
UNIT 2 CONTINUUM OF CARE

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2.0 OBJECTIVES

The purpose of this unit is to provide you with an understanding about the concept of continuum of care with emphasis on home care and the role of the family and the community in caring for the person living with HIV. It is meant to assist you to understand the need for continuity of care for people living with HIV. It also helps the learner to understand the different components involved in continuum of care: day care, hospital care and hospice care. It details the various aspects essential for such care.

2.1 INTRODUCTION

The need for care is often not apparent, whether to the patient or the health providers, immediately after infection with HIV. A reason for this is the slow progression from asymptomatic HIV infection to AIDS. A long time may elapse between first infection, the development of symptoms, and awareness, with serious implications for HIV prevention as well as for care. Another reason is the common belief that since there is no cure for HIV, is there a need for treatment?

One of the considerations is the fact that most people tend to delay appropriate treatment by primarily trying to cure themselves and later visiting traditional healers and quacks as the disease progresses. As patients realize or are diagnosed with HIV, they tend to bypass nearby health services because of the fear of recognition, potential stigma, discrimination and lack of confidentiality.

2.2 CONTINUUM OF CARE

Often for the person and the family, economic problems may be more important than the HIV infection. Thus, it is important to see 'needs' in terms of people's own definitions and priorities. The essence of 'comprehensive care across a continuum' provides a unique opportunity to respond to a wide range of needs. For care to be comprehensive, it must contain a wide range of support services, which need not be met by a single institution or individual. Instead networking with existing services available or capable of being developed within a community is essential.

Comprehensive care must include referrals between home, community and the hospital and vice versa. Continuum of care must include a dynamic set of support services, starting within the community that the person and the family can access. At the minimum, it should include clinical management (early diagnosis, including testing, rational treatment and follow up care); nursing care, to promote and maintain hygiene and nutrition, and palliative care and health education to home based care givers including observance of universal precautions; counselling, psychological and spiritual support, including stress and anxiety reduction, promoting good quality of life and risk reduction to prevent new infections; and social support (information, referral services including legal services).

Table 2.1

Profile of the various components involved in a continuum of care programme

Day Care	Home Care	Hospital Care	Hospice Care
Simple treatment Counselling, Testing, Preventive education, Clinical examination, and Early diagnosis of Opportunistic infections	Training Common symptoms, Maintain nutrition, Supervision, Guidance, Link to systems Psychosocial support, Help with bathing, dressing, studies, cooking, shopping etc.	Diagnosis Laboratory facilities, invasive investigations, Treatment of opportunistic infections, other HIV related infections. Acute nursing care, Surgery, Counselling, and Preventive education	Chronic illness Terminal care, Psychosocial support, Maintain hygiene & nutrition, and Spiritual needs
Dispensary staff Organizations PHC staff Social workers, Counsellors, and Physiotherapist Volunteers	Family/Friends Neighbours Social workers NGOs, Community Doctors, Social workers, Nurses & Health Care Workers, and Nutritionist	Hospital staff Health care workers, Volunteers, Doctors, Social workers, Nurses Counselors Physiotherapists, and Nutritionists	Social NGOs, Community, Volunteers, Family, Friends, Doctors, Social Workers Nutritionists, and Spiritual leaders

2.3 HOME CARE

Home care as you know refers to any form of care given to sick people in their own homes. It involves the things that people might do to take care of themselves or the care given to them by the family or health care worker at home. Care includes physical as well psycho-social activities.

Caregivers

The term 'family' refers to the person/people at home who have the main responsibility for caring for the sick person at home. This person may be a blood relative or relative by marriage.

Reasons for Home Based Care

Good basic care can be given successfully at home.

- Most patients prefer to spend the terminal phase of their illness at home.
- Sick people are comfortable in their own homes and communities, with their families and friends around.
- Home care can reduce the burden on hospitals.
- It is usually less expensive for families to care for someone at home.
- There is a traditional support system to provide care e.g., family, spouse and friends. The health care worker can provide teaching and support to the caregiver on matters of HIV/AIDS/STDs.

Management of Common HIV Related Symptoms at Home

1) Fever

When a person's body temperature is raised, it means the person has a fever. Fever as you know is not a disease in itself but a sign that tells that something is wrong in the body. It may indicate one of many illnesses. The causes of fever may include HIV-related opportunistic infections such as tuberculosis, endemic disease such as malaria and HIV infection itself. High fever can be dangerous especially in small children. As a symptom, fever can make anyone extremely uncomfortable.

What to do at home

Use a thermometer to check the person's temperature. If a thermometer is not available then place the back of your hand on the person's forehead and the back of the other hand on your own forehead. If the person has a fever, his/her forehead will be warmer than yours. Since thermometers are available at affordable price, one should try to buy one for the family.

It is important to lower the temperature as quickly as possible to prevent further complications.

Remove unnecessary clothing from the body and ensure the circulation of cool and fresh air. If possible, cool the skin especially the forehead with cool water sponges. In between bathing and cooling the skin, the skin must be kept dry and

clean. (*Lotions or powders can be used to prevent rashes and sores, and broken areas on the skin*).

A person with fever loses a lot of fluid which may make them feel worse and can cause dehydration. Provide plenty of frequent intake of fluids — water, weak tea, juice etc.

Use medicines that reduce fever: e.g. antipyretics like paracetamol. For children the dose is lower and depends on the size (weights) or age. It is necessary to discuss details earlier with a physician or health workers.

When to seek help

It is essential for the person having fever to seek help:

- If they have fever with chills and rigors (shivers).
- If the fever is accompanied by symptoms such as stiff neck, severe pain, confusion, unconsciousness, eyes turning yellow in colour and sudden severe diarrhea. Patient with convulsions should be referred to a hospital.
- A pregnant lady or a lady who has recently delivered or an infant has to be referred to a hospital.
- If there is continued high fever despite taking the above measures.

2) Diarrhoea

Diarrhoea is very common in people with HIV infection or AIDS. The stools may be clear and watery. When the stools contain mucus and blood, it is called dysentery. At times it is accompanied by abdominal cramps and vomiting. A person has diarrhea if he/she passes three or more loose or watery stools in a day.

There are two types of diarrhoea: Acute diarrhoea, which lasts for less than two weeks and persistent diarrhoea, which lasts more than two weeks. The most common causes of diarrhea in PWHA are: Intestinal infections from food or water; opportunistic infections related to HIV/AIDS and side effects of some medicines especially the new antiretroviral therapy (ART).

It is important to treat diarrhea immediately as it can lead to dehydration and malnutrition. Dehydration occurs faster in infants and young children, in hot climates and in people who have fever. Malnutrition may occur as some people may erroneously think that they should not eat when having diarrhoea.

What to do at home

The person and the family must ensure that they drink clean water. Water should be boiled to kill all the germs. It is ideal to allow the water to boil for more than 10 minutes after it starts bubbling. The source of water should be safe, protected from animals, people washing clothes, bathing and from latrines. Water should be collected and stored in a clean and covered container and a clean long ladle should be used to draw water from it. Clean drinking water must be used when brushing teeth.

Food must be freshly prepared and cooked well. Raw food must be properly

washed and stored well to prevent contamination of disease causing organisms. Previously cooked food must be stored safely and reheated thoroughly at high temperature.

Maintaining clean hands is extremely important. People should wash their hands with soap and water before and after eating food as well as handling food.

Three rules for treating diarrhoea at home (suitable for anyone with diarrhoea):

i) Drink more fluids than usual

Drink as much fluid as possible. If not thirsty, the person may have to force himself or herself to eat. Placing a glass of water at the bedside may help to remind the person to sip it every 5-10 minutes. It is extremely important to restore lost water and salts after each loose stool. It is preferable to have food-based fluids which are present in the house which normally contain some salt (salted) rice water, buttermilk, vegetable soup etc. Fresh clean water, coconut juice and unsweetened fruit juice are also effective. Avoid sweetened aerated drinks, juices, teas, and coffees as they draw the water out of the body and the diarrhoea and the dehydration can worsen.

ii) Continue to eat normal diet

An HIV patient should eat only well cooked food, which is preferably boiled. Eating uncooked food will make digestion difficult. The patient may get infected with other microorganisms like bacteria, fungi and viruses.

HIV patients require lots of energy. They should take lots of starchy food like rice, wheat etc. They also should take more of fats. The total caloric requirement is about 2500 calories per day.

Proteins are necessary for the body for repair as well as proper function of the immune system. High protein diet with good biological proteins is essential. An egg a day as well as half a litre of milk is recommended for the HIV positive patient daily.

Vitamins and minerals have been shown to protect the immune system from damage. Vitamin A is said to protect and improve immune function. Hence the diet should consist of plenty of fruits and vegetables. When fresh fruits and vegetables are used they should be cleaned well before use.

HIV infected patients have altered taste sensation or loss of taste. The food should be made palatable. Cooking skills should be used to produce tasty and appetizing dishes. Spices can be used provided that they do not cause any gastric irritation.

Patients may not be able to have large meals. They must be encouraged to have frequent small meals. Sometimes the doctor may prescribe multivitamin pills or food substitutes. They should be used under guidance.

Fluids taken in cannot replace the need for food. It is important for the person to eat even if they do not have appetite, to prevent malnutrition. Nutrients in the food are essential for a person to stay strong and prevent weight loss. Remind them that a strong person can resist illness better. If unable to eat, the

person must take in small amounts of nutritious and easily digestible food frequently. A person may prefer small amounts of food that are easily digestible. Food can be taken every three to four hours, about six times a day. Eat mixes of cereal and locally available beans, meat or fish. Dairy products, eggs and bananas are also suitable. Avoid high-fiber foods such as fruit or vegetable peels, and whole grain cereals as they are hard to digest. An extra meal a day, after the diarrhoea is gone, will help to regain any weight loss.

iii) Recognize and treat dehydration early

Signs of dehydration are: feeling thirsty, feeling irritable or lazy, skin going back slowly when pinched, dryness of lips and mouth, and sunken eyes.

Oral rehydration solution (ORS) that is easily available may be used. Instructions are given on the packet and must be followed properly. The family must remember to use cooled boiled water to mix with the contents of the ORS packet. The mixture must be stored well and kept covered after use. The leftover solution should be thrown away after 24 hours.

Along with diarrhoeal problems, other problems may also appear like:

- i) **Skin irritation in the rectal area:** To prevent or treat sore or broken skin the sick person or caretaker must: "Clean the rectal area gently with clean water after each bowel movement and pat dry:" Apply a lotion/vaseline to help relieve the discomfort and protect the skin: Sit in warm water containing a little pinch of salt three or four times a day; this may also relieve the discomfort.
- ii) **Hemorrhoids (piles):** A weakening of the walls and blood vessels of the rectum causes hemorrhoids. They can develop after a long period of diarrhoea. The tissues around the rectum become sore and itchy. The blood vessels may become very tender and may bleed: small amounts of blood may be noticed in the stools or while cleaning the rectal area.

It is important that the person must relax and not strain during bowel movements. In addition to the above recommendation cited for skin irritation, paracetamol can also be taken to relieve the pain.

Help a person with diarrhoea who cannot move out of the bed: use a bedpan or some suitable plastic or metal container. Ensure that it is not too high and can be easily slipped under the person in bed. Empty the contents as frequently as possible. Do not use the same container for any other purpose. Change wet and soiled bedding immediately to prevent damage to the skin. If the person is ill for a long period of time this will also prevent getting bedsores. Should linen and clothes must be kept separate from the rest of the household laundry. Hold the unstained part of the linen, rinse out the stains and wash it with soap and water. Warm water is more effective. Dry it in the sun.

Cleanliness and hygiene are utmost importance as they can prevent other infections as well as prevent others in the household from picking up an infection from soiled linen or unclean food or water.

Seek help when the person is at risk of dehydration and no measure has helped or has a fever. If the person is not getting better with home care, seek hospital care as early as possible.

3) Skin problems

Skin problems are common in people with HIV/AIDS. They unfortunately tend to be chronic. Rashes, itching skin, painful sores, increased dryness, slow healing of wounds, boils and abscesses are the common ones. Some of the causes are yeast infections (e.g. thrush), fungal infections (e.g. ringworm), bacterial infections (e.g. pneumonia), shingles (e.g. herpes zoster), infected scabies/poor hygiene, allergic reactions to medications or skin irritants, bed sores (e.g. from lying in one position in bed), eczema, Kaposi's Sarcoma (KS) etc.

What to do at home

Clean the skin frequently with soap and water and keep it dry. This will prevent the most common problems. As most skin problems involve the sensation of itching, encourage the person not to scratch any skin lesion or sore. Scratching the itching skin can make it worse by breaking the skin or by introducing or spreading infection. Keep fingernails always short. This is especially necessary in case of the infants, young children and people who are in confused mental states. Rubbing the skin with the flat of the fingers or palm can give some relief. In addition, Calamine Lotion can also be soothing. Apply liquid paraffin to prevent dryness of skin. If there is a wound, dressing needs to be done daily or as instructed by the doctor.

Care must be taken to keep the skin or wound always clean. Also, the caregiver must observe universal precaution to prevent infections i.e. infections from the patient to the caregiver and vice versa.

When to seek medical help

- If the person's conditions deteriorates and is accompanied by redness or fever (indicating infection).
- If the wound has a bad odour, pus oozes from it and the skin around turns black forming into a blister (this may be gangrene which is dangerous condition).
- If there is an allergic reaction to a medicine.
- If the skin infection or wound does not respond to treatment. Medical care must be sought quickly.

4) Mouth and Throat Problems

Soreness in the mouth usually accompanied by white patches on the tongue is a common symptom in people with HIV/AIDS. Sometimes it progresses into the throat and esophagus, causing painful swallowing thus interfering with eating and drinking. Other associated problems are blisters and sores on the lips, and dental problems. The following diseases could be the cause of these problems.

i) Thrush

Thrush is a *fungal* infection that causes small white patches on the insides of the mouth and tongue. If the white plaques scrape off with a brush or a fingernail it is probably thrush.

ii) Herpes Simplex

Herpes simplex could be present as painful single or multiple sores or blisters that appear on the lips or mouth. It is a sign of immune-deficiency. The patient must consult a doctor urgently for appropriate treatment.

iii) Hairy Leukoplakia

It may look like thrush however it does not cause pain and commonly causes vertical ridges on the edges of the tongue. It does not make a person uncomfortable nor does it interfere with eating. There is no specific treatment for this condition.

Apart from these health problems related to malnutrition, dental problems and cancer like Kaposi's sarcoma could also affect the mouth and the throat.

What to do at home?

Encourage a healthy diet and vitamin supplements as poor nutrition can cause and worsen existing problems. Prevent problems by regular rinsing with warm salt water or with a mouthwash solution after eating and between meals.

General hints for dealing with a sore mouth

Eat soft foods rather than hard or crunchy food.

Eat bland, not spicy food.

Use a straw for having liquids and soups to prevent touching the sore parts with the food or spoon.

Cold food or cool drinks or ice may help numb the mouth and relieve discomfort.

Avoid sweet food as it allows for increased growth of fungi.

It is important to prevent oral thrush from spreading to the throat or esophagus.

Apply 3-4 drops of antifungal oral suspensions three or four times a day. Maintain proper oral hygiene by cleaning the mouth at least twice a day. If it still persists systemic medications are available for fungal infections. Oral thrush can alter the tastes and lead to loss of appetite or being painful or giving difficulty in swallowing. This can be avoided by encouraging the patient to carefully follow the treatment instructions given.

5) Dental Problems

If the person presents dental problems, care should be taken to explain to the patients about dental hygiene and the need for regular visits to the dentist.

What to do at home

Oral hygiene is extremely important. Thorough cleaning of the teeth and gums preferably after each meal is essential. Also many people with HIV suffer from inflammation of the gums, tooth abscesses and infection and so regular oral cleaning is very important. In case of toothaches, a pain reliever like aspirin or paracetamol can be taken. Chewing cloves may also help.

When to seek help

The person or the family must visit a health care worker if the person is unable to drink or swallow properly. If a person has a severe tooth infection with fever, swelling, put, etc. a dentist should be consulted.

6) Cough and Difficulty in Breathing

Respiratory problems are common in people living with HIV/AIDS and can be quite serious. The most common symptoms that the person and family need to watch for are chronic cough, shortness of breath, chest pain and increased production of sputum (mucus). The most common causes include: colds and flu, bronchitis, pneumocystis carinii pneumonia (PCP), and tuberculosis.

What to do at home

The person can be helped to reduce respiratory problems by: frequently turning in bed, and sitting up as it helps the lungs to drain; lying with pillows under the head, or the head of the bed raised up; leaning forward while in sitting position with elbows resting on the knees or a low table, and massages or gentle patting on the back of the chest over the lungs as this also allows drainage of the lungs.

Tightly holding the area, which hurts the most while coughing, with a hand or pillow; coughing and clearing the lungs at least four times a day even if it is painful as it helps to clear up the accumulated sputum and disease-causing bacteria; drinking a lot of water and taking hot water vaporizers to loosen the sputum and ease the pain of coughing; sipping warm tea with sugar or honey which soothes the throat; taking a cough suppressant at night to avoid the cough from disturbing the person's sleep; taking a paracetamol to relieve the pain, ventilating the room and home frequently to allow for free movement of fresh air are some other helping activities.

The person must remember to cover the mouth while coughing, with the hand or clean cloth to prevent spreading the infection to others. Bacteria or infectious agents present in the sick person's sputum can be passed on through air especially when coughing.

When to seek help

The family must observe the person for the following signs and symptoms and if they are present the patient should be referred to a hospital.

- 1) Onset of fever or change in the regular fever pattern of the person.
- 2) Blood in the sputum.
- 3) A sudden or rapid worsening in ability to breathe or catch their breath after normal activity.
- 4) A change in the colour of sputum from clear to grey, yellow or green.
- 5) Severe pain in the chest.

For children particularly under five, respiratory problems can be very serious and they should be taken to the health care worker for immediate attention if they breathe with difficulty or there are noises from the chest or if they breathe faster

than usual; are unable to drink because of breathing difficulty; develop cyanosis (bluish colour of lips or skin) and feel abnormally sleepy or have difficulty in keeping away.

7) Nausea and Vomiting

Nausea and vomiting can be a serious problem for people with HIV/AIDS. These symptoms may be caused by side effects of medications, infections e.g. oral thrush, stomach or intestinal problems and HIV infection itself. In some people these symptoms are very short-lived, and may pass away without treatment or with minimum treatment. With some it may become chronic or long lasting and become a part of daily life.

What to do at home

The person or family can help the patient to reduce the discomfort that comes about with nausea and vomiting through various measures. Medications are easily available to stop or reduce the vomiting for e.g. antiemetics. Initially do not eat any food or drink any fluids for one or two hours. Prevent dehydration (see section on diarrhoea) – gradually commence drinking clean water, ORS or weak tea in small quantities.

Increase the intake of fluids every hour. The patient may not like to drink anything and may have to be forced to drink in order to make up for what he/she has lost. As nausea decreases, commence intake of other foods like dry, plain food such as bread, rice etc. Freshen the mouth, as it will help in taking away the foul smell and taste caused by vomiting. Rinse it with dilute mouthwash or lemon water rinse.

Keep away from smells and odors that trigger off the feeling of nausea like some cooking smells, medicines, etc. Cool compresses applied to the forehead will help the person to relax and feel comfortable. Clean up the vomit and freshen up the room to make it smell clean and nice. You can use detergent with a mild scent.

When to seek help

The person must be encouraged to visit a doctor if the vomiting occurs repeatedly and the person is in danger of becoming severely dehydrated; if the vomiting lasts for more than 24 hours and is accompanied by pain in the abdomen/severe headache, the person persists with fever and the vomit contains blood.

8) Anxiety and Depression

The problem and possible causes of anxiety and depression could be because of the prospect of an HIV test or a confirmatory test; prospect of a CD cell count or viral load test, a forthcoming physical examination of some illness with the family.

Anxiety

Anxiety is a feeling of nervousness, fear or dread of the unknown. It manifests in several symptoms; physical and mental. Some symptoms are lack of appetite, sweating, feeling faint, insomnia, feeling very worried, a feeling of being out of control, difficulty in concentrating, feeling very irritable or confused.

Depression

Depression is a feeling of sadness and hopelessness. This may be due to loss of ability in usual activities or loss of physical appearance. These may manifest due to lack of energy, poor concentration, sleep disorders, isolating oneself and irritability. Care needs to be taken to prevent the person from harming himself/herself (suicidal feelings) and others.

What to do at home

Different people belonging to different cultures differ in their ability to cope with anxiety and depression. Usually, in the Indian context, the elderly and religious provide such support to their own. HIV being a social problem, cultural differences are notable, the extent of communities being unsupportive in reaching out to the affected person and family. Thus families are often left to tend to themselves.

People need to express their thoughts and feelings to help them overcome anxiety and depression. Gently encourage them to go through the stages of grief by encouraging them to talk and then listen to them. It helps to talk to someone who has been through the coping process previously. The contact with peers can be a great support and inspiration. Encourage sick people and family members to learn how to relax. This includes both physical and mental relaxing activities that are extremely helpful.

When to seek help

If the family or the person believes that the anxiety or depression is severe enough that so the patient may commit suicide, or harm himself/herself or harm some one else, a psychiatrist needs to be consulted.

9) Pain

Pain may be physiological or psychological. Causes of pain are several and include immobility, infections such as herpes zoster, swelling of the extremities, headache alone or associated with meningitis or encephalitis, and nerve problems. Emotional causes may be due to depression and anxiety, side effects of medicines and perhaps due to cancer.

What to do at home

The family needs to reassure the person and support them, as the pain can be highly stressful and frightening. Regular breathing or relaxation exercises may help a person to relax and release tension built up due to the pain. Distractions and amusements can help people to reduce their attention on their pain and comfort them. The person should be helped to sit or sleep in positions that will reduce painful movement. If the person is unable to move unaided they should be helped to change position frequently. This will not only prevent soreness but also ease the pain from lying in a particular position. Medications like analgesics can also help to soothe the pain.

When to seek help

If the pain does not get reduced with mild medications or if it is prolonged then the person must seek the help of a health care worker.

10) Tiredness and Weakness

Fatigue can be the result of HIV infection or related illnesses, particularly respiratory illnesses. It could also be due to poor nutrition, anemia and depression. Or it could be due to a different cause unrelated to HIV.

What to do at home

The person needs to take frequent rest periods off and on during the day. The family needs to find out what sort of help is needed by the person and accordingly offer such support. The person may feel low at having to ask someone else for help. Family support and reassurance will help them feel comfortable about accepting help from others. By making people know how they can help, it avoids the problem of having too many people doing the same thing.

Activities of daily living (ADSL) should be undertaken to ensure maximum comfort and ease, and minimize pain. The family helps in offering support and care for the person. Safety precautions are necessary to be at home alone. For example: move loose or dangerous objects out of the way; assist the person when walking or provide a walking stick or cane; and try not to leave the person alone for long periods.

When to seek help

If the patient's condition deteriorates to include other symptoms like high fever, headache or severe pain the person needs to be attended to by a health care worker quickly.

11) Mental Confusion and Dementia

HIV affects the cerebrospinal fluid along with the rest of the cells of the human body. This can lead to differences in the mental conditions of the person living with HIV/AIDS. HIV related illnesses might also lead to some mental problems. Similarly side effects of some medications or severe depression may lead to dementias as well. The mental problems may include:

- 1) The inability to think clearly is a major mental problem. The person may be seen as not able to concentrate properly or be forgetful of tasks.
- 2) Behavioural changes. The person may appear to be irritable, disinterested or unpredictable have coordination problems or failing strength. The person may start misplacing objects, dropping them, have slowness in movements or have shakiness.

What to do at home

Distraction helps to involve the person in some other task. Details of a task must be explained in small steps to avoid confusion. Music helps to release aggressiveness and assists in soothing and relaxing the person. Quietness and serene atmospheres are preferred to noisy ones. This may be difficult if there are children at home, but as far as possible the room must not add to the mental confusion of the person. Encourage the person to do small things that are mechanical, easy and not stressful. Allow the person to know that you are there if needed.

When to seek help

A confused and aggressive person can be very difficult to manage at home. At times the family may be unable to manage at home and may need the help of a health care worker. The health care worker will be able to offer help or provide treatment which is at least sufficient enough to relieve the person from discomfort. The person will need immediate attention if the condition deteriorates and is associated with high fever, headache and difficulty in breathing.

Check Your Progress I

Note: Use the space provided for your answer.

1) Briefly describe the three rules for treating diarrhoea at home.

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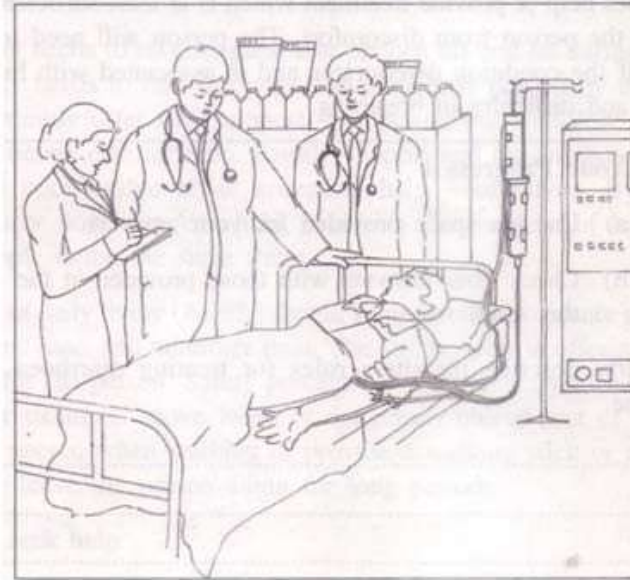
2.4 HOSPITAL CARE

HIV infection is a chronic illness, progressing several years and at a rate that is different for every infected individual. Experience has shown that progression of HIV infection may be slowed down or retarded with appropriate follow up care, use of prophylactic treatments, active treatment of opportunistic infections, etc. therefore continuity of care is an essential component of all aspects of HIV/AIDS care. Coordination of care can be done through an interdisciplinary approach to case management or a multidisciplinary care model.

An interdisciplinary approach allows for effective communication and shared decision making within the team. Care providers from various disciplines join forces with one another and treat the person as whole.

Another method of ensuring care along a continuum is through the multidisciplinary care model. In a multidisciplinary care system, care providers from various disciplines provide care and treatment specific to their clinical expertise. This kind of treatment occurs in isolation of other disciplines. The person may receive specialized care and treatment according to the particular condition.

An interdisciplinary care team may include. Physicians, nurses attendants home care coordinators, a community physician, specialists in pediatrics, gynecologists, social workers, counsellors, pharmacists, physiotherapists, volunteers administrative personnel educationists, spiritual leaders, nutritionists, food service providers, other service providers e.g. a driver for transporting the patient, the patient and the family.



Whatever the type of approach in a hospital, finding a doctor and hospital that is HIV friendly and supportive is most important. Patients have reported neglect and discrimination by health care workers at the hospitals. With increased awareness and consciousness of maintaining universal precaution for all, this fear among health care professionals is being gradually reduced. However, much more needs to be done in the area.

It is also essential that the physician has expertise in the management of HIV. With the availability of antiretroviral drugs freely in the market, a physician should know when to use the medications. Studies have shown that patients who are seen by a trained HIV physician fare better than those seen by untrained physicians.

Often, the family is not able to attend to the requirements of the patient at home. Or the person's conditions may become so severe that they are unable to manage at home. In these cases, active medical care and treatment are required. Such cases may include care and treatment at the hospital and at home.

It is important to remember that drugs alone cannot help improve anyone's conditions. Looking after one's health with proper nutrition and rest, practicing safer sex and avoiding infection (of HIV and other infections) enhances the body's capacity to cope with HIV. Through counselling at the hospital, doctors are able to discuss not only the physical aspects of the illness and treatment but also the social, sexual, financial or legal issues connected to it.

Opportunistic Infections

There are numerous microorganisms in our body surface i.e. skin or the mucosa. In normal circumstances these organisms do not cause illness. These organisms are easily destroyed by a normal immune system. These pathogens have the opportunity to grow and multiply in a body, which has a weak immune system, thereby causing illness. These illnesses are called opportunistic infections. These are the most common AIDS- related illnesses seen. Some common ones are Tuberculosis, Pneumocystis, Carinii Pneumonia commonly called PCP, Candida Albicans commonly known as thrush, Cytomegalovirus (CMV) which affects the eye, and Herpes Simplex and Herpes Zoster caused by the herpes virus.

Cancers

The most common cancers associated with AIDS are Kaposi's sarcoma (KS) and certain kind of lymphomas mainly non Hodgkin lymphoma, Lymphoma of the brain or lymphoma due to Epstein Barr virus. Cancer of the cervix in women is common.

Neurological Complications

Neurological complications in people with AIDS may result from opportunistic infections, cancers, HIV infection itself or other metabolic states related to illness. The toxic effects of various drugs and treatments may also affect the nervous system. All levels of the nervous system may be involved. They may have meningitis, demyelination, and various forms of neuropathy or myopathy.

Wasting Syndrome

Involuntary weight loss, or wasting is one of the most common manifestations of HIV infection. It can occur at any stage of HIV infection but is usually most severe in the later stages of illness. It is essential to improve the muscle mass. It has been recommended that HIV positive patients should walk briskly. In addition to aerobic exercises, resistance training also helps to prevent the loss of muscle mass. Patients who do regular weight lifting exercise have a better muscle mass. It has been suggested that the patients should do resistance exercises at least three times a week. Yoga has also been shown to improve the muscle and immune system. NACO has published a book on yogic exercises for the HIV infected. Although it is difficult to reverse, many people with HIV infection have been able to reduce weight loss or have gained weight.

HIV-related Problems in Women

In recent years the rate of infection in women has grown (and continues to grow affecting infants as well) at alarming rates. Women with HIV are just as likely to contract opportunistic infections as men. Numerous studies have shown that there is no difference in the presentation of opportunistic infections between men and women.

The most common gynecological conditions observed are pelvic inflammatory disease and vaginal fungal infections. It is crucial for the patient to visit the doctor for the above conditions as quickly as possible.

Hospital Stay

The patient may require hospital care for a brief check-up diagnosis, and treatment and he can visit the out patient department (OPD) or the patient may require treatment at the hospital for an entire day and may be admitted into the day care center. At times the patient may require extensive treatment and so may need in patient care for several days.

Discharge from Hospital

Leaving hospital is called being discharged. The patient will require a hospital sheet stating he/she is discharged. This may be done when the patient is deemed well enough to go home or if there is nothing else that can be done for the

patient at the hospital and the best treatment is at home. At times, the patient may want to be discharged or the family members may want to have the patient discharged for various reasons. Under these circumstances, the doctor may issue a discharge sheet stating discharged against medical advice. At the time of discharge the doctor is required to fill out a prescription for the patient. When the doctor or health and the caregivers prescribe medicines, the patient has to follow the prescribed dosage schedule as closely as possible. They need to understand how much of the treatment they need to take and when. Also, possible side effects need to be discussed and whether it can interact with any other treatments. Thus the doctor must be informed of any other medications, allopathic, ayurvedic or homeopathic which may be taken by the patient. The health care workers also need to explain to the patient and the primary care givers the exact care that is required at home.

Check Your Progress II

Note: Use the space provided for your answer.

1) What are the precautions to be taken when an HIV patient has to be discharged from a hospital?

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2.5 HOSPICE CARE

Hospice comes from the Latin word hospes which also refers to other English words like hospitality, hospitable, host, hostess, hospital, hostel and hotel — all associated with ideas of caring for people with kindness and generosity. Hospice is a very old concept meaning a place of sanctuary for religious pilgrims, travelers, the poor, the sick and the dying. Originally, a hospice and a hospital were in the same place. With the rise in curative powers of medicine, the ideas of cure and care became separate. The medical world became increasingly focused on curing disease and often people who were dying were seen as a shameful admission of failure. The disease became more important than the patient and patient's wishes were not considered important. The idea of hospice has undergone a renaissance in reaction to these attitudes.

The use of word hospice refers not only to an organisation of people devoted to caring for the dying but also to the philosophy of care that values quality of life of the patient until death. It is philosophy that puts the patient at the center and in control of his or her own life and care.

A hospice is essentially a home away from home; wherein the person may come into receive active medical treatment with the help of other in-patients and families.

It is also a place for recreational activities, other forms of treatment like relaxation therapies, yoga, meditation and acupuncture. It can be both residential where the person becomes and in-patient or community based wherein the person can engage in day activities of the hospice. It serves as a therapeutic centre for the person and the family.

There are various reasons for having a hospice available for people in need. For some it can be a beautiful place to rest during painful and stressful times, allowing others to support, and rendering this support and care to others who are in need. For others, it may seem a reflection of what has been lost; it can make them desolate and unwanted by their family and community. Needless to say, it is thus of grave importance to make the person make their own decisions. Of course, for health reasons, the team might be unwilling to discharge a patient but it is important for the medical team to know that the person needs to make their own choices. Also in the Indian context, hospices may be mistaken for dumping grounds and so patients may perceive the entire situation differently. Also, residence at the hospice is impossible for a long length of time and spaces in needed for other who require help.

The term palliative care is often used to describe the broad type of health care that a hospice provides for those who are dying. Palliative care provides suitable treatment to the patient when cure is not possible. It does not only alleviate symptoms, it helps a patient psychologically, spiritually, physically and socially. For more information on palliative care, please refer the unit on Palliative Care from Block 2, Unit 4 of the elective course on HIV/AIDS.

As new treatments are available, HIV/AIDS with no longer be seen as a terminal diagnosis but rather as a chronic condition that reduces life expectancy. We all hope that there will be a cure. Still hospices are required to look after the special needs of those living with AIDS.

Strengths, weaknesses, opportunities and threats of hospice

Table 2.2

Hospice Care of Patients with AIDS

Strengths

More relaxed atmosphere than hospital.
 Reduces fear of admission.
 Supervised medication.
 Allows respite for the family
 Less expensive than the hospital

Weaknesses

Less medical supervision than the hospital
 Possible delay in emergency treatment
 Possible risks of cross infection

Opportunities

Continuity of care between home/hospice
 To train care attendants
 Education to reduce fear and prejudice
 Encourage a caring sharing community

Threats

Resistances from traditionalists
 Dilutes professional experience

Basic to hospice care is the principle of holistic care. The care team extends beyond the primary team to include a variety of professionals, including physiotherapist, occupational therapist etc.

Reasons for Hospice Care

The person who is dying must be part of all the decisions regarding care. You can find out about their physical or emotional state and discuss what can be done for them.

There are various reasons why one may require hospice admission. In case of supervised medication and treatment, there is need for a medical person to be present. As we saw in the section on home care, very often the family is unable to attend to the care needs of the person. Or the person may have been ill for a long duration of time. This may result in gradual burnout of caregivers that can lead to severe physiological and psychological problems for themselves as well as the patient. To prevent such things from happening, hospice care is recommended to alleviate the stress of the caregivers and to provide maximum comfort to the patient.

Many people living with HIV may worry about a time when their health will deteriorate, that they will be unable to function as well as before and provide services for themselves. Some may have seen a spouse, close friend or neighbour pass through the last stages of infection and may anticipate the pain and grief, which may leave a desolate picture in their minds.



Who provides such care?

People with an understanding of the disease, experience in treatment and a compassion for helping others can provide hospice care. Health care professionals who have special skills and experience, counsellors, social workers and volunteers are important in providing hospice care. In addition, family members, friends, spiritual leaders and other people living with HIV may be interested in joining the hospice team.

Check Your Progress III

Note: Use the space provided for your answer.

- 1) Briefly list the strengths, weaknesses, opportunities and threats of a hospice.

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2.6 LET US SUM UP

In this unit we have discussed the need for continuity of care and support for those living with HIV/AIDS. The unit deals with various aspects of care i.e. day care, home care, hospital care and hospice care.

Continuity of care is the process of providing a wide range of services to the patient in order to help him/her to cope with his/her deteriorating health. Most of the care an HIV/AIDS patient requires can be given at home. Therefore under home care, details for the management of common HIV related symptoms in the home have been discussed. Some of them include fever, diarrhoea, skin problems, mouth and throat problems, dental problem, cough and difficulty in breathing, nausea and vomiting, anxiety and depression, pain, tiredness and weakness and mental confusion and dementia. Some information on opportunistic infections provided in this unit is really useful.

2.7 SUGGESTED READINGS

NACO (2000), *Manual for Control of Hospital Associated Infections*, NACO, New Delhi.

NACO (2000), *Voluntary Counselling and Testing*, NACO, New Delhi.

NACO (2000), *Guidelines on Clinical Management of HIV/ AIDS*, NACO, New Delhi.

NACO (2000), *Guidelines on Rational Use of Antiretroviral Drugs*, NACO, New Delhi.

NACO (2000), *Training for Health Workers & Supervisors on RTI/STD and HIV/AIDS Prevention and Control*, NACO, New Delhi.