occurs. When death approaches there is often decreased levels of consciousness or a person may have become unconscious. There are still levels of awareness, keep communicating to the person even though the unconscious person may not be able to respond.
Breathing is often difficult, irregular and noisy. Sometimes a person might have trouble with mucus in the throat and this causes them to gurgle, because they are unable to cough it out. The person's skin can become pale cool, covered in perspiration, and their hands and feet turn blue. During this time, the only thing you can do is ensure that the person is comfortable and wait.
There's your feeling of grief and loss, which can hang around for a while or which may go away and come back when you least expect them. Some people may feel exhausted.

## D. PREPARING FOR DEATH

- Provide support by allowing the person and their family to talk about how they are feeling
- Self esteem may be enhanced by looking at life achievements and reflecting on past events
- Accept people's feelings of anger, grief and other emotions and reactions.
- If the person asks, and having assessed what they want to know, describe what will happen as he or she nears death. Give reassurances about controlling the pain and symptoms, resulting from the process of dying, where possible.

## E. BEREAVEMENT COUNSELLING (counseling principles)

- Help the survivor actualize the loss – one of the best ways to help the survivor is to talk about the loss. The counselor can encourage this.
- Where did the death occur?
- How did it happen?
- Who told you about it?
- Where were you when you heard it?

- Help survivor to identify and express feelings- expressing feelings may be difficult for many people, due to unpleasantness many feelings may not be recognized by the survivor. Anger, guilt and sadness need to be addressed
- Assist living without the deceased – this principle involves helping people to accommodate to a loss by facilitating their ability to live without the deceased. The counselor can help the person to learn effective coping and decision making skills so the individual will be able to take over the role of the partner
- Facilitate emotional withdrawal-this means encouraging the survivor, in time, to form new relationships.
- Provide time to grieve.
- Interpret normal behavior-understanding and interpreting normal grief behavior is important
- Examine defenses and coping styles – it is important to examine the coping style, whether they are healthy or unhealthy. The counselor can highlight the different coping skills and help the client to evaluate their effectiveness.

## EFFECTIVE APPROACHES

## i Continuum of care & support

- The comprehensive care concept encompasses medical treatment, nursing care, counseling and other social and psychological support for people with HIV/AIDS, their families and dependants.
- This requires establishing an effective mechanism for linkages between the different levels of care – hospitals, health centers, communities and homes – through a good referral network
- Using this model –which integrated AIDS care as apart of general health services – hospitals will provide diagnosis, clinical management and treatment of acute conditions, while care in general is intended to be provide in a community setting by NGOs and at home by the family members.

Comprehensive care consists of four inter related elements

1. **Clinical management –**early diagnosis and treatment and planning for follow up care of HIV related illness
2. **Nursing care-** care to promote and maintain hygiene and nutrition, provide palliative care, educate individuals and families and practice infection control by observing universal precautions
3. **Counseling –** psychological support, promoting positive living and helping individuals make informed decisions on HIV testing, planning

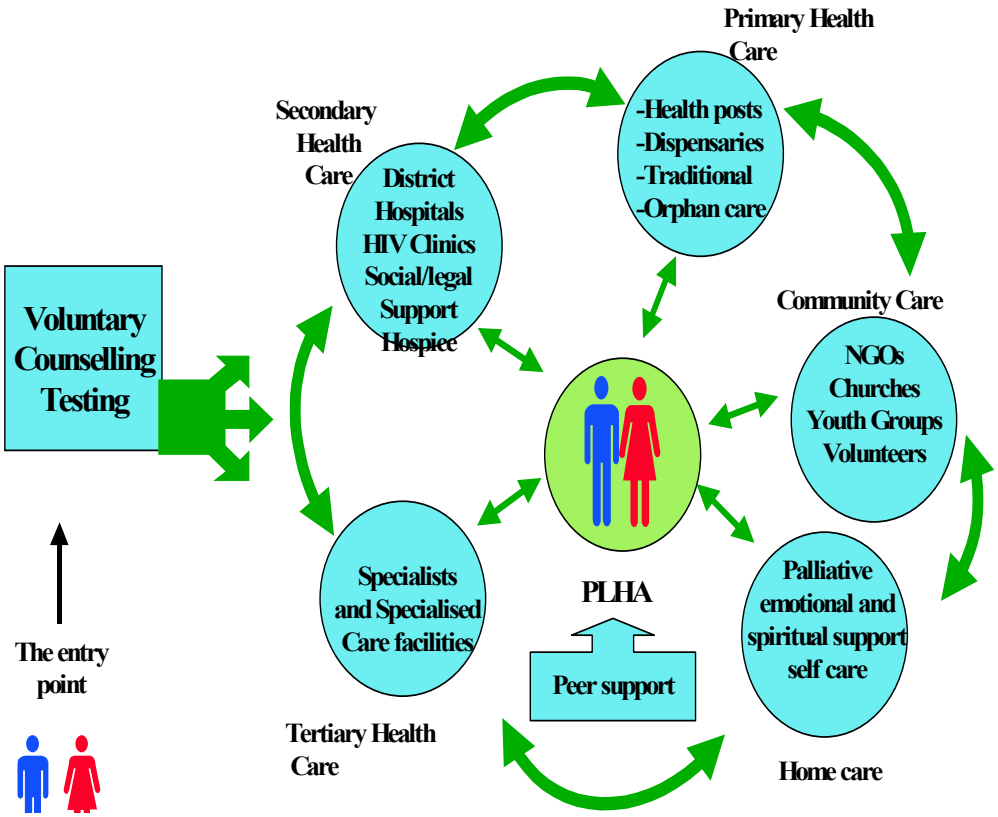
for the future and behavioral changes, and involving sexual partners in such decisions

4. **Social support-** information and referral to support groups, welfare services and legal advice for individuals and families, including surviving family members.

## ii Communities

Communities have major roles to play in care and support of PLHAs. Communities should be encouraged to organize care and support to people infected with HIV and to their families. They should be able to make use of full use of the existing programmes of the government and NGOs in health and social sectors. Example: These organizations can train community workers who may be family members and volunteers.

# CONTINUUM OF CARE MODEL:




**HIV/AIDS Continuum of Care**

**The various elements in Continuum of Care model include-**

**(1) Voluntary Counseling and Testing for HIV infection (VCT)**

(2) **Psychosocial support** - Counseling, spiritual support, support to enable disclosure and risk reduction strategies, medication adherence, and end of life and bereavement support.

**(3) Home and community-based care**

(4) **Medical management** - Diagnosis and treatment of HIV-related diseases, adequate nutritional advice to PLHA, Palliative care, Prevention of HIV-related diseases, Antiretroviral treatment, Family planning, Promotion of safe sex and condom use to clients in HIV care and support programs, Antiretroviral treatment, Family planning Promotion of safe sex and condom use to clients in HIV care and support programs, Diagnosis and treatment of STIs, Intervention to reduce mother to child transmission of HIV, Post exposure prophylaxis of HIV infection for occupational exposure to HIV and for rape victims.

(5) **Behavioral issues in HIV/AIDS care and support -** Avoid stigma and discriminatory attitudes, Management of drug-addicted people and vulnerable groups, Social and legal support.

# MODULE 3 KEY POINTS

- Common opportunistic infections are TB, Pneumocystis Carinii Pneumonia (PCP), recurrent bacterial pneumonia, cryptococcal meningitis, toxoplasmosis, oral candidiasis, cryptosporidiosis
- The goals of antiretroviral treatment are: to delay disease progression and prolong survival, suppress HIV-1 replication, preserve and restore immune function, minimize toxicity, prevent emergence of drug-resistant virus, and reduce HIV transmission.
- In order to attain viral suppression a patient must take his/her medications 95% of the time.
- HIV medications have many side effects making compliance very difficult.
- The most available first-line regimen in India is a combination of d4T/3TC/Nevirapine (known as Triomune) taken as bi-daily fixed dose combination.
- When a patient is starting medications a nurse should assess the patient's: attitudes of medication taking, history of medication taking, habits, living situation, and general health, and what other medications he/she is taking including ayurvedics.
- The goals of palliative care are: to provide the patient with as much control over their symptoms as possible; to keep the patient comfortable; to assist the person in grieving for and coping with the continuing losses they are experiencing consequent to the impact of HIV infection; to help the person, their families and care givers organize their lives; to prepare the person and their loved ones for death.
- Palliative care does not just apply to end of life issues.
- The elements of the continuum of care model are: psychosocial support, home and community based care, testing, medical management, behavioral issues in HIV/AIDS care and support.

## Nursing Actions:

1. Explain to the patient the need to use HIV medicines 95 percent of the time.
2. Work out a schedule with the patient as to where/when the dose is to be taken.
3. Explain what can be done if there are side effects.
4. Plan for each patient what components of palliative care are necessary and applicable.
5. Be familiar with the symptoms of opportunistic infections