THE UNITED REPUBLIC OF TANZANIA
MINISTRY OF HEALTH

TRAINERS GUIDE FOR HOME
BASED CARE PROVIDERS

NATIONAL AIDS CONTROL PROGRAMME

August 2005
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ACKNOWLEDGEMENT

This document is one of various guidelines developed by the Ministry of Health (MoH) to strengthen the training of home based care providers in Tanzania. The document is a result of efforts of many individuals and organizations involved in the response to HIV/AIDS in the country.

This document is based on the earlier Guideline and training materials that were developed in 1999, and the members who developed it continued to provide technical advice during the development process. The Ministry of Health is grateful for their input. Special appreciation is also extended to the technical team consisting of trainers and health care providers who reviewed the draft and gave very valuable inputs to concretize it.

The content of the document is based on available World Health Organization (WHO) guidelines and the organization provided a continued technical support towards the completion of the document. The Ministry of Health recognizes this important contribution.

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INTRODUCTION

Illnesses on the already over-stretched and over-burdened Health Care System have been enormous and continue to grow. This situation has led the Ministry of Health to review the health care services, especially the care given to PLWHA and other chronically ill patients. In searching for alternatives that could efficiently serve their needs and improve their quality of life, the MoH has established a system of continuum of care that extends to the community through a model of Home Based Care.

The Ministry of Health through National AIDS Control Programme has developed a HBC Model to be implemented at district level. The model that is implemented at district level was first piloted in 8 districts of Rukwa and Coast regions. To date more than 50 districts have been covered. The aim is to multiply this model in all districts of Tanzania. The purpose of developing this model is to provide quality care across the continuum, which extends from the health care system to the community, household and families and back. The model will also enable the communities especially families to be more responsible in providing care to their patients.

In order to implement the model efficiently, there is a need to build capacity at the district, health centre, and community levels on the provision of these services by equipping care providers with necessary knowledge and skills for implementing HBC. The organization of HBC in Tanzania is such that the health facilities are expected to implement HBC policy guidelines, train HBC providers and provide back up to the community and family based home based care providers.

The Ministry of health has developed and widely distributed HBC Policy guidelines, training guidelines and manuals. This guide is based on the available National guidelines.
PURPOSE OF THE GUIDE

This trainer’s guide has been prepared to assist the trainers/facilitators of HBC in identifying the main areas of emphasis while training.

It may not be complete on its own but requires more information from other resources (references) stipulated in the course content outline. The trainers guide will be useful in:

- Orienting the trainer and trainee on the national health policy, other guidelines and strategies relevant to HBC.
- Directing the trainer on how to go about planning, organizing, conducting and evaluating HBC teaching and learning activities.
- Assisting the trainer in teaching each unit of the national course plan for training HBC providers at T.O.T level, and after modification, to suit the trainees at community level.
- Stipulating the scope and roles of HBC, tasks that the HBC provider has to learn and competencies for HBC.

This trainers guide covers on all areas of quality HBC services, HBC supervision guidelines and monitoring tools, strategies and tools for community involvement and participation to mention but few.

TARGET GROUP

This guide is targeted to trainers of Home Based Care Trainers
UNIT 1:
INTRODUCTION TO HOME BASED CARE TRAINING

SESSION 1: GETTING STARTED

OBJECTIVE
By the end of the unit the trainee will be able to:
i. Familiarize themselves with the training

SUMMARY OF CONTENTS
Registration
Introduction
Participants expectations
Norms
Logistics
Pre-test
Overview of the training
Course objectives

CONTENT
In this unit the trainees familiarize themselves with the training. It involves self-introductions; Participants’ expectations from the course, norms and logistics of the course will be explained. Pre-test will be provided to assess trainees level of understanding. In this unit the trainees will also be oriented to the overview of the training and the course objectives

SESSION II: OVERVIEW OF HOME BASED CARE

OBJECTIVES
By the end of the unit the trainee will be able to:
i. Discuss the overview of Home Based Care
ii. Describe the national policy framework which supports HBC
INTRODUCTION
Home Based Care for the sick in Tanzania is not a new thing, has been there since time immemorial.

The increasing number of HIV/AIDS and other chronically ill patients, who cannot be taken care of in the existing health facilities, prompted the need of establishing HBC services in Tanzania. Since the scope of HBC was not clearly defined, patients with HIV/AIDS and other chronic illnesses were discharged from health facilities without any proper referral system for continuum care at home. Hence there was a need to train HBC providers who would be responsible for training and supporting the patients’ families, who in turn will continue taking care of theses patients at home.

The need for establishing HBC services in Tanzania was also revealed by various studies that were conducted in various parts of the country. In these studies, patient with HIV/AIDS preferred being taken care of in their homes, close to relatives, friends and loved ones, especially during the last days of their lives. Further ore, the Demographic and Health Survey done in the country in 1996 showed that about 40% to 60% of hospital bed capacity is allocated to AIDS or to patient with AIDS related diseases.

For all HBC services by Ministry of Health (MOH) were initiated in 1996 as a pilot study in 8 district of Rukwa and Coast regions. The main objective of this pilot study was to train HBC providers, who in turn would train the family members who are the main actors in the HBC services. Between 1996 and 1998, 51 HBC providers have been trained, in the two pilot regions. They have proved to be very useful and their services are very much needed and appreciated by communities.

HBC should therefore be integrated into the District Health Care Delivery System, and be part and parcel of the District Health plans.

CONTENT
THE NATIONAL HEALTH POLICY

INTRODUCTION

The National Health Policy in Tanzania emanates from the Primary Health Care (PHC) approach proclaimed in 1978, but whose effective implementation started in 19983. The actual of what PHC is, was in 1978 after the Alma Ata conference.

Before the Arusha Declaration of 1967, the priority was on curative services, centre mostly in urban centre leaving the rural areas preventive services neglected. From 1967, priorities for provision of health services changed and preventive services were rated as first priority. Health services were to be provided equitably in the whole country. Thus, priority in establishing and improving “health services, turned to the rural areas with great emphasis on preventive care, hence the establishment of health centers and dispensaries with maternal and Child Health (MCH) services”.

Other activities like community based health care, child survival programs, and family planning are all part and parcel of the Primary health Care strategy.

In an effort to improve the health services, health sector reforms have been introduced and are being implemented to facilitate the overall objective of the health policy. They are intended to facilitate increased productivity of quality health services in the most cost – effective way.

OVERALL OBJECTIVE OF THE NATIONAL HEALTH POLICY

The overall objectives of the health policy in Tanzania is to improve the health and well-being of all Tanzanians, with a focus on those most at risk, and to encourage the health system to be more responsive to the needs of the people.

Specific Health Policy objectives:

- To mobilize the community on participation in terms of contribution, management and development of health services.
• To develop and sustain a health culture through safe life styles, dietary habits and environmental maintenance.

• To support and encourage research on communicable diseases, traditional medicine, people’s habits and customs towards improvement of health status.

• To improve the existing health infrastructure and facilities so that they render better health services.

• To improve multi-sectoral and inter-sectoral collaboration in strengthening provision of health services.

• To improve mother and child health with particular emphasis on preventive, curative and family planning.

• To be self sufficient in health personnel of all disciplines at all levels from village to national level.

• To improve the system of procurement and distribution of drugs and medical supplies to make sure they are available at all health facilities.

**STRATEGIES TO ACHIEVE OBJECTIVES**

• To develop health services to the district level in line with the on-going Local Government Reforms, so that communities are directly involved in the improvement of health services and infrastructure.

• To improve health services and infrastructure to both urban and rural areas by utilizing the available resources.

• To ensure adequate supply of drugs and medical equipment.

• To control diseases that crop up as a result of poor nutrition and environment.

• To improve operational research on the health care system and make use of research findings to improve health services delivery.

• Monitoring and supervision of health activities to the public/government facilities, including those by Non-Governmental Organizations (NGOs) and the private sector to be carried out by central government, regions and districts.

• Rehabilitation and maintenance of existing infrastructure, replacement and equipment health facilities and placement of qualified personnel.

• Gradual shift of government/public resources from curative to preventive services, massive campaign on control of communicable
diseases and strengthening of MCH services and health education on the importance of nutrition.

- Through cost sharing there will be additional funds to supplement Government efforts in supply of drugs and hospital supplies to health facilities. The user-fees will be revised to reflect the actual proportion of costs to be shared.
- To enforce existing rules and regulations that safeguard health services provision in general and in particular workers in industries and estate farms against health hazards.
- To continue training and retraining of health personnel at all levels. Emphasis will be put on correct strategies to ensure equal distribution of health personnel.
- To make follow-up and ensure that health Regions, Districts, NGOs adhere to guidelines, and private health facilities, which will be obliged to follow the standard, staffing levels recommended by MOH.

**To achieve health policy objectives in respect to resources, the policy therefore recommends**

- An increased role of the community in financing health services especially cost of curative services. Users’ fees will be enhanced in government health facilities and Ministry of Health training institutions, so that they render better health services.
- Encouragement of the private sector in providing health services and running of training institutions.
- Government concentrate on health services qualifying as public services, e.g. preventive health services that are not attractive to the private sector, but of interest to public e.g. health inspectors.

**PRIMARY HEALTH CARE STRATEGY**

Primary Health Care is essential health care, addressing the main health problems in the community, providing primitive, preventive, curative and rehabilitative services to all individuals and families with their full participation. It is an integral part of the country’s health system of which it is the central function and main focus.
It should be emphasized that PHC is a vehicle for implementation of the health policy. PHC is applied at the first level of control of individuals, the family and community with the national health systems, be at village health post, dispensary, health centre or hospital.

Primary Health Care must start with the community and in the community providing care as close as possible to where people live and work.

**SESSION III: CONCEPTS OF HOME BASED CARE**

**INTRODUCTION**

**HBC CONCEPT**

- HBC is perceived as assisting the individual, sick or well, in the performance of those activities contributing to health or its recovery or to a peaceful death. The individual can perform those activities unaided given the necessary, and adequate, strength, will or knowledge; and to do this in such a way as to help gain independence, as rapidly as possible.
- The scope of HBC involved continuous caring for chronically ill patients from the health care facility to the home.
- The environment is part of medical care and is linked to the health support and referral system.
- HBC shall be established at all levels in the district as part of existing health care system. The community has to be sensitized on the importance of these services and should own it.
- The main actors for implementing HBC services (care providers) shall be the family members who will be trained by the community HBC provider.
- The community HBC will continuously assist, support, supervises, monitor and evaluate HBC activities involving the patient and family members (the careers) as all stages of implementation of the caring model. The community HBC provider shall be a link between the patient/family and contact person stationed at a health facility.
- The contact person stationed at a health facility will train the community HBC provider to implement HBC guidelines. He/She will report to the contact person at district level, who will report to the
DHMT all HBC activities within the district including services provided by NGOs/Volunteers, and relatives of patients.

• The HBC provider (contact person) must have accepted qualities of the profession such as adequate knowledge and specific norms. She/He should adhere to the code of professional ethics related to HBC.

• The HBC provider (contact person) must be familiar with the National Health Policy guidelines and strategies relevant to HBC in Tanzania, while providing HBC services.

OBJECTIVES

By the end of the unit the trainee will be able to:

i. Discuss the concept of HBC
ii. Outline the roles and responsibilities of key actors in HBC
iii. Explain competencies of HBC provider
iv. Apply ethical standards in provision of HBC
v. Identify key qualities and characteristics of an effective HBC provider

SUMMARY OF CONTENTS

• Definition of HBC
• Philosophy related to HBC
• Scope of HBC
• Benefits of HBC
• Roles and responsibilities of key actors in HBC
• Competencies for HBC provider
• Quality assurance cycle related to competencies in HBC
• Ethical consideration in relation to HBC
• Qualities and characteristics of an effective HBC provider

TEACHING METHODS

• Brainstorming
• Lecture/Discussion
• Group work
• Plenary sessions
• Role plays
CONTENT

DEFINITION OF HOME BASED CARE
Home-based care is defined as any form of care given to chronically ill people in their homes. Such care includes physical, Psychological, social and spiritual activities (WHO/GPA, 1993)

PHILOSOPHY RELATED TO HOME BASED CARE

- Each person with HIV/AIDS and other chronic conditions is an individual with the right to appropriate skilled HBC, to meet his needs for alleviation of pain and to have real freedom of choice in his care. He has the right to a knowledge and understanding of his condition and problems to enable him and his family to make realistic choices. This person is to be given help and information so that he can understand and accept the treatment and care needed, including terminal care.
- The HBC provider has to work in partnership with the client, his family, relative and friends in order to help him maintain and improve health, comfort, and life satisfaction. It also includes helping with investigations, correct diagnosis, treatment and rehabilitation during the entire time of illness.
- The HBC provider must act as part of the family and community in promoting care of the patients, maintaining his independence and fostering his sense of identity and dignity.
- Assisting the patients has a peaceful and pain free death in the terminal stages of life.
- The home and community are to be utilized as appropriate resources and maintained at a level where all activities are focused on the central function of caring for the person living with HIV/AIDS or other chronic conditions.

Within the home – based care environment, it is recognized that, the needs of the patient in particular, the family and care provider is to develop their knowledge, skills and positive attitudes.

Interpersonal relationships of a positive nature is considered to be significant in the HBC and can be encouraged and nurtured to avoid stigma, managing pain – both physical and emotional. This can be achieved through constant training and support.
• Health care workers (contact persons, trainers and supervisors)
• Setting an example of clinical service and educational competence and continued evaluating these standards.
• Organizing the care providers, the community and family to attain their full potential and effectiveness in HBC services.
• Ensuring that HBC philosophy, procedures, policy guidelines and training objectives are adhered to.
• Controlling the costs of HBC and preventing wastage.

**SCOPE OF HBC**

HBC aims at providing a continuity of care for persons with chronic conditions and those living with HIV/AIDS from any level of health facility to the Home environment.

The elements covering the scope are:

- Continuity of services
- The family is the key actor in providing HBC services
- The community to formulate the sense of OWNERSHIP for HBC Services
- The health facility shall have one member of staff to act as “Contact /focal person”
- There will be a trained HBC supervisor at district
- Presence of community HBC Providers, these could come from the Government, NGOs or the community.
- The District is the main implementer of HBC services, it will integrate HBC into Other services.

**BENEFITS OF HOME BASED CARE:**

**To Patients**

- Permits them to receive care and treatment in a familiar, supportive environment
- Allows them to continue participating in family matters
- Maintains the sense of belonging in social groups
- Maximizes their emotional health
- Makes it easier for them to accept their condition
- Reduces medical and other related costs
• Death occurs at home amongst loved ones

**To the family**
• Strengthens family ties/attachment
• Helps the family to accept the patient’s condition
• Provides opportunity to learn about chronic illnesses
• Can reduce medical and other care related costs
• Makes it easier for family members to who provide care to PLHAs to attend other responsibilities.
• Involvement of the family in care enables the grieving process to be easier

**To the community**
• Promotes awareness about prevention of the infection, care and support of chronic illnesses
• Promotes awareness about prevention of chronic illnesses
• Helps the community understand the disease and to correct myths and misconceptions about chronic illnesses and therefore reducing stigma
• Encourages sustainability of care services
• Makes easier for the community to provide support

**ROLES AND RESPONSIBILITIES OF KEY ACTORS IN HBC SERVICES**
• The community should first see the need for ownership of the model. If there is not felt need then the community must be sensitized, motivated and encouraged to establish and sustain the HBC services by the District Health Management Team (DHMT).
• Several factors are likely to affect the provision and quality of HBC services. Such factors may be related to the patients, family, community HBC provider, health facility contact person, and community based organizations or groups involved in patients care. In order to get optimum benefits from HBC services, the players will be required to perform their respective roles as indicated hereunder:

**The Family Team**
1. **The Patient**
   A patient receiving HBC services will be expected to:
i. Take his/her medicines accordingly.
ii. Keep to the required visit schedules to the care and treatment clinics
iii. Report any complications and side effects
iv. Appoint an adherence assistant and keep in regular contact
v. Cope with the illness.
vi. Prevent transmission of their infections to others.
vii. Provide care and support for orphans and vulnerable children of the patient and families for HBC

2. The Family
Patients with chronic illnesses will to a large extent be cared for in their homes. Since hospital based staff will not be available to provide care to such patients on a full-time basis, family members are expected to take over the responsibility of providing care at home. Indeed it is envisaged that family members will be the main actors in providing high quality HBC services.

a) The family will be required to choose among themselves at least one person who will be trained on specific elements of care for their patient. However, it is essential that more than one family member knows about the general care of the patient so as to support each other and assure continuity of care in case the primary care provider is absent.

b) With the patient’s consent the family should be counseled about their patient’s illness and informed about the cause, signs and symptoms, treatment, possible complications and prevention. This should be done at the health facility where the diagnosis is made before referral for HBC

It is recommended that men in the households should be actively and directly involved in the care and nursing of the chronically ill and not to leave all the chores to women only.

The family needs to:

i. Provide the patient with adequate balanced diet
ii. Nurse the patient according to her/his prevailing condition.
iii. Prevent complications.
iv. Prevent transmission of infections e.g. HIV, PTB
v. Link with the community HBC provider for support and referrals.
vi. Alleviate pains as much as possible
vii. Provide comfort to the patient.
viii. Make sure that the patient takes his/her medicines according to doctor’s instructions.
ix. Make sure that the patient keeps his/her clinic appointments and observes medical advice appropriate for his/her disease.
x. Support the patient in order to avoid risk situations for infections and complications
xi. Provide emotional support and spiritual care to the patient.
xii. Provide care and support for orphans and vulnerable children

Requirements at the family/ household level.
- Patients take drugs according to prescription.
- Equipment (locally available) for avoiding infection.
- Disinfectant at the household (hypochlorite solution for households with AIDS patients).
- Food and other basic need of the patients.
- Physical exercises, fresh air and ambulation

3. The treatment adherence assistant
The adherence assistant is a person selected by the patient who assists the patient in ensuring that he follows the drug regimen as prescribed. The adherence assistant will discuss the needs of the drug regime with the HBC provider and the client and set up a routine that they can follow through. It is essential that the adherence assistant accept this task and be available and on hand at the required drug taking times. He/she may even assist in providing the drugs and water for the drug taking.

Chronically sick people who are on life-long medication need support in ensuring that they abide with drug schedules and clinic appointments. A close family member will be required to know the patient’s prescriptions and clinic visit schedules and constantly remind him/her to adhere to the same. The adherence assistant should also know and be known by members of the clinical care team and the home based care service provider.

4. The Community HBC provider.
i. Responsibilities of the HBC provider
The principal responsibility of the community HBC provider is to implement the HBC policy guidelines by:
(a) Providing health care support to families with chronically ill patients.
(b) Training families on how to care for the chronically ill patients including;
   • Nursing care
   • Feeding
   • Providing comfort.
   • Alleviating pain
   • Preventing infections.
   • Detecting complications and danger signs.
(c) Linking the family with the health facility and other relevant services in the community by reporting and referring patients.
(d) Reporting on the state of his/her patients to the health facility contact monthly
(e) Raising the community awareness on new developments concerning the chronic illnesses and prevention of infectious ones including HIV/AIDS and PTB
(f) Support the patient adherence to medication and clinic visit schedules

ii. Requirements for community HBC provider
The community HBC provider should be provided with a First Aid kit containing the following items:
• Simple reading materials on different diseases.
• Register for recording patients receiving HBC services.
• Stationery.
• Drugs and supplies as per HBC kit

iii. Qualification of community HBC provider
Community HBC providers will have access to sensitive and confidential information while performing their duties. In addition they will be expected to work under difficult conditions and for long hours. Consequently, only persons of sound integrity should be considered for the task. Communities are therefore advised to consider person with the qualities listed below:
• Should be based in the community she/he is going to serve.
• Should know how to read and write.
• Should be able to build good interpersonal relationships
• Should be interested in caring for sick people.
• Should be willing to volunteer.
• Should be accepted by the community he/she is going to serve.
• Should be reliable and does not easily despair.
• Someone who can maintain confidentiality.

5. **HBC Contact persons in health care facilities**

The facility based contact person for community HBC service providers should be stationed at the nearest health facility and would be expected to:

i. Educate and provide support to the family to implement the policy guidelines.

ii. Train the community HBC providers in their catchments areas.

iii. Follow up patients discharged from their health facilities and those from higher-level hospitals.

iv. Supervise patient’s adherence to ARTs

v. Supervise the Community HBC providers in their catchments areas.

vi. Raise awareness of the community and mobilize them for involvement in the provision of quality HBC services and stigma reduction

vii. Provide nutrition education to PLWHAs and their families

viii. Network with other health care providers in her/ his community.

ix. Keep patients records and report to the district contact person.

x. Participate in HIV prevention activities.

xi. Provide counseling services to the patients/ families.

xii. Train families to provide care and support to orphans and vulnerable children

**Requirements**

- Drugs as per recommended list.
- HBC guidelines.
- Supervision guidelines and tools.
- Training manual.

6. **HBC service organizations (FBO, NGO, CBO)**
Faith Based Organizations, Non Governmental Organizations and Community Based Organizations that have interest in providing care to chronically ill patients in the home environment should be encouraged to:

a) Provide HBC to chronically ill patients according to the national guidelines for HBC
b) Link with the health care facility HBC contact persons for referrals and supervision.
c) Provide counseling and spiritual support to patients/ families and communities.
d) Raise community awareness on various health issues and educate them accordingly, aiming at prevention of communicable disease including HIV/AIDS, STDs tuberculosis, leprosy etc.
e) Initiate and support efforts to reduce stigma and discrimination in the communities and families
f) Establish effective functional linkages and referral systems with other relevant institutions to create a conducive environment for a good continuum of care for patients

Religious leaders are often called upon to provide guidance, counseling and spiritual support to patients and families. Where appropriate such persons should be encouraged to:

a) Continue giving spiritual and emotional support and counseling to patients.
b) Continue sensitizing the community on health issues to keep them healthy.
c) Sensitize the community on the importance of supporting the sick through HBC services.
d) Refrain from claiming to cure AIDS through prayers.
e) Encourage patients to obtain medical care.
f) Continue providing social support.
g) Strive to reduce stigma and discrimination in the communities and the families

8. Administrative levels
i. The Central level – Ministry of Health
   i. Develop policies to ensure good quality care
ii. Develop the HBC policy guidelines and standards which will enhance the implementation, quality assurance and monitoring of the services.

iii. Develop and regularly review service guidelines for HBC services.

iv. Develop and frequently review training guidelines and manuals.

v. Develop mechanisms for effective linkages and referrals to enhance a continuum of care.

vi. Evaluate reports on HBC service provision aiming at its improvement from time to time.

vii Develop mechanisms for dissemination and feedback of new policy guidelines and standards

viii. Develop mechanisms for coordinating HBC implementing organizations and donors at central level

1. Advocate for improving food availability as an essential component of comprehensive care and support

2. Develop mechanism to address nutrition care and support for chronically ill including HIV/AIDS patients.

ix. Ensure pre-service training in HBC. The training on HBC should be incorporated/included in the training curriculum in medical, paramedical and nursing.

x. Integrating the Home Based Care into District Health Care System. This implies that these services should be part and parcel of the district health care delivery system.

Requirements.

- At least two experts of HBC at the NACP
- A Multidisciplinary Technical Advisory Team
- Monitoring and evaluation tools, protocols and plans
- Resources.

ii. The Regional Level.

The responsibility of the Regional Health Management Team (RHMT) will be to:

i. Interpret the HBC Guidelines and standards and ensure their implementation

ii. Co ordinate the link between the districts, Ministry of Health and Development Partners

- Monitor and evaluate HBC plans and budget in all the districts.
• Assess training needs for HBC contact persons in the districts.
• Ensure and maintain effective linkages and referrals for continuum of care
  iii. Supervise data collation, processing, analysis and utilization in all districts
iv. Maintain quality assurance of HBC
v. Prove HBC technical of support to districts
vi. Carry out operational research to improve on HBC services
vii. Compile HBC data, quarterly/annually and submit reports to the MOH and give feedback to districts
viii. Oversee the implementation of HBC guidelines in districts.
ix. Facilitate efforts for improving nutrition care and support for chronically ill including HIV/AIDS patients.

Requirements
• At least one HBC contact persons at the RHMT level (preferably, a medical officer or a nursing officer).
• HBC guidelines for service provision, training and supervision
• HBC sensitization campaigns
• Relevant monitoring and evaluation tools

iii. The District Level
Within the health sector reform policy, HBC services are planned to be integrated in the Primary Health Care programme. Therefore, the District Health Management Team will be responsible to:
  i. Implement the HBC policy guidelines
  ii. Integrate HBC activities in the council comprehensive health plans
  iii. Create awareness of the community on the need and importance of HBC aiming at their involvement.
  iv. Conduct a needs assessment and plan for HBC to be integrated in their health care delivery system.
  v. Establish an effective networking and referral system for the patients to benefit from a functional continuum of care at facility, community and household level.
  vi. Conduct the required training for personnel to ensure provision of effective HBC services in the district.
  vii. Support and ensure community involvement and participation.
viii. Regularly monitor and supervise the services
ix. Provide the necessary equipment, supplies, drugs and transport for HBC
x. Identify the health center/dispensary contact persons for HBC and monitor/supervise their work.
xii. Evaluate the service every two years aiming at its improvements.

- Allocate resources needed for HBC in the district.
- Compile and analyze HBC data quarterly and annually and submit reports to the region and give feedback to the health centers and dispensaries.
- Support activities directed at improving nutrition care and support of chronically ill including HIV/AIDS patients through:
  - Mobilization of community and partners for food provision.
  - Mobilization of resources for improving household food security for PLWHA.
  - Coordination and support of extension staff rendering support to households with PLWHA for improved household food security.
  - Insuring that food security for households with PLWHA and their family is a permanent agenda for the Ward Development Committee (WDC) meeting.

Requirements
- The HBC guidelines for:
  - Service provision.
  - Training of trainers and community HBC providers.
  - Resources for supportive supervision.
- Drugs and equipments for HBC services as per suggested list.
- Transport for supervision.
- HBC sensitization campaigns.
- Resource allocation for HBC
- Competent HBC personnel at least two for each health facility.

COMPETENCIES FOR HBC
The competencies for HBC provider, the trainer and supervisor shall be centre on the following:
i. Alleviating chronic pain.
ii. Managing different clinical conditions.
iii. Educating and supporting families on nursing care of their patients; and
iv. Counseling families and patients on managing pain, crisis and stress associated with HIV/AIDS and other chronic illness.
v. Identification of patients who require referral for further management and keeping records and providing reports using standard monitoring tools.
vi. Fostering network with other groups or organization for comprehensive care of the patient.

The DHMT shall train the health facility workers (the contact person for district and facility level).
The health facility worker shall train the community HBC provider
The community HBC provider shall train and support the family in providing care to their patients.

THE QUALITY ASSURANCE CYCLE FOR HOME BASED CARE SERVICES

The aim of the proposed cycle is to ensure that the services have a process for continuously improving the quality. The cycle should be reviewed annually, especially at the beginning of the HBC strategy for care of the chronically ill patients by the relevant DHMT and each health facility.
ETHICAL CONSIDERATION IN RELATION TO HBC

Ethics is associated with morality and professional conduct. Professional ethics in the health sector in the context of home based care activities require the actors to perform their activities in accordance with health professional requirements in a community context. The ethics deal with the methods employed in the process of executing activities in the communities. In doing HBC services to chronically ill patients, it is absolutely necessary to abide with following ethical requirements:

(a) Confidentiality.
(b) Respect of other people.
(c) Commitment to work on HBC
(d) Reliable person.
(e) Ability to recognize ones limitations and seek support where necessary.
(f) Respect and cooperate with professional orders.
(g) Should work within the existing legal framework
QUALITIES AND CHARACTERISTICS OF AN EFFECTIVE HBC PROVIDER

- Knowledgeable in HIV/AIDS and other chronic illnesses
- Competent in his/her work
- A good listener
- Empathetic and understanding
- Accepts differences in people, tolerance, and good will.
- Flexible and genuine
- Respect other peoples opinions and professions
UNIT 2:

HOME BASED CARING MODEL

INTRODUCTION
In giving care to anyone there are principles of care, which, if adhered to, ensures appropriate care in a given situation. In HBC, a model has been derived where by the HBC provider be a professional, a family member or a community volunteer can follow and provide appropriate and quality care to the client/patient. This is known as the “Caring Model”.

OBJECTIVES
At the end of the unit the learners will be able to: -

i. Describe the process of caring model
ii List categories of patients for Home Based Care
iii Mention the common procedures done in HBC services
iv Explain ‘Quality Care’ and its components.
v Explain the role of HBC provider in supporting prevention and mitigation approaches.

SUMMARY OF CONTENTS
- Caring model process
- Categories of patients for HBC
- Common procedures in HBC
- Definition of quality
- Definition of quality HBC
- Components of quality care
- Continuum of care
- Referral and networking

TEACHING METHODS
- Brainstorming
- Lecture/Discussion
- Group work
- Buzzing
- Role plays
• Demonstration
• Simulation

CONTENT

THE PROCESS OF THE CARING MODEL

The caring model should be used to identity and solve the problems of persons with HIV/AIDS and other chronic illnesses.

The process of caring has the following 4 steps:

i. Assessment.
Assess the patient’s health status/condition in order to identify his/her needs and problems (physical, psychological, social and spiritual) and detect what is not normal.

This is done by:
- History taking
- Physical examination (head to toe examination)
- Using the observation skills

ii. Planning
After identifying the needs and problems:
- Set objectives of care
- Plan patient’s care in priority order and involve him/her and family members in planning care and decisions making.

iii. Implementation
- Implementing the planned decision (care) involving the patient and the family.
- Use of the principles of care to provide the basic nursing care to the patient based on the needs and problems of individual patient. The needs may be physical, psychological social and spiritual.
- The HBC provider/caregiver should remember that he/she is caring for a person, not just a body. Their feelings (patients) and important. Since every person is different, there are no rules about what to do or say. Here are some ideas that may help:
  - Respect the patients’ independence and privacy
  - Keep them involved in their own care, don’t do everything for them or make all their decisions. No body likes feeling helpless
- Have them do what they can. Everybody likes to feel useful; they want to be part of the group and contributing what they can.
- Include them in the household e.g. make them part of the normal talk. Many people will want to feel involved in the things that are happening around them.
- Talk about things. Sometimes patients may need to talk about their own situations/illness e.g. AIDS as a way to think out loud.
- Having chronic illnesses such as AIDS can make a person angry, frustrated depressed or scared. Listening, try to understand; showing you care and helping them work through their emotions is very important in HBC services.
- Meeting all the patients’ needs, physical, psychological, social and spiritual is of prime important in HBC.

iv. Evaluation
- Evaluate the care given using the objectives set
- If objectives are not met, why and then re-plan.

CATEGORIES OF PATIENTS FOR HBC
Patients living with HIV/AIDS and other chronic illnesses may be categorized into 5 categories
- Living well with HIV/AIDS and taking ART
- Those who can perform full range of activities
- Those who can perform limited activities
- Seriously ills and confined to bed
- Terminally ill
From the above categories, the care required differs;
- The patient who is completely independent requires no or minimal caring help
- The patient who is totally dependent requires maximum caring help

COMMON PROCEDURES/ACTIVITIES DONE IN HBC
- Observation of vital signs (temperature, pulse, respiration)
- Bed making and methods of changing bed linen
- Positions used in nursing
• Keeping the patient’s environment clean and safe
• Bed bath, Oral hygiene, care of hair and nails
• Prevention of pressure sores
• Feeding of helpless patients
• Wound dressing
• Administration of oral medicines
• Providing exercises (active and passive)
• Elimination maintaining bladder and bowel integrity
• Recreation
• Providing rest and sleep
• Giving Health Education
• Recording and reporting

Definition of Quality
Quality can be defined as a measure of how good something is. Something has quality if the object or the service meets or exceeds the expectation of the user.

Meaning of quality HBC
The word Quality is used as a judgment of excellence in various situations. It can also be considered as doing the best with available resources, or expressed as doing the right thing in the right way at the right time.

Components of Quality Care
There are 10 components of quality.

i. Policy: The government has the responsibility of protecting the public from poor-quality. Therefore it has to have sound policies to protect the poor, unprivileged and the risk groups as one aspect of quality of care.

ii. Technical competence
This is the knowledge and skills which a health worker needs to have in order to do a good job. These are obtained through formal training, experience, on the job training and in continuing education.

iii. Efficiency
Efficiency refers to using the minimum amount of effort or resource needs to achieve intended results. It involves making the best use of the available resources. Efficiency minimizes wasted time, drugs and other materials.
iv. **Interpersonal relationship**
The working relations between health workers, managers, patients, community and other sectors affect the quality of service provided. Good interpersonal relationships are essential in health services to build respect, confidentiality, trust, credibility, courtesy, responsiveness and empathy.

v. **Effectiveness**
Effectiveness is achieving the intended results (from the planned objectives). Since quality is measurable, methods of determining effectiveness are important as a way of monitoring performance.

vi. **Access to service**
This refers to the proportion of the people in a catchments area who are able to utilize the services e.g. in HBC:

- Some people may not be reached because of long distances from a health facility, the existence of bad roads, rivers, and mountains etc.
- Cultural barriers due to cultural beliefs and attitudes
- Attitudes of the community HBC providers who may negative attitude and lack confidentiality.
- Ignorance community should be educated on the HBC services provided

vii. **Continuity**
A good referral system, good record keeping, and keeping the patient informed about their conditions help to maintain continuity of care.

viii. **Safety**
HBC activities should be safe and able to produce desired results. The HBC provider must consider the safety of the patients, communities and themselves. The HBC provider should make correct diagnosis, give correct treatment and prevent cross infection while providing care to patients.

ix. **Acceptability**
Acceptability is interpersonal relationship. The patients, family and community will accept the services provided if there is satisfaction of the care given.
The attitude of HBC provider and time spent will influence the acceptability and utilization of the services.

x. **Equity**
There are two dimensions in ensuring equity in health care i.e. the issue of density and geographical distribution of health services. In HBC equity should be considered for all citizens irrespective of their gender orientation, color, race, income and social status.

**CONCEPT OF CONTINUUM OF CARE**

People with HIV infection and AIDS have many needs and concerns during their illness. These begin right from the time they are diagnosed with HIV to the time they develop AIDS and succumb to the disease. The range of their needs is so vast that they can only be adequately met within a multi-disciplinary approach.

To meet these varied needs the concept of comprehensive HIV/AIDS care across the continuum has been advocated and promoted by World Health Organization (WHO)

**DEFINITION OF CONTINUUM OF CARE**

**Definitions:**

*Continuum of care* refers to comprehensive holistic care, which includes care from Home and Community to institutional services and vice versa. Continuum of care involves a network of resources and services that provide comprehensive care and support to the ill person and the family care giver. Comprehensive care involves the provision of care, treatment, nursing care, support and preventive services as well as referral.

Within the continuum of care, the health sector aims to achieve the following objectives:

- To train home and community care providers and support them through at least monthly visits to ensure provision of quality clinical and nursing care to AIDS patients,
- To mobilize resources (human and material through organizations and individuals) and coordinate them towards providing care of AIDS patients and their families,
To ensure that community organizations and families are involved before the patient is discharged for care in the community/home, and to encourage referral back to health institutions where indicated.

**PRINCIPLES OF CONTINUUM OF CARE**

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

- **Respect**: for human rights, ethics, confidentiality, informed consent, Privacy and individual dignity. Fighting discrimination enhancing respect of individual autonomy and human dignity are all of paramount importance in HIV care and support.
- **Equity**: affordable care of acceptable quality should be provided to all people regardless of gender, age, race, and ethnicity, sexual identifies level of income and place of residence.
- More attention should be given to those groups of population that have more problems to access care e.g. widows, orphans, women, youth/children, the elderly and the uneducated and the poor.
- **Quality Care**: Care should be of good quality; interventions and services have maximum benefit if they are of good quality. Quality of services can be measured in terms of the nature of services provided and in specific interventions. Their measures of quality services include indicators such as waiting time, attitude of health workers and type of facilities available. Crucial to ensuring quality care is provision of care by trained care providers.
- **Efficiency and Effectiveness**
  Care should be provided at reasonable societal cost. Resources invested should be result oriented and there should be corresponded concrete quantifiable results. Efficiency considerations fuel the need to co-ordinate and integrate health systems so as to ensure the continuity of service delivery among different provider and different levels of care.
- **Accessibility and availability**
  All levels of the health system should make care accessible to as many people as possible. The provision of care appropriate to the
resources available and levels of HIV prevalence need to be decided through local consensus. Building that involves the whole community. This requires regular review with stakeholders.

**Sustainability**

Initiatives in provision of care and support will remain meaningful and other principles of cure and support will only be viable where they are embedded in a sustainable program of provision. Thus there is a need to put into account human, logistics and financial resources requirements.

**ELEMENTS OF COMPREHENSIVE CARE AND SUPPORT**

HIV/AIDS comprehensive care consists of four interrelated elements that respond to the medical, psychological, socio-economic and legal needs of people and families affected by HIV, as illustrated in the figure below.
**ESTABLISHING AND MAINTAINING NETWORKS AND REFERRAL**

**INTRODUCTION**

Effective referral systems are required to ensure that PLWHA and those affected can benefit from the variety of services that comprise comprehensive care and support throughout the course of infection and disease. Therefore, timely information on where to seek services and strong referral linkage among the various services partners will ensure a continuum of care, avoid duplication of services and maximize available care and support resources.

**DEFINITION:**

**Referral:** Is a process of transferring a person from one place to another according to his/her problems or needs for further assistance.

**Networking:** Is an individual contact (circled) between and branched out.

**Referral involves 4 steps**
1. Identify the need to refer
2. Evaluation/identifying referral resources
3. Preparing the client for the referral
4. Coordinating the transfer.

**Issues to consider during discharge**
1. Discharge card should be issued to all discharged patients. The discharge should contain necessary and adequate information that is understandable to those who will be caring for the patient without violating the patient’s confidentiality.
2. The patient’s discharge should be documented in the discharge register and should contain the date of discharge, condition on discharge, where discharged to and name of discharging officer.
3. The patient should be referral back to his/her home catchments health facility as well as to the community HBC provider.

**V. Criteria for referring patients to a higher level**
i. Within the district health care delivery system one should make sure that referral for chronically ill patients fulfils the followings:-
   1. Referring facility is unable to provide required care
   2. There is an agreed system of referral within a district.
   3. The referred individual is treated preferentially.

ii. General criteria for referral to higher level
   1. Patient whose condition is deteriorating.
   2. Patient’s condition does not improve despite treatment.
   3. Emergency conditions which need surgery or specialist attention.
   4. If the diagnosis cannot be established.

iii. Private referral
   1. Nearly all referrals to private health facilities are self referrals
   2. Private hospitals should be encouraged to discharge their patients to HBC services. Referral from HBC to a private health facility will depend on the patient’s request. For those who cannot pay for their back referral to a private facility should be referred to the nearest public health facility. If any of the criteria in the right hand column occur, the chronically ill patient under care of the HBC provider should be referred to the higher level.

Networking for home based care
People living with HIV/AIDS (PLHA) and their survivors have a variety of needs beyond those requiring provision of clinical care. Other needs include psychological, spiritual, nutritional, educational, economic and legal. Since no one organization may be able to provide all the care comprehensively, it is essential that a network of care and support organizations should be established and strengthened in every community (See the diagram below). The main strategy for achieving continuum of care is the forging of partnerships and networks of stakeholders at community and higher levels. The capacity of all partners and network members in the planning, providing and evaluating the complementing services will need to be strengthened according to identified gaps. Respective councils will need to include care of AIDS patients in their plans, and encourage the participation of the
communities in order to enhance sustainability, integration, co-ordination and ownership.

The following diagram illustrates the type of care and support services and the referral networks in the community.

Diagram 1: Active Referral Network in community home based care
UNIT 3:
BASIC FACTS ABOUT HIV/AIDS/STIs

INTRODUCTION

THE SITUATION OF HIV/AIDS EPIDEMIC GLOBALLY AND NATIONALLY

The global HIV/AIDS situation:
Due to the nature of the disease, accurate figures for the prevalence of HIV infection do not exist, and all figures are estimates and most of them are based on hospital statistics.

Globally, about 40 million are living with HIV/AIDS, with 5 million newly infected and 3 million deaths occurred in 2003. 25 to 28 million (about 70%) are from Sub Saharan Africa.

THE AIDS SITUATION IN TANZANIA

- Tanzania has been hit hard by the HIV/AIDS epidemic affecting almost all sectors.
- Since 1983 when the first 3 AIDS cases were reported, the HIV epidemic has progressed rapidly and extended to all regions variably in various population groups. Early in the epidemic, urban populations and communities located along highways were most affected. Recently, the epidemic has rapidly spread to rural area too.
- According to the Ministry of Health, a total of 12,675 cases were reported to the NACP from 21 regions during the year 2002 resulting into 157,173 reported cases since 1983. Estimating that only 1 in 5 AIDS cases is reported, the Ministry of Health estimates that a total of 63,375 cases may have occurred in 2002 alone. A cumulative total of 785,865 cases since the beginning of the epidemic.
- The main mode of transmission is heterosexual accounting to 85% of all cases, mother to child transmission ranking second (6%).
Most cases fall within the age group 20 – 49, with the highest number reported in the age group 25 –34 for females and 30 –39 for males.

- Of all cases diagnosed 56% were married and 25% were single.
- Antenatal clinic sentinel surveillance data available from 24 in six regions indicated that the overall prevalence in these regions was 9.6%.
- The overall HIV sero-prevalence among blood donors in 2002 was 9.7%.

According to the Ministry of Health using the prevalence among blood donors and the 2002 census to estimate the burden of HIV infection in Tanzania mainland, a total of 1,894,160 individuals (791,318 and 1,102,842 females) aged 15 years and above were living with HIV in Tanzania during the year 2002. Increased vulnerability to the infection among women and youth continue to be observed.

**OBJECTIVES:**

By the end of the session the HBC providers should be able to:-

(i) Describe the terms HIV / AIDS
(ii) Explain the magnitude trends, pattern and impact of HIV/AIDS epidemic
(iii) Determine the main stages and main clinical features of HIV infection according to WHO Classification
(iv) Describe modes of transmission
(v) Mention the methods of preventions.
(vi) Discuss and correct misconception about HIV/AIDS

**SUMMARY OF CONTENTS:**

i) Definition of HIV/AIDS
ii) Overview of HIV/AIDS situation
iii) Magnitude, trends, patterns and impact of HIV/AIDS Epidemic
iv) Clinical stages and major and minor signs of HIV infection
v) Mode of transmission
vi) Diagnosis of HIV/AIDS
vii) Prevention and control of spread of HIV/AIDS.
viii) Common myth and misconception about HIV/AIDS

TEACHING METHODS

- Brainstorming
- Lecture/Discussion
- Group work
- Plenary sessions
- Role play

CONTENT

Definition of HIV/AIDS

HIV stands for: -
Human - in the body
Immune - deficiency lack of defense against diseases
Virus - Germ/micro – organism causing infectious diseases.

HIV is the name of the Virus, which causes AIDS.
Viruses are smallest living organism. They are parasites and can only reproduce themselves inside the cells of another living organism.

To be infected with the virus means: -
You have the virus in your body
You can always pass the virus to others
You can look and feel healthy until you become sick with AIDS and this might take many years.

AIDS Stands for:
Acquired - something you get from another source
Immune - protection against diseases – immune system
Deficiency - a lack of
Syndrome - a group of different sign and symptoms

Clinical stages of HIV infection

The clinical manifestations of HIV/AIDS are classified into 4 stages as follows:

1. **Clinical Stage I**
Asymptomatic
Persistent generalized lymphadenopathy (PGL)

2. **Clinical Stage II**
Weight loss <10% of body weight.
Minor mucocutaneous (seborrheic dermatitis, pruritis, fungal nail infections, and recurrent oral ulcerations, angular cheilitis)
Herpes Zoster, within the last 5 years.
Recurrent upper respiratory tract infection (i.e. bacterial sinusitis)

3. Clinical Stage III
Weight loss >10% of body weight.
Unexplained prolonged diarrhea > 1 month.
Unexplained prolonged fever (intermittent or constant) > 1 month.
Oral candidiasis (thrush).
Pulmonary tuberculosis within the past year.
Severe bacterial infections (i.e. pneumonia, pyomyositis).

4. Clinical Stage IV
HIV wasting syndrome
Pneumocystic carinii pneumonia
Toxoplasmosis of the brain.
Cryptospodiosis with diarrhea > 1 month.
Cryptococcosis extra pulmonary.
Cytomegalovirus (CMV) disease of an organ other than liver, spleen or lymph nodes.
Herpes simplex virus (HSV) infection mucocutaneous >1 month or visceral any duration.
Non-typhoid salmonella septicemia.
Extra-pulmonary tuberculosis
Lymphoma.
Kaposi’s Sarcoma
Candidiasis of esophagus, trachea, bronchi or lungs.
Atypical mycobacteriosis, dissemination.
HIV encephalopathy.
Major sign/symptom of AIDS:
Fever for more than 1 month
Weight loss – more than 10% of body weight.
Diarrhea for more than 1 month.

Minor sign/symptoms of AIDS.
Cough for one month without evidence of TB.
Generalized pruritis dermatitis
Herpes zoster
Oral pharyngeal candidiasis (oral thrush)
Generalized lymphadenopathy
Cancer – Kaposis sarcoma
Neurological symptoms – such as confusion.

Children experience similar symptoms but in addition they have:
Failure to thrive
Repeated common infections like car infection and pneumonia
Most children infected will be symptomatic within 3 years of life.

Modes of transmission: -
The leading modes of HIV/AIDS transmission are:
Sexual intercourse with infected person (whether anal, vaginal oral)
Blood transfusion with infected blood.
Infected Mother to Child during pregnancy delivery and breast-feeding.

Risk factors and practices that contribute to HIV infection include:
Un protected sex:
Having multiple sexual partners
Presence of STD (Genital sore or discharges),
Use of alcohol and drugs
Receiving un screened blood for transfusion
Cultural issue e.g. wife inheritance
HIV infected mothers infecting the unborn child.

Prevention of HIV/AIDS infection:
Prevention of HIV infection depends on the mode of transmission as elaborated below:

1. Preventing sexual transmission:
Abstaining
Having one faithful, none infected partner.
Exercising safer sex practices such as using a condom, engaging in non-penetrative sex etc.

2. Preventing infection through blood transfusion and blood products:
Blood received for blood transfusion should be tested for HIV.
Needles syringe, razor blades and other skin piercing instruments should not be shared or should be sterilized after each use.
Use of gloves when dealing with infected materials, blood and secretions as well as making proper disposal of used materials should be practiced.
Blood transfusion should be limited to patients where the procedure may be life saving. Infections should be avoided wherever possible; instead, tablets should be used.

3. Preventing infection from mother to child.

Preventing pregnancy is the most effective way that an infected women can be sure of not passing the virus to her unborn child. Tanzania has already embarked into an effort to provide anti retroviral drugs to prevent mother to child transmission (PMTCT programs). There are plans to establish these services to all antenatal clinics in the country. Where the services have been established all to HIV positive pregnant mothers should be put in the regiment.

Administration of Anti retro viral to newly born babies also helps.

HIV positive women should be counseled on breast-feeding.

Laboratory diagnosis of HIV infection.

Testing of the presence of antibodies to the HIV virus confirms the diagnosis of HIV infection.

The widely used tests include:

Rapid tests that give same day results, such as capillus and determine 1 & 2. Elisa. This is conducted when the tester has more than 9 samples at a time.

Western blot – this is a Confirmatory test that is used to confirm the results.

Myth and misconceptions about HIV/aids

**HIV infection is not transmitted through:**

Mosquito bites or other insect bites)
Shaking hands
Coughing or sneezing of an HIV infected person
Sharing food with an infected person
Sharing toilets, bath room showers with an HIV positive person
Traveling on buses or taxis with HIV infected persons.
Sharing swimming pools with HIV infected persons
Hugging of social Kissing on HIV infected person
Sharing cups, cutlery, with an HIV infected person.
Witchcraft.
UNIT 4:
COMMUNICATION SKILLS

INTRODUCTION
The ability to develop trustful and cooperative relationship with other people and to exchange information without misunderstanding are the skills that are very important for a Home Based Care provider to develop and use. Daily, clients and their families need supporting interpersonal relationship that are genuine, respectful and are based on accurate understanding of their needs.

HBC providers spend a great deal of their time with clients, patients and families as many situation seek, examining a sick patient, giving an educational talk, counseling a client, explaining the proper use of medications talking to a community group about sanitation, supervising CHBC, each of these groups involves some kind of face to face communication.

OBJECTIVES
- Define communication
- Explain components of communication
- Explain the types of communication
- Identify barriers to effective communication
- Explain the points to consider in giving and receiving feedback
- Explain skills in establishing interpersonal relationship with patients
- Manage communication in difficult issues/situations
- Demonstrate skills in planning conducting and evaluating client education sessions

SUMMARY OF CONTENTS
- Definition of communication
- Components of communication
- Types of communication
- Barriers to effective communication
• Giving and receiving feedback
• Skills in establishing interpersonal relationship
• Dealing with difficult issues/situations
• Skills in planning conducting and evaluating client education session

TEACHING METHODS
• Brainstorming
• Lecture/Discussion
• Group work
• Plenary sessions
• Role plays
• Demonstration

CONTENT
Definition
Communication is a process in which people affect one another through exchange of information, ideas and feelings.
Interpersonal communication involves sending and receiving messages between two or more persons.

Purpose of communication
• Allows a Home Based Care provider to establish maintain and improve contacts with clients
• Establishes interpersonal relationship and allows individuals to associate
• It is a process that enables the HBC provider to establish a working relationship with the client and eventually help him met his health care needs
• Creates relationship with other professionals.

Basic elements of communication process
• Sender
• Message
• Channels
• Receiver
• Feedback
• Interpersonal variable such as gender, emotions, educational level etc.
MODES OF COMMUNICATION
Verbal communication- (spoken or written words)
Non-verbal communication- (gestures, facial expression)

BARRIERS TO EFFECTIVE COMMUNICATION
- Differing perception
- Language differences
- Emotional reaction
- Distrust

TIPS FOR EFFECTIVE COMMUNICATION
- Clarify own attitudes and feelings towards the issue being communicated
- Know your subject or issue in details
- Speak clearly and with confidence
- Emphasize and repeat important points in order to convince the other person
- Where appropriate use participatory approach, let the other person contribute his feelings and understanding
- Make the person being addressed feel important, and that they have the power to make a difference

GIVING AND RECEIVING FEEDBACK
The following points needs to be considered:
- Establish rapport
- Maintain Privacy
- Give timely feedback
- Provide descriptive objective feedback .not judgmental
- Use what how and not why
- Feedback is clear and straight to the point
- Uses specific statement supported with specific examples
- Provide both positive and negative feedback as necessary

SKILLS IN DEVELOPING INTERPERSONAL RELATIONSHIP
- Listen actively
• Empathize
• Be honest
• Be genuine

STEPS TO IMPROVE INTERPERSONAL COMMUNICATION WITH PATIENTS AND FAMILIES
• Slow down- communication can be improved by speaking slowly.
• Use plain, non medical language
• Show or draw pictures-visual image can improve patients recall of ideas.
• Limit the amount of information provided, and repeat it. Information is best remembered when it is given in pieces that are pertinent to the task at hand. Repetition further enhances recall.
• Use the teach-back or show-me technique
• Create a shame-free environment.

CLIENT EDUCATION SESSION
Client education is the part of health care that is concerned with promoting healthy behaviour.
A person’s behaviour may be the main cause of a health problem, but it can also be the main solution. Client education helps individuals to understand their behavior and how it affects their health. Client education encourages behavior that promotes health, prevents illness, cures disease, and facilitates rehabilitation.
Correct information is certainly a basic part of client education, but client education must also address the other factors that affect health behavior such as availability of resources.
Target group for client education session is patients, families and the community.

Steps in conducting client education session
• Identify educational needs of patient and family
• Set educational goals for patient and family
• Select appropriate education methods to meet each educational goal set for patient and family.
• Carry out the educational program
• Evaluate patient and family education
UNIT 5:
COUNSELING

INTRODUCTION
• While teaching this unit the facilitator should keep in mind that some patients receiving HBC services have already received pre and post counseling on HIV/AIDS. There may be some with chronic conditions (diseases) e.g. cancer, stroke with paralysis, and diabetes who have also been counseled on their conditions but need supportive counseling for existing problems/complications of their disease. However, pre test and post-test counseling may be required for new cases.
• A qualified counselor may be invited to come and teach this unit (as an area of her/his specialty).
• The counselor/or HBC provider should be knowledgeable on HIV/AIDS and other chronic illnesses, and should use counseling skills in giving accurate information on diseases to avoid causing unnecessary anxiety to the patient and family.
• Confidentiality is the cornerstone of counseling

OBJECTIVES
1. Define and differentiate counseling and advice
2. Mention types of counseling
3. Explain roles of HBC provider in counseling
4. Identify key qualities and characteristic of an effective counselor
5. Explain the different counseling techniques
6. Describe counseling technique for children
7. Describe psychological needs of a person living with chronic illnesses
8. Demonstrate key client-counselor interacting skill.

SUMMARY OF CONTENTS
• Definition of counseling
• Types of counseling
• Roles of HBC provider in counseling
• Qualities and characteristic of an effective counselor
• Counseling techniques
• Counseling technique for children
• Psychological needs of person living with HIV/AIDS
• Key client-counselor interacting skills

TEACHING METHODS
• Brainstorming
• Lecture/Discussion
• Group work
• Plenary sessions
• Testimonies
• Video shows
• Demonstration

CONTENT
DEFINITION
Counseling is a helping relationship, which is characterized by a face-to-face communication in which the client is helped to identify, clarify, and able to make informed decision. HIV counseling is a confidential dialogue between a client and a counselor aimed at enabling the client to cope with stress and make personal decisions related to HIV/AIDS. The counseling process includes evaluation of the personal decisions related with HIV/AIDS transmission and with such as testing for HIV or to resolve his/her own problems.

TYPES OF COUNSELING
• Individual counseling
• Client centered
• Counselor centered
• Family counseling
• Group counseling
• Couple counseling
• Nutritional and dietary counseling
• Supportive counseling
• Pre-test counseling
• Post-test counseling
- Coping with loss and bereavement

**The role of HIV counseling:**
- Giving information on HIV/AIDS to clients and their partners.
- Encourage preventive behaviors
- Helping the HIV positive clients and those close to them to cope with the diagnosis
- Discussing decisions that need to be made, according to the client’s life circumstances
- Referring clients to appropriate treatment and care services.

**Counseling concepts:**

**Counseling is not:**
- Giving advice, because advice is one way while counseling is two way interaction
- Counseling is not health education, because information provided during counseling is tailored towards the clients needs.
- Counseling is not conversation, nor is it interrogation. The client is not questioned to find the truth but to guide the client to understand the situation and take appropriate action.

**Elements of good counseling:**

Ample time

Providing the client with adequate time in order to build relationship

Acceptance

Counselors should be non judgmental. They should accept clients regardless of their socio-economic status, religion, occupation or personal; relationship.

Accessibility

Clients must be made to feel that they can ask question or call on the counselor any time.

Confidentiality

The client must trust the counselor, and belief that the information released will be kept in confidence.

**Basic counseling skills:**

Interpersonal skills:
Establishing rapport with the client. This demonstrates trust. This is facilitated by:

- Respect and lack of judgment
- Presence of common complementary goals
- Mutual trust

The role of the counselor is to:

- Identify the person’s strengths and resources and capitalize on them in encouraging them to continue to live productive lives as much as they are able to.
- Refer the person for services that the counselor or the health facility is unable to provide, such as financial, legal, education and other material support.

COUNSELING TECHNIQUES

- Joining
  This is establishing a relationship with the client. It is a process, which starts when a counselor meets a client and it continues right through the sessions.

- Listening
  Every client has a story to tell and the way you respond effectively depends on how you listen. It involves attending carefully to the client’s verbal and not verbal messages.
  Listening occurs in two parts:
  - Listening to contents: this involves listening to the story as the client is giving it to you.
  - Listening to the process: this involves listening to the feelings, concerns, worries etc.

- Empathy
  Is an ability to see between the words through the other’s eyes without judging them. One can only empathize when he/she has listened to the other’s story and understood it.

- Questions
  This is the primary tool counselors use to obtain information or seek clarification. There are two types of questions.
Closed questions – These demand short or one word answers e.g. what is your name? Where do you live? Are you married? etc.

- Open-ended questions- they demand long explanatory answers. These are the best to use in a session because they allow the client to talk more and also come up with their own solutions.

- Clarifying
  Counselor checks his/her understanding of what the client has said by seeking clarification e.g. Are you saying that.......?
  Never make assumption in counseling, always seek to clarify. If you are not sure of the meaning check it out.

- Commenting on the process
  This is a way of shifting out the less relevant material and also summing up the client’s main concerns or issues discussed so far.

  - Widening the system
    When people are in crisis they usually forget the other people who can be there for them. Thus, widening the system is looking for support from any of the give systems surrounding a person.

  - Taking a one down
    This is a way to acknowledging the client’s expertise in a certain area e.g. after talking to a person for 30 minutes; a counselor cannot become an expert on the client’s family or culture etc. A good counselor would take a one down and say something like how are such problems solved in your family or according to your culture?

Use of exceptions
Usually when there is a problem, it is not present 24 hours a day. There are times when it does not happen. When exceptions have been identified, what would be happening when the problem is not there? Can the exceptions be simplified in order to eliminate the problem?

- Externalizing
  Very often when we speak of a person with a problem, we attach a problem so firmly to a person that we make that person the problem, i.e. we often speak of an alcoholic, a schizophrenic, a bully, a delinquent, a bed wetter a liar etc.
  In counseling, the counselor should externalize the problem by always talking about it as something separate from the client’s e.g. the problem is the problem and not the person.

- Enactment
This is a technique used to make a counseling session different from merely a talking session and is done by asking the client to act or show what happens when the problem arises. Clients can be asked to act out both the problem situation and the solution. Enactment gives the counselor and the individual considerable information and helps in the formulation of intervention strategies.

- **Reframing**
  
  Involves taking a set of events described by the client and giving them back in a different frame. A reframe is best regarded as a different perspective rather than the truth. The aim is to shift the client’s view but not necessarily to make him/her accept the counselor’s opinion.

- **Normalizing reframe**
  
  This involves normalizing pathology for the developmental difficulties.

- **Coping reframe**
  
  This is news of a difference. Counselor picks up small things that the client did well and praises him/her for it.

- **Positive innovation**
  
  Counselor commends the individual or family for coming to seek help.

- **Scaling**
  
  Instead of asking clients to describe intensity of feelings or behaviors’ scaling is best done using the hand show e.g. “Last time you were this angry, show me how angry you are today”. With adults it is better to use a number scale of 0-10 where 0 is not angry at all and 10 is extremely angry.

- **Empty chair**
  
  Empty chair technique is used to symbolically bring in an absent member of the family to significant persons. The counselor might say to the client, “If your husband was sitting in this chair, what would you say to him? How would he respond to that? or if Mr. Kassim was sitting in that chair how you do think he would respond to what you have just told me? The empty chair helps the counselor to hear the voices of the absent people.

- **Use of silence**
  
  A counselor needs to be comfortable with silence. Silence forces the clients to speak and share more. When a counselor poses a question and the client does not respond immediately, the temptation is to simplify the question or ask another one.
COUNSELING IN CHILDREN

Counseling in children is different from that of an adult. When counseling a child the following should be considered:

- Use language and concepts that are appropriate to their age
- First ask them what they are thinking and discuss what they understand about HIV/AIDS.
- Use words, pictures, drawings and role-plays
- Be direct and use language they can understand
- Ask them if they have any questions they would like to ask
- Ask them to draw a picture about it. This may help you to understand what they are thinking and their reaction. A lot can be learnt about how a child is feeling by listening to them and at the pictures they draw.

KEY CLIENT- COUNSELOR INTERACTING SKILL

- **Basic skills**
  - Relationship building
  - Exploration
  - Understanding
  - Action plan

- **Use of confidentiality and ethical consideration in counseling**

Confidentiality has two meanings:

i. It means privacy. e.g.
   - The right to protect from:
     - Physical search, or
     - Use of picture for advertising without consent
     - To control information about oneself by:
       - Restricting or preventing date collection
       - Restricting the use of personal information, and
       - Imposing obligations of confidentiality to prevent unwarranted disclosure of collected information.

ii. Confidentiality also means:
   - The obligation owed by one person to another, not to disclose information given by or about another or the obligation to disclose it only in limited circumstances.
LIVING POSITIVELY WITH HI/AIDS
Counseling of persons with HIV/AIDS is very important. The objective of counseling is to assist an individual with HIV/AIDS understand the problems he/she has and find ways and means of facing it. It also assists the individual to make the correct and best decision on how to continue living with the problem positively after accepting the situation. Proper counseling helps the affected person in reducing the psychological and physical effects, which would otherwise increase stigma.

CHARACTERISTICS OF PERSON LIVING POSITIVELY WITH HIV/AIDS
- Not blaming anyone for the problem he/she has
- Not feeling guilty or ashamed
- Having positive attitude towards one-self and others
- Following medical advice by seeking medical care quickly in case of infections such as bronchitis, thrush and skin sores.
- Eating plenty of foods rich in protein, vitamins, mineral and carbohydrates
- Getting enough sleep and not getting overtired
- Taking enough exercise to keep fit
- Continuing to work, if possible
- Occupying oneself with different activities
- Receiving both physical and emotional affection
- Socializing with friends
- Receiving counseling to maintain positive attitude express his/her feelings, whether angry, sad, blaming or hopeful.
- Always using a condom during sexual intercourse, even if both partners are HIV positive in order to prevent pregnancy and STDs.
- Avoiding pregnancy because it lower the body’s immunity and hastens the outset of AIDS in HIV positive women.
UNIT 6:

INFECTION PREVENTION AND CONTROL IN HBC

OBJECTIVES
At the end of this unit the trainee should be able to:
- Define infection prevention and control
- Identify sources of infection at home
- Explain standard precaution
- Apply practical aspect of infection prevention and control in the home

SUMMARY OF CONTENTS
- Definition of infection prevention and control
- Sources of infection at home
- Standard precautions

TEACHING METHODS
- Lecture/Discussion
- Group work
- Demonstration
- Plenary session

CONTENTS
DEFINITION
Infection prevention means hindering the invading of microorganism into body parts e.g. lungs, gastrointestinal tract etc.

SOURCES OF INFECTION AT HOME
- Patients infectious body fluids
- Patients clothes
- Patients equipments

STANDARD PRECAUTIONS
Standard precautions are designed:
• For the care of all patients, clients and staff, regardless of whether or not they are infected
• For handling of blood and all other body fluids, secretions and excretions (except sweat), non intact skin and mucous membranes
• To reduce the risk of transmitting microorganisms from known or unknown source of infection (e.g. patients, contaminated objects, used needles and syringes, etc)

COMPONENTS OF STANDARD PRECAUTIONS
The key components of the standard precautions for preventing infection transmission in the following
• Hand hygiene
• Personal protective equipments
• Patient care equipment
• Patient resuscitation
• Environmental cleaning
• Handling of sharps
• Patient placement

In preventing the infections, the HBC provider educates the patient, family, and the community by doing the following:
• Emphasizes hand washing with soap and water after handling soiled linen, or clothing having contact with body fluids and before and after performing procedures.
• Emphasizes covering all open wounds with dressing bandage or clean cloth – both HBC provider’s and those of the patient.
• Uses a piece of plastic paper, gloves or big stick or leaf to handle soiled items
• Washing and cleaning of clothing and equipment stained with blood, diarrhoea or other body fluids after soaking them in Hypochlorite solution.
• “No sharing” of sharp skin-piercing instruments, toothbrushes, razors, needles or anything which can cut or come into contact with blood.
• Emphasizes on practices that ensure good hygiene and proper disposal of wet and dry waste (dressings and excreta).
• Emphasizes on the use of clean linen and clothes
- Avoidance of pricks needles and other sharp instrument used by the patient
- Avoidance of mouth to mouth resuscitation
- Protects AIDS patients from Malaria
- Attends a patient who may be a source of cross infection last. (E.g. those with septic wounds).
UNIT 7:

NUTRITIONAL CARE FOR PEOPLE LIVING WITH HIV/AIDS

INTRODUCTION
Malnutrition is a serious danger for people with HIV/AIDS. Even at the early stages of HIV infection, when no symptoms are apparent; HIV makes demands on the body’s nutritional status. The risk of malnutrition increases significantly during the course of infection.

Good nutrition cannot cure AIDS or prevent HIV infection.

Good nutrition strengthens the immune system and improves the quality of life.

OBJECTIVES:
At the end of this topic participants should be able to:

1. Explain basic concepts in Nutrition
2. Describe the interaction between nutrition and HIV/AIDS.
3. Describe the process that leads to malnutrition and wasting for people living with HIV/AIDS.
4. Outline the nutritional management for HIV positive individuals
5. Describe the relationship between ART and nutrition.
6. Explain infant feeding and HIV/AIDS including breastfeeding
7. Discuss dietary management of HIV/AIDS related complications
8. Describe the principles and practice of nutritional status assessment.

CONTENT
- Definition of nutrition
- Types of nutrients and their sources and function
• Interaction between nutrition and HIV/AIDS.

• Process that leads to malnutrition and wasting for people living with HIV/AIDS.

• Nutritional management for HIV positive individuals

• Relationship between ART and nutrition.

• Infant feeding and HIV/AIDS including breastfeeding

• Dietary management of HIV/AIDS related complications

• Principles and practice of nutritional status assessment.

TEACHING METHODS

• Brainstorming

• Lecture/Discussion

• Group work

• Plenary sessions

DEFINITION

Nutrition is the science of utilization of nutrients by the body

TYPES OF NUTRIENTS THEIR SOURCES AND FUNCTION

There are three (3) groups of foods in providing balanced diet; these are

• ENERGY GIVING FOODS:
  Maize, Sorghum, Cassava, rice, millet, potatoes, etc.

• PROTECTIVE FOODS:
  - Different fruits with vitamins (like pawpaw, oranges, mangoes, bananas)
  - Different green vegetables
  - Also pumpkins, cabbages & carrots

• BODY BUILDING FOODS
  - Meat, fish, eggs, milk, etc

INTERACTION BETWEEN NUTRITION AND HIV/IDS:

There is a close relationship between nutrition and HIV/AIDS because HIV suppresses the Immune system and results into:

• Body weakness

• Malnutrition & other Micronutrient Deficiencies
• Anemia
• Muscle wasting.
Appropriate nutrition improves Immune system hence protect the body against infections.

PROCESS THAT LEADS TO MALNUTRITION AND WASTING FOR PEOPLE LIVING WITH HIV/AIDS

The wasting syndrome typically found in adult AIDS patients is a severe nutritional manifestation of the disease.

Wasting is usually preceded by:

- Decrease in appetite
- Repeated infections
- Weight fluctuations
- Subtle changes in body composition

Weight loss and wasting in PLHA develop as a result of three overlapping processes:

1. Reduction in food intake, due to:

- Painful sores in the mouth, pharynx and/or esophagus
- Fatigue, depression, changes in mental state, and other psychological factors
- Economical factors affecting food availability and nutritional quality of the diet.
- Side effects from medication, including nausea, vomiting, metallic taste, diarrhea, abdominal cramps, anorexia.

2. Nutrient malabsorption

- Some HIV-infected individuals have increased intestinal permeability and other intestinal defects even when Asymptomatic.
- HIV infection itself may cause damage epithelia to the intestinal walls and malabsorption.
- Malabsorption of fats and carbohydrates is common at all stages of HIV infection in adults and children

3. Metabolic alterations

- Infection results in increased energy and protein requirements, as well as inefficient utilization and loss of nutrients
- HIV-related metabolic changes come severe reductions in food intake and the immune systems response to the infection.

**NUTRITIONAL MANAGEMENT FOR HIV POSITIVE INDIVIDUALS**

-Ascertain circumstances that may have lead to weight loss
- Identify and treat any underlying infections early, routine deworming
- Provide specific advice on how to maintain intake during infection period
- Increase intake to promote nutritional recovery following periods of appetite loss, fever, or acute diarrhea.

**RELATIONSHIP BETWEEN ART AND NUTRITION**

Main food and drug interaction including ARVs

- Food can affect the drug efficacy and its side effects. eg ddi does not work if taken with meals, so always take on empty stomach
- Drugs can affect the nutrient absorption, metabolism, and excretion. Most ART nucleosides have GI side effects first few weeks: Zidovudine, ddi, and abacavir. Some often with diarrhea: nelfinavir and kaletra all affect appetite.
- The side effects of drugs can affect food intake and nutrient absorption. Kaletra syrup very bad taste (impossible with kids), ddi nelfinavir may cause diarrhea
- Drugs and food interactions may cause unhealthy side effects.
INFANT FEEDING AND HIV/AIDS INCLUDING BREASTFEEDING

- Exclusive breastfeeding for the first 6 months generally promoted and supported
- Benefits to infants outweigh the risk regardless of their HIV status
- The mother should make the final choice about the feeding method
- Whatever her choice may be, HBC provider should provide support to ensure optimal nutrition of mother and child
- Support infant feeding option chosen by mother
- If breastfeeding is chosen as an option encourage exclusive breastfeeding and advise early cessation (up to 6 months)
- If replacement feeding is chosen, ensure safety and provide support such as preparation, hygiene, follow up

DIETARY MANAGEMENT OF HIV/AIDS RELATED COMPLICATIONS

Take the following points into consideration:

- Preservation of lean body mass remains important at this stage; maintain earlier recommendations about energy and protein consumption as long and as often as possible.
- During periods of nausea and vomiting, people with AIDS should try to eat small snacks throughout the day and avoid foods with strong or unpleasant aromas. They should maintain fluid intake to avoid dehydration.
- To minimize gastrointestinal discomfort, gas and bloating, consume foods that are low in insoluble fiber and low to in fat. If there is lactose intolerance, avoid milk and daily products. Caregivers should try to identify fermented foods (for example, sour milk, porridge or yogurt) or nondairy, high-protein foods that are easy to prepare and consume. Avoid spicy foods.
- During diarrhea, ensure that fluid intake is maintained (30 ml/kg body weight per day for adults and some-what more for children). Patients should continue eating and drinking, whenever possible. Give oral rehydration solution to avoid life-threatening dehydration.
- People with mouth and throat sores should avoid hot and spicy or very sweet foods, as well as caffeine and alcohol. Encourage patients to eat preferred foods and that are softened, mashed or liquefied, if necessary.
- For patient with depressed appetites or lack of interest in eating, caregivers should try to increase dietary intake by offering small portions of food several times a day. Set specific eating times; try to find ways to make eating times pleasant and supportive.
- Treat all infections that affect appetite, ability to eat and nutrient retention immediately
- Avoid tobacco products

**NUTRITIONAL COUNSELLING.**

Nutritional counseling is assisting with knowledge/skills, which enables patient / caretakers to understand nutritional values of locally available foods and how these foods contribute in the management of the HIV related illnesses. The ultimate goal is to guide the individual or family towards informed decision about the type of foods to eat in order to be health and combat nutritional related health problems.

The education should stress the fact that nutrition plays a role in:
- Stimulating the immune system
- Fighting weight loss
- Replacing lost nutrients
- Stimulating appetite and
- Improving quality of life.

**NUTRITIONAL ASSESSMENT**

**Elements of Nutritional assessment**
- Identify risk factors
- Determine weight gain or loss, linear growth, growth failure, or body mass index (BMI)
- Take a dietary intake and feeding history of actual food intake, types of foods, fluids breast milk consumed and amounts

**Two ways to discover whether patient is losing weight**
- Weigh the person on the same day once a week and keep a record of the weight and date.
  For an average adult serious weight loss is indicated by 10 percent loss of body weight.
- When clothes get loose and no longer fit properly.

**ASSESSMENT**

**Check nutritional laboratory values (if available)**
- CBC
- ESR
- Total protein
- Albumin

**Take dietary intake and feeding history of actual food intake, types of foods, fluids, breast milk consumed and amounts.**

Other helpful information:
- Length of time it takes the patient to eat
- Any chewing, sucking, or swallowing problems
- Nausea, vomiting, or diarrhea
- Abdominal pain
- Any feeding refusal, food intolerance, allergies, and/or fatigue
UNIT 8:

MANAGEMENT OF COMMON CONDITIONS SEEN IN HIV/AIDS

INTRODUCTION:
The HBC provider will manage and treat common conditions of patients with HIV/AIDS in the home together with the family. This will enable the patient to live a healthier life.

Most patients with HIV infection succumb to complications that the HIV induced immune deterioration cannot handle. However, even through we have no drugs for the cure of HIV infection, most of the opportunistic infections resulting from HIV induced immune Deterioration can be treated. It should always be recognized that we only treat and cure the associated diseases and symptoms but not the HIV itself.

It has also been revealed that, infections common in Africa can be prevented by Co-trimoxazole prophylaxis.

OBJECTIVES

• Explain common conditions seen in AIDS
• Describe management of common conditions

SUMMARY OF CONTENTS

• Common opportunistic infection due to lowered body immunity after HIV infection
• Treatment and management of the most common conditions seen in PLWHA

TEACHING METHODS

• Brainstorming
• Lecture/Discussion
• Group work
• Plenary sessions
• Case studies
CONTENT

MOST COMMON CONDITIONS SEEN IN HBC

Most common opportunistic infections/conditions seen to patient living with HIV/AIDS (PLWHA) including:

- Fever
- Weight loss
- Diarrhoea
- Oral thrush
- Respiratory conditions
- Cough
- Lymphadenopathy
- Viral infections
- Fungal skin infection
- Bacterial skin infections
- Other skin diseases
- Headache
- Pain.

TRIAMENT AND MANAGEMENT OF THE MOST COMMON CONDITIONS SEEN IN PLWHA AND OTHER CHRONIC ILLNESSES

FEVER:

Fever is manifested by the rise of the body temperature above 38.5°C

Causes: Fever may be due to a variety of causes and clinical features which may bacterial, fungal viral, or HIV itself. Malaria is another common cause of fever.

-In case of malaria follow the national standard treatment guidelines.

Management/treatment:

- Take history and physical examination
- Give antipyretic (paracetamol or aspirin tablets) and anti malarial treatment such as sulphadoxine Premethamine-SP If fever persists and if the patient is on prophylaxis cotrimoxazole give Amoxyciline 500 mg three times per day for 3 days and review.
- If the patient is not on Co-trimoxazole prophylaxis give Co-trimoxazole 480mg twice daily for 5 days
If the patient improves within 3 days of treatment continue treatment for 10 days.
If no improvement by 3 days of above management, REFER the patient for further management.

**CHRONIC/RECURRENT DIARRHOEA**

Chronic diarrhea is a very frequent and frustrating problem in PLWHA, of whom at least 50% experience it at some time during the evolution of the disease. It is often accompanied by nausea, weight loss, abdominal cramps and dehydration. There is often an intermittent watery diarrhea without blood or mucus and in most cases no cause is identified.

**Definition:** Chronic or recurrent diarrhea is characterized by passing liquid stools three or more times a day. This is one of the major manifestations of HIV/AIDS it may be persistent or recurrent one. Diarrhea is usually associated with - loss of body fluids resulting into dehydration and electrolyte imbalance, which may be severe and fatal.

**Causes:** Mainly caused by infection which may be bacterial, protozoa, toxin induced (E.Coli), helminthes infestation viral or fungal. It is also caused by mal-absorption in the intestinal tract due to HIV.

**Management/treatment:**

- Take history and physical examination
- If patient is dehydrated assess for severity. Correct with oral dehydration salts (Plan A&B). If the patient is serious refer for parenteral fluids replacement (plan C).
- If the patient not dehydrated maintain hydration status, by encouraging uptake of fluids especially potassium rich fluids.
- Use of Loperamide has proved very effective in stopping diarrhoea. Give Loperamide 2 – 4 mg twice daily for 5 days, with close monitoring of signs of fluid and electrolyte balance.
- If the patient improves within one week on one of the above treatment, give health education, counseling, discharge and make follow-up.
- If no improvement refer for further management.

Prevention consists of attention to personal hygiene (hand washing), drinking safe boiled water, and eating only thoroughly cooked meat and vegetables. If
vegetables should be eaten raw, they should be washed properly preferably with running water.

**ORAL THRUSH**

Many different conditions involving the oral

**Definition:** Is characterized by presence of whitish patches on the inside lining of the mouth. Oral thrush may extend to the esophagus and cause pain on swallowing.

**Cause:** It is caused by candida albicans.

**Management:**

- Take history and perform physical examination. If the patient has oral sores, oral pain or painful swallowing give Miconazole adhesive tabs 10 mg daily for 7 days. OR.
  - Apply local Gentian violet 1% aqueous solution twice daily OR

Dissolve 100,000 units of Nystatin in a glass of water and use as mouth wash OR Fluconazole 150mg daily for 14 days.

If the patient has oral pharyngeal or esophageal candidiasis and Fluconazole 150mg/day till symptoms resolve.

If the patient improves with treatment continue till signs and symptoms resolved and follow-up as needed.

If no improvement REFER.

**WEIGHT LOSS**

**Causes:** Weight loss in persons with HIV/AIDS may be due to reduced food intake, difficulty/painful swallowing, diminished gastrointestinal uptake (malabsorpiton, diarrhoea), TB (caused of rapid weight loss).

**Management/treatment:**

Take thorough history and physical examination

If it is due to low food intake without any cause, counsel the patient on nutrition especially on high calories and protein foods

- Frequent feeds, vitamins foods
- Appetizing preparations
- Treat underlying causes.

- If low food intake due to painful swallowing treat for oral pharyngeal candidiasis (miconazole tabs 200 mg/day x 2 weeks or muco-adhesive tabs) and no improvement for 2 weeks REFER.
• If body weight loss due to poor appetite/vomiting symptomatic treatment is needed so consult clinician for symptomatic treatment which include to advise the patient to:
  • choose foods which the patient prefers
  • eat small frequent meals
  • eat whenever they feel like, not at scheduled times
  • do physical exercises
  • friends or family to keep the patient company during a meal

RESPIRATORY CONDITIONS
Pulmonary involvement is among the most common complains in AIDS patients. Cough lasting over one month is seen as in at least one-third of patients some time during the progression of the disease.

**Definition:** In HIV infected patients, respiratory conditions present with worsening cough, chest pain and or dyspnoea.

**Cause:** may be either caused by pulmonary conditions which could be bacterial, viral or fungal infections.

**Management/Treatment:**
Take history and physical examination
If the patient has severe dyspnoea (respiratory rate more than 40 per minute) Give supportive treatment and REFER immediately.
If patient is on Co-trimoxazole prophylaxis treat with Amoxycline 500mg 8 hourly for 3 days if the patient improves, continue the treatment for 10 days.
If patient is not on cotrimoxazole prophylaxis treat with Cotrimoxazole 480 mg bid for 5 days.
No improvement with above treatment REFER.

**COUGH:**
**Definition and Cause:** Persistent cough can usually be attributed to pulmonary TB or other bacterial or viral infection. It may not be possible to determine the causes by clinical history and physical examination, so laboratory tests should be performed.

**Management:** May include:
History taking and examination
• If cough is acute and the patient NOT on cotrimoxazole prophylaxis, start on cotrimoxazole 480mg 2 tablets twice daily x 5 days
• If patient on cotrimoxazole prophylaxis start on amoxycillin 500mg 8 hourly daily for 5 days.
• If the patient improved with above treatment discharge form the Clinics give health education and counseling
• If no improvement with above treatment REFER the patient for further investigation
• Some time cough is long standing (more than 21 days)
• REFER for sputum examination.

LYMPHADEMOPATHY:
Swelling of the lymph nodes is a frequently encountered symptom in HIV positive patients. It is important to carry out a careful history and symptom patients.

Causes: May include the following
- HIV itself
- Mycobacterium tuberculosis infection
- Kaposis sarcoma
- Pyogenic bacterial infection
- Syphilis
- Fungal or viral infections

Management: Includes
History taking and physical examination
If any local infection that might explain lymph adenopathy treat accordingly.
If not local infection identified send for a VDRL/RPR investigation. Results shows positive treat with benzothine penicillin 2.4 mu single dose (consult STI clinic for drug) or erythromycin 500 g 8 hourly x 2 weeks if is allergic for penicillin.
If VDRL/RPR is negative and present any of the following fever, weight loss unilateral nodes increasing in size, matted nodes or fluctuant nodes REFER for TB investigations.
VIRAL INFECTIONS

(a) **Herpes zoster infection (shingles)**

**Definition:** are painful group of vesicles along one or several dermatomes (appear 2-4 days after onset of fever).

**Causes:** by vermicular-zoster virus with early symptoms of severe pain, fever and vesicular rash.

**Management/treatment:**

History and physical examination

Diagnosis confirmed give the patient analgesia, tabs, Declofenac 50 – 100mg 8 hourly

Apply calamine lotion

Provide acyclovir 800mg 5 times per day for 7 days

If bacterial super-infection erythromycin or cloxacilline 500g 8 hourly for 7 days.

If eye is involved REFER.

**Herpes simplex**

**Definition:** Prodromal sensation of itching, burning, group of vesicle break quickly, form ulcer with or without fever

Lesion usually resolve within 10 – 21 days after primary infection

**Management:** Includes

History and physical examination

Apply Hydrocortisone 1% skin ointment

Give Acyclovir tabs, Declofenac 50 – 100 mg tds.

Other Viral skin infection like mollucum contagious, viral warts, planter warts and genital warts refer to clinical for proper examination and treatment.

**FUNGAL SKIN INFECTION:**

(a) **Dermatophytosis**

**Definition:** Round/circular scaly lesion with raised active margin with or without central clearance healing.

**Management:**

- If on the body apply Whitefield’s ointment twice a day for 2 – 3 weeks
- Apply 2% miconazole cream until clear
• If is on the scalp give Griseofulvin tabs 10mg/kg daily for 6 weeks with food.

(b) **Skin Candidiasis:**

**Definition:** Erythema of the affected skin, surrounded by satillite pustules and papules.

**Management:**
- Local application of 1% aqueous solution of G.V
- Nystatin ointment apply twice daily until lesion are cleared
- 2% miconazole cream.

**BACTERIAL SKIN INFECTION**

(a) Boils and other acute bacterial skin infections:

**Management:**
- Local lesion care
- Antibiotics (cloxacilline or erythromycin)

(b) Acne” Conedommes, papules, nodules cysts and scarring

**Management:**
- Keratolytic agent i.e. apply benzyl peroxide
- Doxycycline 100 mg od x 3 months.

(c) Any other skin infection REFER.

**OTHER SKIN DISEASES**

Scabies:

**Definition:** Small pruritic papules, burrows in wet moist areas i.e. finger web spaces, axillar, buttocks.

**Management:**
- Give Benzyl Benzoate Emulsion (BBE) 12.5% for children, 25% for adult apply the whole body surface except the face and scalp for 24 hours daily for 3 days
- Repeat after 7 days
- Common benzine hexachloride apply once repeated on 5th day
- Treat the whole family
- Health education.

(a) **Kaposis Sarcoma:**
**Definition:** Often begins on the legs and feet. Hyper pigmented papules, plaque, and nodule with or without sclerotic and woody hard lower leg.

**Management:** REFER.

**HEADACHE**

Headache in a patient with symptomatic HIV infection patient is often persistent or severe and rapidly increasing or not responding to common drugs used for pain. It can be with or without fiver.

Causes: Includes infections e.g. (TB meningitis, cytococcal meningitis) malignancy or malaria.

**Management:**

History and physical examination
If any common cause identified treat accordingly and Health education, counseling and follow-up.
If any neurological signs identifies REFER immediately.
If associated with fever treat empirically for malaria (SP)
Improved follow-up as needed
If no fever and or nor improvement with SP REFER.

**PAIN**

Is the most common among PLWHA. It is also the commonest system experienced by the dying and certainly the most feared. Pain can be either somatic or neuropathic.

The accurate diagnosis and cause of pain is essential.

**Management of pain:**

- Take history and physical examination
- Determine primary causes of pain, secondary causes
- If pain is PSYCHOLOGICAL PAIN do the following:
  - Counseling the patient
  - Reassurance
  - Support (spiritual and material)
- Sedatives (diazepam 5 – 10mg tds per day for 7 days
- Review after 2 weeks and inform Home based Health care team.
- If pain is PHYSICAL PAIN

(a) Somatic
• Give paracetamol 2 tabs TDS for 7 days or aspirin 2 tabs tds for 7 days
• Declofenac 50 – 100 mg tds for 7 days for moderate pain
• Oral morphine 5 – 10 mg 6 hourly
• If improved appoint in 2 week time and inform HBC team
• No improvement REFER.

(b) Neuropathic pain:
(c) Give tab phenytoin 50 – 100 mg twice per day for 7 days
(d) Vitamin B complex 2 tabs tds for 4 days
(e) Review after 7 days, if no improvement REFER.
UNIT 9:

MANAGEMENT OF CHRONIC CONDITIONS IN HBC

OBJECTIVES
• List common chronic conditions in HBC
• Describe management of chronic conditions at home
• Identify the stage at which the above condition need referral

SUMMARY OF CONTENTS
• Common chronic conditions seen in HBC
• Management of chronic conditions at home
• Conditions which need referral

TEACHING METHODS
• Brainstorming
• Lecture/Discussion
• Group work
• Plenary sessions
• Role play
• Simulations
• Case studies

CONTENT
Common chronic conditions includes:
• Cancer
• HIV/AIDS
• Hypertension
• Stroke/paralysis
• Diabetes
• Sickle cell disease
• Asthma
• Mental illness
• Epilepsy
• Developmental disability
• TB and Leprosy

Management of chronic conditions-refer to national guideline for HBC.
UNIT 10:
CARE OF THE CHILD INFECTED WITH HIV

INTRODUCTION
The problem of infant and child morbidity and mortality in Tanzania has considerably increased due to the HIV/AIDS epidemic. At the same time the number of orphans due to HIV has also increased. Some of them who are more unfortunate are also infected with the virus or are already sick due to AIDS. Proper management of the HIV infected children, Education and counseling of parents on the care of infants borne to HIV positive mothers is an essential component of the management of HIV infected children.

OBJECTIVES
- Explain WHO staging for diagnosis of HIV and AIDS in children.
- Identify common clinical conditions associated with HIV/AIDS in children
- Explain specific needs for HIV/AIDS infected children
- Describe basic care for infants and children with suspected or confirmed HIV infection or AIDS.

SUMMARY OF CONTENTS
- WHO staging for diagnosis of HIV and AIDS in children
- Clinical conditions associated with AIDS in children
- Specific needs of children infected with HIV/AIDS
- Care of an infant and children with suspected or confirmed HIV infection or AIDS

TEACHING METHODS
- Brainstorming
- Lecture/Discussion
- Group work
- Plenary sessions
- Case studies

CONTENT
WHO STAGING FOR DIAGNOSIS OF HIV AND AIDS IN CHILDREN

Clinical stage 1 (Asymptomatic)
- Generalized lymphadenopathy

Clinical stage II (Symptomatic)
- Chronic diarrhea >30 days duration in absence of known etiology
- Persistent fever >30 days duration in the absence of known etiology
- Severe persistent or recurrent candidiasis outside the neonatal period
- Recurrent severe bacterial infections other than septicemia or meningitis (e.g. osteomyelitis, bacteria pneumonia, abscesses)
- Weight loss or failure to thrive in the absence of known etiology

Clinical stage III
- AIDS defining opportunistic infections
- Malignancy
- Severe failure to thrive-wasting in the absence of known etiology
- Recurrent septicemia or meningitis
- Progressive encephalopathy

COMMON CLINICAL CONDITION ASSOCIATED WITH HIV IN CHILDREN
- Bacterial pneumonia
- Tuberculosis
- Viral pneumoniasis
- Fungal pneumonia
- Oropharyngeal candidiasis
- Neurological problems
- Persistent generalized lymphadenopathy
- Chronic parotitis
- Persistent or recurrent fever
- Malnutrition
  For more details refer to National guideline for clinical management of HIV/AIDS
THE BASIC NEEDS OF AN HIV INFECTED CHILD ARE:

- Proper feeding –breast or artificial
- Proper feeding and weaning
- Safe environment and clothing
- Love and affection
- Security
- Growth monitoring through RCH
- Prevention of illness including immunization and good hygiene
- Psychological support through counseling and education to care takers

PROVIDING CARE TO AN HIV INFECTED CHILD

The basic needs of a child affected by HIV infection are

- Exclusive breast feeding (after counseling or informed choice)
- Maintaining good nutritional status and safe weaning
- Growth and development should be evaluated at all stages of development through adolescence
- Prevention of illness through immunization safe environment and good hygiene
- Educating parents and care givers on how to care for such a child
- They should receive routine pediatric care and should be monitored for their HIV disease status
- Children exposed to ARV should be closely monitored throughout their life
- Providing early and vigorous therapy for common pediatric conditions
- Providing supportive care at home
- Providing recreation for the child
UNIT 11:
ANTIRETROVIRAL THERAPY

INTRODUCTION
- After a decade of slow progress in the treatment of HIV infection, the last few years have seen dramatic advances in the development of antiretroviral drugs (ARV). This now offers greater patient survival and improved quality of life.
- HIV life cycle involves transcription of viral RNA into DNA and integration into human genome.
- Mutational potential of HIV-1 results in worldwide diversity (subtypes), viral escape from immune response and development of drug resistance.
- Viral replication persists throughout infection
- Fundamental pathology is the inability of the host immune system to eradicate the HIV infection resulting in a progress destruction of the immune system.

OBJECTIVES
- Explain the concept of ART
- Describe the process and criteria for starting ART in people living with HIV/AIDS
- Describe and recognize common side effects of ART
- Explain issues in adherence to ARV drugs
- Explain the role of HBC in ART

SUMMARY OF CONTENTS
- Definition of ART
- Goals of ART
- Types of ART
- Criteria for starting ART in adults and children
- Process of initiation of ART
- Common side effects of ART
- Adherence in ART
• Role of HBC in ART

TEACHING METHODS
• Brainstorming
• Lecture/Discussion
• Plenary sessions
• Case studies
• Simulation

CONTENT

DEFINITION
ART means Treatment of HIV patients using Antiretroviral drugs in order to prolong their life by preventing viral replication.

GOALS OF ARV THERAPY
The primary goals of antiretroviral therapy are:
Maximal and durable suppression of viral load
Restoration and/or preservation of immunologic function
Improvement of quality of life
Reduction of HIV-related morbidity and mortality.

TYPES OF ANTIRETROVIRAL DRUGS
The current existing antiretroviral drugs fall into three main categories:
Nucleoside-analog reverse transcriptase inhibitors (Antis)
The drugs are- Zidovudine(AZT), Stavudine(d4T), Lamivudine (3TC), Abacavir(ABC), Didanosine(ddi).
Non-nucleoside reverse transcriptase inhibitors (NNRTIs)
Drugs in this class are Nevirapine(NVP), Efavirenz(EFV)
Protease inhibitors (PIs)
The drugs are- Lopinarvir(LPV/r), Squinavir(SQ/r) Nelfinavir(NFV)

CRITERIA FOR STARTING ART IN ADULTS AND CHILDREN
Recommendation in Tanzania
For adults
• Asymptomatic with CD4<200 cells/mm3
• Symptomatic or AIDS stage 4 disease
• Others
  - Post exposure prophylaxis
  - Prevention of Mother to Child Transmission

**Categories of identified HIV+ individuals**

![Diagram of HIV+ Categories]

- **AIDS defining illness or CD4 count <200 cells**
  - Initiate treatment

- **No AIDS defining illness and CD4 count 200-350**
  - Regular monitoring every 4 months

- **No AIDS defining illness and CD4 count >350**
  - Periodic monitoring every 6 months

Special considerations for children-or HIV+ children under 12 years old, where absolute CD4 counts are not an accurate measurement of immunological suppression, treatment will be recommended for all who fit any of the criteria below:

- Are under 1 year of age,
- Have a CD4 less than 15-20%, or
- Develop an AIDS defining condition.

Children who have a CD4 count of between 15/20% and 25% will be brought to the clinic every four months for evaluation and to have the CD4 measurements. Children with a CD4 count above 25% will be brought to the clinic every six months for evaluation and CD4 counts.

**PROCESS FOR INITIATION OF ART**

- Counseling for ART
- Laboratory tests
• Selection of treatment partner/adherence assistant
• Prescription
• Monitoring for adherence

SIDE EFFECTS OF ARV

Side effects can often occur at drug initiation but may decrease or disappear entirely after several weeks or may persist throughout the entire time a person is taking the therapy.

Common side effects are
• Fatigue
• Anemia
• Headaches
• Nausea and vomiting
• Diarrhea
• Weight loss
• Dry mouth
• Rash
• Peripheral neuropathy
• Menstrual problems
• Hair loss,

ADHERENCE IN ART

Definition:
The extent which a client's behavior coincides with the prescribed health care regimen as agreed upon through a shared decision making process between the client and the health care provider.

Adherence to ART is essential for treatment success
Adherence rate >95% is necessary

Overview of adherence
• General observations about adherence have been acquired from studies in the disease areas of coronary heart disease, TB, and in the geriatric population.
• Adherence to drug regimen is poor across all populations and diseases.
The proportion of patients who fail to self-administer medication as prescribed can range from 20% to 100%. The average is 50%.

Clinicians consistently overestimate the percentage of patients who will adhere and generally are unable to predict who will adhere or not adhere to recommended drug regimen.

Non-adherence accounts for a significant % of admissions in patients being treated for heart disease.

DOT has been used in other diseases (TB) to improve adherence.

Adherence is difficult over the short and long term.

The accepted definition of successful adherence for most other chronic diseases is >80% of pills taken.

The standard does not apply to HIV disease and antiretroviral therapy.

Greater than 95% is the goal.

CONSEQUENCES OF POOR ADHERENCE

Poor adherence can lead to virus breakthrough hence:

- Evolution of drug resistance
- Immunologic and clinical failure
- Treatment failure

Factors that influence adherence

Factors related to drug regimen:

- Cost of the regimen
- Complexity of the regimen
- Storage of drugs e.g. refrigeration
- Duration of the therapy
- Extent to which the regimen interferes with the patients daily life
- Side effects associated with the regimen.

Factors related to the patient and/provider

- Provider not familiar with the antiretroviral therapy, side effects, drug-to-drug interactions etc.
- Lack of understanding by patient/provider of relationship between adherence and drug resistance.
• Poor communication between provider and patient
• Lack of trust between patient and provider/health care system
• Lack of self efficacy (belief in self and therapy)

Psychosocial issues
• Depression or stress related to living with HIV (stigma and discrimination)
• Fear of disclosure
• Chronic alcohol or drug use
• Lack of support from family, friends, community
• Unstable living environment, lack of food or shelter, other basic needs.
• Cultural beliefs and practices regarding the disease and treatment.

Adherence intervention strategies
Reasons for poor adherence are multifaceted; therefore a combination of interventions must be considered.
Strategies to enhance adherence must be tailored to individual needs.
- Patient related strategies
- Clinician/health team related strategies
- Drug regimen strategies

Patient related strategies
In order to improve adherence:
• Health care worker should negotiate a treatment plan that the patient understand, fits their daily routine and to which he/she commits.
• Patients readiness to be on life long medication should be clearly established
• Patient must understand that the first ART regimen has the best chance of a long-term success.
• Adherence assistant should be recruited to become participants in the plan for medication.
• Linking medication timing with day-to-day activities e.g. news broadcast, call for prayers etc.

Clinician/health team related strategies should include:
• Do not rush to treatment-assess and prepare carefully
• Building of a trust relationship with patients
• Provider attitude and behaviors that are supportive and non-judgmental will encourage patients to honest about their adherence and about problems they have with adherence.
• Monitoring and encouraging adherence for several sessions before starting ART.
• Effective communication between clinical team and home based care providers.

Regimen related strategies includes:
• Regimens should be simplified by reducing the number of pills and the frequency of therapy
• Minimizing drug interactions and side effects through rational drug selection
• Minimizing differences between medication requirements e.g, with food, without food.
• Using pill boxes where possible

The role of HBC provider in ART
• Preparing client, family and community on expectations of the treatment
• Promoting disclosure in the home care setting.
• Early recognition of clients who need referral
• Assisting the clients to identify treatment assistants
• Discuss drug storage issues in the home
• Promoting adherence to treatment
• Early recognition of side effects and effective referral
• Addressing nutritional issues
UNIT 12:

PRINCIPLES AND PRACTICE OF PALLIATIVE CARE

INTRODUCTION
In spite of recent advances in the treatment of HIV/AIDS, there is no known cure: the final outcome forever HIV-infected patient is death. Unlike other terminal diseases, it is not easy to predict when death is imminent. A patient may die as a consequence of his or her first HIV manifestation or may develop a life-threatening OI and recover if appropriate, timely treatment is given.

Most patients, however, will experience an increasing frequency of health problems and finally reach a stage of severe immunosuppression over a period of several years. As the disease progresses, the need for symptomatic relief will become more important than curative treatment.

OBJECTIVES

*Explain the concept of palliative care*
  * b) Identify care needs of a terminally ill patient
  * c) Describe the management of common symptoms in palliative care

*Explain issues in mental health and illness in palliative care*
Explain palliative care issues in children
Assist relative in the care of the dead body

SUMMARY OF CONTENTS

* Definition of palliative care
* Goals of palliative care
* Initiation of palliative care
* Identify care needs of a terminally ill person
* Management of common symptoms in palliative care
• Issues in mental health and illness in palliative care
• Palliative care issues in children
• Care of the dead body

**TEACHING METHODS**

- Brainstorming
- Lecture/Discussion
- Group work
- Plenary sessions
- Demonstration
- Role play

**CONTENT**

**Definition**

Palliative care is the active total care of patients and their families and friends when a patient’s disease is no longer responsive to curative treatment and life expectancy is relatively short.

**Goals of palliative care**

To provide support and care that makes life comfortable for patients throughout all phases of disease so that they can live as comfortable as possible.

**The role of HBC in palliative care**

- The HBC provider will be responsible for
- Identifying the pain and symptom needs of the patients including the need for strong analgesic e.g. morphine which will be available at the health facility
- Educate on the administration of drugs for symptom relief monitor the side effects.
- Refer where appropriate

**Initiating and managing palliative care**

**a. Initiation of palliative care**
The decision to stop causal treatment should be based on two criteria:

- The patient has had a long course of progressively worsening illness (is in an advanced stage of immunodeficiency).
- Everything possible has been done to investigate and manage the specific conditions from which the patient is suffering and, despite adequate management, the patient continues to deteriorate.

b. Managing palliative care

It is essential to establish interdisciplinary teams to deal with all the problems, for no single health or social worker can adequately address HIV-related problems in all their complexity, and it is emotionally draining or staff to support persons and families affected by HIV.

The core of this team are the medical, nursing, counseling, social and other services working in collaboration with NGOs, the private sector, volunteers faith based and community-based support groups.

4. Management of symptoms

The most common symptoms are:

Pain
Fatigue/weakness
Shortness of breath/dyspnoea
Persistent diarrhoea
Difficulty sleeping/insomnia
Nausea and vomiting

Providers must be trained to manage these symptoms and be able to refer accordingly. Patients may avoid acknowledging them to providers because they believe they must “put up with them”.

Effective symptom management is based on a thorough understanding of the symptom and education of patient and family.

It requires a multidisciplinary approach

Symptoms can be identified by reviewing each of them: ask about its character (what it feels like), the location, what makes it worse, what makes it better, are other symptoms associated with it and how does it limit or affect the patient’s daily life.
Asking these questions conveys your interest in the patient. Just the act of asking and being aware how important a symptom is to the patient provides some relief from it; a symptom often worsens when a patient has to deal with it alone and has growing fear about what is causing it. A review of symptoms will also alert the provider to the appearance of new symptoms that might herald progressing of disease.

5. Management of pain

a. Definition:

Persistent or recurrent pain lasting more than 48 hours and not alleviated by simple comfort measures. It can be burning, tingling; flashes of pain or unremitting pain that it sharp, aching or dull.

b. Assessment of pain

- First principle in managing pain is an adequate and full assessment of the cause, bearing in mind that most patients have more than one pain and different pains have different causes.
- Take a detailed history of the pain:
  - Site and radiation (where it is localized or radiating)
  - Nature (sharp, pulsating, dull, burning, stabbing, aching, squeezing)
  - Duration (continuous or intermittent, how long and how frequent)
  - Factors: Aggravating (what brings it on; what makes it worse), relieving (what reduces the pain: drugs and dosages, resting position, and the like)
  - Effect on patient’s mobility, activities of daily living and sleep
  - Intensity and severity (mild, moderate or severe)
  - Assess the intensity using a numeric pain scale (or a faces pain scale for children)

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Associated symptoms (nausea, difficulty swallowing, diarrhoea or constipation, vomiting, fever, neck stiffness, seizures, neurological
symptoms, fatigue, skin problems, anorexia, dyspnoea, cognitive problems)

Common types of pain are headache, peripheral neuropathy, abdominal pain, Oral pharyngeal and esophageal pain, chest and generalized pain.

ISSUES IN MENTAL HEALTH AND ILLNESS IN PALLIATIVE CARE

Mental health issues and mental illness include the following

- Anxiety
- Depression
- AIDS dementia
- AIDS related mental confusion
- Anger/irritability

SELECTED PALLIATIVE CARE ISSUES IN CHILDREN

- For children, as for adults, palliative care is an integral part of the spectrum of care and is not limited to the terminal stages of illness.
- Children are often unconsciously aware of the seriousness of their condition. Many children with HIV/AIDS will not have been told their diagnosis. Families may need support in order to address the children’s emotional needs.
- Several factors determine and affect the decision and experience of caring for a very ill child at home. These include:
  - Going home might look like a loss of hope
  - No one outside the family knows the diagnosis
  - The parents themselves may be ill
  - The family might not have access to community resources and support
  - A reduction in the Childs appetite is often very stressful to families and they need reassurance and support in dealing with this issue
- Bereavement follow up is important for families, especially when the care giver may be the only one aware of the Childs diagnosis.

CARE NEEDS OF A TERMINALLY ILL PATIENT

Aims of HBC for terminally ill patient
- Allow patient to live as full a life as possible
• Relieve his discomfort and distress
• Provide for his needs in the different stages
• Help patient achieve death with dignity.

**ROLES OF THE HBC PROVIDER**
Those caring for the terminally ill or dying patient should know that even the unconscious patient could hear and also feel pain. So care should continue to the very end; including hygiene, grooming, nutrition, love and attention
- The person can be encouraged to talk about death if he/she wishes
- Counseling of the patient and family members is essential, during the different stages of dying
- Cultural norms are followed on planning for:
  - Whom to inform after death
  - Place of burial
- What is to be done to the patient after death such as cleaning the body, dressing, prayers and the burial ceremony.

Use the HBC caring process to identify the patient’s needs and problems to plan for his/her care
Verbal communication is encouraged throughout the care so that the patient’s dignity is maintained
You don’t always have to talk; just being there is sometimes enough.

**NURSING CARE NEEDED FOR TERMINALLY ILL DYING PATIENT**

**A. PROVIDE COMFORT**
Comfort can be physical, mental, spiritual and social. The following are some of the interventions to meet these needs.

**PHYSICAL**
- Respiration: a clear airway must be maintained
  - Position the patient comfortably so that breathing is not interfered with
  - Removal of excess mucus/sputum from the mouth by available means; to enable free passage of air.
- Nutrition is promoted to the optimum level possible. Rehydration is done when needed.
• Pain relief is promoted through position, cold/warm compresses, medications etc.
• Elimination is maintained safely and the patient is left clean and dry
• Personal hygiene and grooming makes him feel good
• Pressure areas are cared for to prevent pressure sores

ii. Mental: (emotional, and psychological)
• The family should support the dying patient emotionally
• Many like companionship and feel relief on being touched
• The patient should be encouraged to hope – it is therapeutic. Hope goes away after the acceptance stage. The family or HBC provider must avoid reinforcing hope after the patient has accepted dying (Given up hope).

iii. Spiritual
• The patient may need prayers, so a religious leader may be requested to attend to his/her spiritual needs.
• Some request for scripture reading

iv. Social Needs (Be close to relatives and friends)
• HBC encourages the family to be together
• Companionship is needed by the terminally ill patients
• Activities e.g. play cards could help him take his mind off his condition
• He/she may want to tell stories and needs attentive listeners who encourage him to continue.

B. AUTONOMY

Independence is encouraged:
- Those activities he can perform are encouraged
- If he refuses e.g. food, getting up he is not forced.

• Requests: Wishes are respected and respects are met to the best ability of the family
• Personal feelings are accepted as they are, although they can be quite strange
• Writing a will:
  - When a dying patient has accepted his condition he may wish to leave his estate in order. e.g. Will writing should be encouraged.
- Counseling for writing a will should be done and the written document is duly signed and witnessed. This will make it into a legal document.

C. COPING WITH LOSS AND BEREAVEMENT

- Support – the patient and relatives may feel relief when they are able to talk about their feelings.
- Since the HBC provider will deal with clients/patients with chronic illnesses, it is essential that she knows how to deal with the family members, relatively and friends. She/he should remember that people are undergoing a very difficult time for it is not easy for them to cope with the loss of the loved one. Bereavement is a state of acute distress which is a company with a sequence of emotional reactions. It is important that a HBC provider understands this and supports them to move from one stage to another. Though in the later stages, they can work out what to do next and find a new integrity; they need to voice their ideas to check with another person.

PREPARATION FOR DEATH

The family should be prepared for the death of their relative, although it is customary to hope and not to give up.

Those caring for the terminally ill or dying patient should know that even the unconscious patient can hear and also feels pain. So care should continue to the very end; including hygiene, grooming, nutrition, love and attention.
- The person can be encouraged to talk about death if he wished
- Counseling of the patient and family members is essential, during the different stages of dying.
- Cultural norms are followed on planning for:
  - Whom to inform after death
  - place of burial
  - What is to be done to the patient after death. i.e. Cleaning the body, dressing, prayers and the burial ceremony.

CARE OF THE DEAD BODY
Precautions and care the family needs to take of the dead body of a person who died after HIV/AIDS e.g.

- Wearing gloves when handling the body
- Not touching blood, faeces, urine and other body secretion with bare hands, always wear gloves.
- Cover all open wounds/ulcers with plaster or bandage
- Pack with cotton wool all body orifices (opening).

**CARE FOR CAREGIVERS**

- Caring for anyone with chronic illness is a physical fatigue and emotional (stress) challenges for even the most dedicated caregiver, (e.g. health care workers, counsellors and care givers in the home) who gives care to PLWHs. These also need support to help them do their work well, avoid “burnout” and keep themselves free from infection.

- For health care workers the key to such support is an environment where work is appreciated, shared and well supervised. On going training opportunities, regular social events and support groups for caregivers

**Burnout**

Burnout happens when people care too much about others and do not take enough care of themselves, they feel out of control, or stressed out and may complain that they cannot take it any more. Burn out happen when people remain in “crisis” mood for too long.

HIV/AIDS has been a crisis for 20 years now, and it still is. So we have to identify the symptoms of stress, and find ways of overcoming them

  a) Recognize symptoms of stress
  b) Identify sources of stress
  a) Reduce stress

**SIGNS OF BURNOUT**

Signs of burnout vary from individual to individual, however have following Symptoms seem to be most common.
**PHYSICAL SYMPTOMS**
- Continual exhaustion inability to get sufficient rest
- Susceptibility to illness and illness lasting longer
- Frequent accidents

**EMOTIONAL SYMPTOMS**
- Impatience or irritability with other people
- Increasing desire to be alone away from people
- Forgetfulness
- Emotional “numbness” inability to experience enjoyment
- Feeling of panic.

**COPING SYMPTOMS**
- Denial of burnout symptoms
- Increase in compulsive addictive behaviours
- Withdraw, fewer social contacts
- Discontinued hobbies, recreational activities
- Few activities outside of care giving responsibilities.

**SPIRITUAL SYMPTOMS**
- Questioning the purposes of living
- Loss of meaning
- Feeling of emptiness

Health institutions should provide a safe environment for care given by providing infectious diseases control policies. Ensure that health care workers have knowledge, skill and equipment they need to follow drugs universal precautions for safety handling of blood and other body fluids. Health workers should have access to voluntary, confidential HIV counseling and testing to post exposure prophylaxis with antiretroviral.

**Important issues**
- Never pose as know “alls”, know your limitation/expertise these gaps can be filled by other professionals
- Have an inventory of all referral resources
- Operate with the established network
- Up date their inventories periodically.

A good referral, network will also make it easier for families to access appropriate care and support services thus saving them time and other costs.
UNIT 13:
STIGMA AND DISCRIMINATION REDUCTION

INTRODUCTION

MAGNITUDE OF STIGMA AND DISCRIMINATION IN TANZANIA

Many studies and surveys in Tanzania indicate that quite a few Tanzanians increasingly desire to be tested for HIV. Many of them however remain hesitant to fulfill their desires due to various reasons including lack of testing facilities, fears and uncertainty on what to do with the results, as so far there is no cure for HIV/AIDS. But the most significant obstacle is stigma.

In a study conducted in Dar es Salaam by NACP in 2000 (Fimbo et al), for the needs assessment on voluntary counseling and testing (VCT) services, 570 respondents were interviewed and 396 (69.5%) of them were willing to utilize the VCT services. However, 17.4% of those willing to use these services expected to be stigmatized against if their sero-status was disclosed. For those who were not willing to use these services, 77.6% of them indicated that stigma was the major obstacle of using these services. 76% of the respondents indicated or believed that they will be discriminated by very close family members and colleagues. Only 20% of them believed there would be no discrimination at all,

The success of many of the HIV/AIDS interventions for prevention or care and support will largely depend on whether stigma has been addressed. Ignoring stigma will be suicidal to any undertaking in HIV/AIDS. The services being established are under-utilized because of stigma. HIV prevalence and incidences are still high because stigma is widespread. Any intervention cannot work as many people still fear of discrimination and outright rejection from services and certain rights.

OBJECTIVES

- Define stigma and discrimination
- Describe the sources of stigma and discrimination
- Discuss stigma and discrimination at different levels
• Explain the effects of stigma and discrimination
• Describe ways of helping people cope with stigma

SUMMARY OF CONTENTS
• Definitions of stigma and discrimination
• Sources of stigma and discrimination
• Stigma and discrimination at different levels
• Effects of stigma and discrimination
• Ways of helping people cope with stigma

TEACHING METHODS
• Brainstorming
• Lecture/Discussion
• Group work
• Plenary sessions
• Role plays

CONTENT
DEFINITIONS
STIGMA
• Mark of shame or disgrace: shameful feeling and labeling or attributing undesirable qualities targeted towards those who are perceived as being “shamefully different” and deviant from the social ideal or norm.
• An attribute that is significantly discrediting used to separate the affected persons or groups apart from the normalized social order (separation implying devaluation).
• Other people look at people who are stigmatized negatively and they are often discriminated against.

DISCRIMINATION
• Is any distinction, exclusion, restriction or preference which is based on exclusionary perceptions or structures (e.g. race, religion, beliefs, sexuality, gender etc); and which has the purpose or effect of nullifying or impairing recognition, enjoyment or exercise by all persons on an equal footing of all rights and freedoms.
• Are those actions or treatments based on the stigma and directed towards the stigmatized. Discrimination can be seen through sanctions,
harassment, scapegoat and violence based on infection or association with HIV/AIDS/STIs

Precisely, **Stigma** is the *Attitude* and **Discrimination** is the *Action*.

**SOURCES OF STIGMA AND DISCRIMINATION**

- Lack of understanding of HIV/AIDS
- Myths about the transmission of HIV
- The fact that AIDS is incurable
- Irresponsible media reporting
- Social fears about sexuality
- Fears relating to illness and death

**STIGMA AND DISCRIMINATION AT DIFFERENT LEVELS**

**Individual level**

PLHA experience internalized stigma, which may cause them to isolate themselves and no longer feel part of civil society and are unable to gain access the services and support they need.

**Family level**

In the household and family setting, stigma is manifested in the form of verbal abuse, rejection, eviction and imposes restrictions on person. People with HIV/AIDS are subjected to blame, bitterness, anger, denial and withdrawal of treatment and care.

**Community level**

- Communities often shun or gossip about PLHA.
- Verbally and physically attacked
- PLHA are labeled as irresponsible, having improper behaviors and are blamed for contracting the infection
- Family of PLHA may also be stigmatized and discriminated

**Education and school**

Children with HIV/AIDS or those associated with infected family members are stigmatized and discriminated against in education settings. Stigmatized of these children led to teased by classmates, exclusion from collective activities and expelled from school.
Employment and the workplace
- Pre employment screening and denial of employment on those who tested positive
- Termination of employment for PLHA
- Co-workers refuse to work next to PLHA
- Prevent access to training and promotion
- Gossiped about
- Isolated

Health care setting
- Treatment delayed
- Treatment withheld
- Premature discharge
- Refusal to admit patients to health care facility
- Testing without consent
- Breach of confidentiality within the health care
- Non-attendance to patients in bed
- No-attendance to individuals in outpatient clinics
- Inappropriate comments and behaviour (e.g. shouting, rudeness, etc)
- Health care providers also may fear stigmatization themselves because of their work with HIV-positive patients
- Negative perception that treating or taking care of PLHA is pointless since HIV/AIDS is incurable

In the Religious Context: Many religious organizations in general are known to respond negatively on issues of HIV/AIDS, e.g. on condom use. They have judgmental attitudes towards people living with HIV/AIDS in contrast to the principles of morality. There are some PLWHAs who have been denied spiritual services, when they were known to be living with HIV/AIDS or when they fell sick. When they died, sermon services were not provided during burial services. The perpetual requirement for pre-marital HIV testing by religious leaders ends up into segregation, discrimination and denial of certain rights and services for those found HIV positive. There is a lot of dysfunction between beliefs and practice among religious leaders with imposition dominance.

In the Media: For a long time the media has played a major role in maximizing stigma in the society. HIV/AIDS reporting in the media is often
negative, fear arousing, discrediting and victimizing. Words such as AIDS is DEATH, a killer disease, or disaster, a horrendous scourge (Umeme, nyambizi, PHD, miwaya etc). Addressing persons living with HIV/AIDS as AIDS sufferers, victims or associating the situation with promiscuity, all provoke attitudes of stigma among the people.

It is only recently (late 90s) when the media started reporting HIV/AIDS with a human face, but even then, the ‘After a Long Illness Syndrome’ still lingers on. The media in Tanzania even after repeated training on HIV/AIDS is still reporting sensationally, doing more business than services. They are yet to start reporting thematically – e.g. on mother to child transmission, on national or District response, on stigma, on VCT, support groups etc.

THE EFFECTS OF SIGMA AND DISRIMINATION

• Deterioration of interpersonal relations
• Negative emotions
• Rejection of the HIV antibody test
• Stress related to the hiding of the condition
• Anxiety
• Depression
• Guilt
• Loss of support
• Isolation
• Difficulties with family dynamics
• Emotional or physical violence
• Deterioration of relations with health care providers

Stigma also prevents people from:
• Learning their status
• Disclosing
• Changing unsafe behaviour
• Using services
• Caring for people living with HIV/AIDS (PLHAs)
• Women to access services (e.g. PMTCT)

Stigma is a barrier to people with HIV disclosing their status and getting access to available support and care services, and to HIV prevention that encourages people to adopt safer behaviour.
Associated HIV with bad behaviour and death discourages people from finding out if they are HIV positive or from disclosing their status if they know that they are.

Stigma intensifies the pain and suffering of PLHAs and their families. Stigma constantly reminds members of discriminated groups that they are social outcasts or even deserve to be punished. If people are mocked or treated with hostility, they may feel uncared for and are therefore less likely to take steps to protect themselves.

Stigma and discrimination can be reduced or eliminated if health workers especially Home Based Care Providers are equipped with skills to deal with all these.

**What is to be done to reduce stigma?**

- To create recognition of stigma
- Find common language to talk about stigma
- Self disclosure of HIV status
- Supportive counseling
- Use of non discriminative language
- Developing positive HIV prevention messages that help to normalize HIV
- Recognizing the diversity of sexual behaviors. Whilst in most societies normal sexual behavior is defined as sex between a man and a woman within marriage, in reality people practice a wide range of sexual behavior. Prevention programs can reduce discrimination by promoting appropriate approaches to safer sex among different groups.
- Encourage HIV-support groups that help empower people to challenge stigma and discrimination
- Ensure a central role for people living with HIV and AIDS
- Providing quality-counseling involving both partners wherever possible in pre- and post-test counseling.

**Helping individuals, families and Communities to cope with stigma**

- Interventions to prevent HIV-related stigma and discrimination are integral components of the comprehensive approach to HIV/AIDS in Home Based Care Services.
The following are important steps HBC providers need to follow:

Policy Development

- Involve consumers in program design, development, and evaluation of programs and policies.
- Support and engage other agencies in promoting confidentiality and nondiscrimination.
- Promote community development and mobilization.

Program and Services

- Use public education opportunities to put a human face on AIDS.
  - Involve people living with HIV/AIDS in public education.
  - Show the diversity of the epidemic.
- Support HIV prevention education materials developed by and for communities.
- Maintain a proactive presence in the community (e.g., in schools, at health fairs, at World AIDS Day, and at National HIV Testing Day events).
- Involve and support families and communities (infected and affected).
- Engage leaders from the business community and faith communities (e.g., "Business and Labor responds to AIDS," Faith Forums, Black Church Week of Prayer).
- Develop and implement training, policies, and procedures for all staff activities and programs.
- Integrate within contracts relevant provisions for prevention, care, and supportive services.
- Seek, value, and support a staff reflective of the diversity of communities.
- Provide training and technical assistance on confidentiality, nondiscrimination, and cultural diversity to staff, and other health and human service providers.
- Educate clinicians so that they are not reluctant to treat people living with or at risk of HIV/AIDS.
- Ensure access to confidential and anonymous HIV testing.
- Integrate HIV prevention into primary care.
- Integrate primary and secondary prevention.
- Communicate that HIV-related discrimination is illegal.
- Support and promote legal services for consumers.
- Remain cognizant of issues related to social isolation and stigma in rural areas.
- Identify and support a staff person(s) in the role of consumer advocate.
- Implement policies and procedures for complaints.
- Follow through on enforcement.
UNIT 14:
COMMUNITY INVOLVEMENT AND PARTICIPATION IN HBC

INTRODUCTION:
The National Health Policy clearly stipulates the need and role of community based health care in the overall improvement of the people’s well being. Indeed the main objectives of the policy are to improve the health and well being of the people. The specific aims of the health policy are to:

i. Make health services more accessible to all people in Tanzania
ii. Increase community participation and involvement in promoting healthy life styles.
iii. Promote multisectoral action in health care.
iv. Support and promote family health.
v. Reduce mortality and morbidity by providing preventive and promotive health care services.
vi. Train human resources from village level to the national level.

The health services policy accommodates HBC for chronically ill patients because the service improves access of health services to the very sick individuals within the confines of their homes. However, for the HBC to be successful it is vital that there be active community involvement and participation in the promotion of the service.

OBJECTIVES
- Explain the concept of community involvement and participation
- Describe the strategies for community involvement and participation
- Mobilize the community in support of HBC activities for PLHA and other chronic illnesses

SUMMARY OF CONTENTS
- Concept of community involvement and participation
The strategies for community involvement and participation in HBC services
Modalities for community mobilization-lobbying and advocacy
Community actors to be involved in sensitization
Role of community in HBC

TEACHING METHODS

Brainstorming
Lecture/Discussion
Group work
Plenary sessions
Role play

CONTENT

1. Definition of concepts
   (a) A community is defined as a group of people living together in the same geographical area and under the same administrative system sharing more or less common social and economic conditions
   (b) Community involvement is defined as a process by which partnership is established between the public sector and local communities in the planning, implementation, monitoring and evaluation of development projects and activities that are executed in the community. Genuine community involvement is an essential prerequisite for successful implementation of community based HBC activities.
   (c) Community participation in HBC is the involvement of the community in taking care of chronically ill patients providing social and material support to the patients and their families in homes.

2. Objectives of Community Involvement and Participation in HBC Services
   (a) To assist communities to identify their health and development problems through understanding of HBC as an essential part of the health care system.
   (b) To assist communities to plan and mobilize resources available locally and elsewhere for sustainable HBC services for chronically ill patients.
(c) To assist communities to plan and implement HBC activities aimed at supporting chronically ill patients receive quality continuum of care in the communities.
(d) To assist communities asses and address stigma and discrimination against HIV/AIDS related illnesses.

3. Strategies For community Involvement and Participation in HBC Services
(a) Provision of community education and sensitization to raise awareness in order to mobilize communities for action to solve their identified problems
(b) Identification and training of community HBC providers and patient care providers on the home based care mode and its operation.
(c) Finding ways and means to be used by the community to motivate HBC providers.
(d) Strengthening home-based care management information systems that is appropriate and efficient.
(e) Coordinating a focused inter-sectoral response with all stakeholders from village level to district level.
(f) Identification and supporting of economic groups conducting income generating activities.
(g) Identification and utilization of resources available locally as well as resources from else where.
(h) Strengthen community health care service delivery system and integration of vertical programs in the districts.
(i) Identification and utilization of community based organizations and structures.
(j) Ensuring regular availability of essential and appropriate medicines and supplies.
(k) Conducting operational research on HBC and using the findings for re-planning and implementing HBC activities.

Community Understanding of Home Based Care (HBC)
The community is the key stakeholder in HBC activities. It is therefore important for community members and leaders to have a clear understanding of the nature and functions of HBC. The community needs to fully conceptualize their roles and responsibilities in the planning,
implementation and monitoring of successful and sustainable HBC services.

In order to fully sensitize the communities and get them to understand the HBC concept and internalize it, strategies should be developed to create proper awareness among key stakeholders in the communities and these should include health workers, religious leaders, civic leaders, government workers and professionals e.g. teachers and media people, NGOs, CBOs, and other influential members and groups such as PLHAs.

**Key strategies for effective sensitization will include:**
(i) Conducting regular meetings in the community  
(ii) Using religious sermons and sessions  
(ii) Conducting specific seminars for strategic groups and players.  
(iv) Effective use of newspapers, radio, TV, leaflets brochures, posters.  
(v) Conducting culturally appropriate plays and events with youth and women groups.

**Roles and Responsibilities of the Community in HBC Services.**
A community has a variety of roles and responsibilities in the provision of HBC services. Effective implementation of HBC activities rest on the community’s understanding that chronic illness among community members is not a problem of one individual but rather a problem of the whole community. On this basis, the community has to undertake broad and specific actions to address the need of providing care to chronically ill patients.

**The major roles and responsibilities of the community on the HBC services**

<table>
<thead>
<tr>
<th>Roles</th>
<th>Responsibilities</th>
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| (i) **Conducting Situation Analysis** | • Collection of data or information on chronically ill patients in the community.  
• Assessment of needs and problems of chronically ill patients in the community.  
• Review what is being done about the situation of chronically ill persons.  
• Determination of the number of orphans in the community and their problems.  
• Make strategic decisions on what should be done to redress the situation. |
| (ii) **Development of a Community HBC Program** | • Identification of planning team. |
- Setting achievable objectives for HBC
- Identify target groups and criteria for their selection
- Design strategies i.e. the approach to be taken
- Set out activities to be implemented
- Identify resources that will be required
- Set out time frame for monitoring and evaluation. Identify collaborators and resources available in the community.

(iii) Development of Plan of action
- Decide on major activities to be undertaken
- Determine who should do what, how when and where.
- Plan for resources needed.
- Do training needs assessment
- Agree on how to fill gaps of the required resources.

(iv) Implementation of Planned Activities
- Determine management and organization i.e. how the program will be managed and administered
- Make decision on supervision of HBC activities: Follow up and reporting
- Supply requirements, storage and utilization.

(v) Monitoring and Evaluation
- Make assessment of program performance and trends; Resource utilization and community involvement and participation.

(vi) Re – Planning Activities
- Set new objectives and targets based on evaluation of program performance and results achieved.
UNIT 15:
SUPERVISION AND MONITORING OF HBC

ACTIVITIES

INTRODUCTION
All HBC activities must be supervised and monitored so that the service objectives are met to the highest level possible. Supervision in HBC must be done at all levels starting from central to the households. Standards that have been set will be the parameters in guiding both the supervisor and those being supervised. Supervision reports must be used to improve quality of care.

SUPERVISION
Supervision is an essential management activity that must be carried out regularly and systematically.

SPECIFIC OBJECTIVES:
By the end of this topic each participant will be able to:
1. Define supervision
2. Explain the aim and importance of supervision.
3. Explain the process and stages of supervision.
4. Conduct supervision at the community and household levels.

SUMMARY OF CONTENTS
- Definition of supervision
- Aim and importance of supervision
- Process and stages of supervision
- Supervision at the household and community level

TEACHING METHODS
- Brainstorming
- Lecture/Discussion
- Group work
• Plenary sessions
• Trainee to practice filling in each form

CONTENT
DEFINITION:
• Supervision can be defined as a set of necessary activities for improving the quality of health services.
• It is the overall range of measures to ensure that personnel carry out their activities effectively and become more competent at their work.
The purpose of supervision is to promote continuing improvement in the performance of personnel.

Supervision in the context of HBC is a management function planned and carried out to give support and assist the Community/home based providers in carrying out their tasks. It involves on-job transfer of knowledge and skills between the supervisor and the one being supervised through opening of an administrative and technical communication channels.

AIMS OF SUPERVISION:
Supervisory visits aims at:
• Assisting the CHBC providers to improve their performance.
• Ensuring uniformity to set performance standards.
• Identification of problems and solving them at appropriate time.
• Maintaining and reinforcing the administrative and technical link between higher and lower levels.
• Follow up decisions reached during previous supervision visits.
• Identification of the HBC provider’s needs for implementing services to patients.
• Promoting skills development as well as preventing “burn-out” of the HBC providers.

Through supervision the following elements are appraised:
• Quantity of work output
• Quality of care provided
• Time management.
• Utilization and management of resources.
• Assistance to co-workers(s).
• Support to community/family careers.

LEVELS AND SCOPE OF SUPERVISION

Planning for supervision
Supervision must be included in the annual health plans at each district and health facility.

Types of supervision
Supervision of HBC services can be categorized into routine, focused and emergency supervision.

• **Routine supervision** is carried out to check how daily activities are being performed.
• **Focused supervision** addresses specific areas that need more time and thorough examination.
• **Emergency supervision** is carried out in the event of change or divergence from performance and ethical standards in health care delivery.

The administrative routine supervision of HBC providers is the responsibility of the CHMT. The National level conducts periodic supervision and monitoring to measure quality and progress of implementation.

Areas to be supervised in HBC services include:

1. **Clinical package**
   - Clinical management of patient and nursing care
   - Referral support.

2. **Materials management**
   - Establishing procurement system and adequacy.
   - Maintenance of supplies records.

3. **Facilities and equipment management**
   - Adequacy of equipment and supplies.
   - Condition of equipment and supplies.

4. **Human resources management**
   - Placement of staff according to qualifications.
   - Norms, ethics and standards of performance.

**Monitoring and evaluation**
- Routine recording and reporting
- Submission of reports
**PROCESS OF AND STAGES OF SUPERVISION**

Before conducting the supervision the team should familiarize itself with:

- Main objectives of the supervision.
- The project to be supervised.
- The meaning of quality health care.
- The roles and responsibilities of the staff to be supervised.

The process consists of:

i) Preparatory phase

ii) Actual supervision/supervisory visit and

iii) Immediate feedback.

**Stage One: Preparatory phase**

- Arrange schedule for supervision.
- Identify priority issues for supervision (areas which need assistance).
- Prepare necessary tools for supervision.
- Review objectives, standards and level of performance.
- Review progress, supervision and recent evaluation reports if any.
- Prepare checklist to be used for supervision.

**Before conducting the supervision the team should familiarize itself with:**

- Main objectives of the supervision.
- The meaning of quality health care.
- The roles and responsibilities of the staff to be supervised.

**Stage Two: The supervision visit**

- Introduction of the supervisor.
- Explain purpose and objectives of supervision visit.
- Observe HBC provider(s) performing their duties and tasks and identify support needs.

**Stage Three: Immediate feedback**

Findings from the respective areas are discussed immediately with the management teams. Pointing out areas of strengths, weaknesses and discussing on how improvement can be made. The supervision and provider must agree on the course of follow-up action.
Supervision of HBC Services at health Center/Dispensary, Community and Household levels

The HBC Provider at health Centre and dispensary (contact person) will supervise the community HBC Provider, who in turn will supervise the family/care givers directly.

i. Supervisory activities at H/C and Dispensary
   - Conduct supervisor visits to all community HBC Providers in their catchments areas.
   - Monitor adherence to service standards and policies.
   - Compile report on monitoring forms 1 – 4 and submit to respective Project Managers of WHO/Italian Initiatives and to NACP of the Ministry of Health.
   - Conduct regular supervisory visits to support the community HBNC Providers and during the visits conduct one home visiting.

ii. Supervisory activities at community level
   This involves supervision of patient, families and care takers:
   - Supervisory visits should be carried out to patient family and caretakers, on how to care for the patients.
   - To monitor the adherence to service standards i.e. see how caregivers provide services to the patients e.g. procedures taught.
     Keeps records/register for all patients being cared for
   - Filling the HBC Forms
   - Compiling reports for health center and dispensary.

iii. Supervision at household level
   - The care giver/family member assists and supervises the patient in care provision.
   - The family member/care giver need support from the community HBC Provider who educates them on how to care for the patient and works very closely with them.
   - Patient is encouraged to perform self CARE (AUTONOMY) as much as possible.

Supervision report:
In addition to the oral immediate feedback the supervisor will be required to provide written feed back to the responsible administrative authority level of health services.

Purpose of supervision report:
Is to inform the supervised HBC providers and those have the authority to make decisions on what has been observed and discussed during the whole supervision exercise, including performance of HBC provider(s) in provision of HBC.

The issue of drugs, supplies and equipment should also be taken care of:
Supervision of HBC should be integrated within the district supervision activities.

Structure of the supervision report
Supervision report may be structured as follows:

- **Title page**
  This page is the front page of the report which has the title, date, place of supervision and the people or team, which conducted the supervision.

- **Acknowledgement**
  Word of appreciation to individuals and organizations, who participated and assisted in the supervision.

- **Acronyms/list of abbreviations**
  Elaborate meaning of short forms (e.g. H.I.V. = Human Immuno-Deficiency Virus).

- **Executive summary (if required)**
  This section may be important if the report has to be sent to top officials who often do not have time to read the whole report. It need not be more than one page. It needs to disclose to the reader the most essential points of the whole report. I.e. aims and objectives of the supervision, how the supervision was conducted, constraints, conclusions and recommendations made. In the report, the summary comes first, but it is written after all the sections of the report have been completed.

- **Introduction/Background**
  Describes the objectives of the supervision, places visited and people met. A brief description of methods used to do the supervision should be included in this section.

- **Main report**
Observations done, analysis of findings/observations/situation analysis: Also this section describes all strengths, weaknesses and constrains observed during supervision.

- **Conclusions and recommendations**
  Recommendations include action taken on the spot and action to be implemented based on conclusions. By the supervised community HBC Provider.

- **Summary**
  Supervision is important in HBC as it aims at assisting and supporting the HBC provider in meeting their patients needs of quality HBC which is the right of every individual patient.

- **Appendices**
  This section may be included in every report. It will include all the references which are not reflected in the main report.

**NB:** The completed report is sent to the appropriate authorities e.g. The District HBC coordinator, Project manager, NACP etc. for action.

**SUPERVISION TOOLS**

**Check lists**
The purpose of a checklist is to guide the supervisor on areas to be addressed during supervision. It also serves as a reminder to the supervisors on areas which would otherwise be overlooked. A well-filled checklist will act as a good reference in the future for the supervisors and the health staff who are supervised in the subsequent visits.

**Performance assessment**

1. It there a qualified HBC provider?
   - Does he/she have job description?
   - Check-is the HBC provider patient relationship good?
   - Is history taking adequate?
   - Is the patient given correct treatment?
   - Is the patient counseled properly?

**Equipment, drugs and supplies**

2. Is there a record of drugs and medical supplies?
- Are the equipment maintained in good condition? Check the standard list.
- Are drugs/supplies ordered in time according to needs and resources?
- Are there adequate supplies of drugs?

**MONITORING:**

**Definition**
On-going, systematic data collection and analysis for action. Monitoring intends to answer the question: Is the project implemented according to plan and schedule? Are targets being met? The aim of monitoring is to detect deviations from the plan and to institute timely corrective measures.

**What is to be monitored?**
In-puts and outputs are monitored. Specifically the following will be monitored:

i) Financial resources  
ii) Drugs and supplies  
iii) Activity implementation  
iv) Human resources

**Who will be responsible?**
The dispensary and NGO HBC providers fill in the data collection tools. They fill in the management form for each patient that they visit indicating the condition of the patient and services/care provided. The patient management form (Tool I), is kept at the health facility. The providers also fills in form IIA indicating the number of other care takers that they have trained, including those from the community, volunteers, NGOs and other groups in the community. Form IIIA is filled to indicate the number and categories of patients receiving HBC services, and states new cases, old cases and deaths. These statistics are disaggregated according to age and sex. Tool IVA is for reporting on the utilization of drugs and supplies. Copies of Tools IIA to IVA should be sent to the district every month. The district HBC coordinator uses the monthly reports for monitoring the services and conducts regular visits to the sites. They will compile the reports.
from implementing sites, and submit district reports using Tools IIB, IIB, and IVB to the MoH (NACP) at the end of each quarter. The supervision tools are available.

EVALUATION

Definition
Evaluation is usually undertaken annually. The aim is to determine whether the project is achieving its objectives.

2. What is to be evaluated?
   In HBC the following evaluation indicators are be tracked:
   (i) Number and per cent of participating health facilities with HBC guidelines
   (ii) Number and per cent of health care providers receiving training on clinical AIDS management guidelines
   (iii) Number and per cent of community and home-based care clients receiving at least one home care visit by participating C/HBC organizations
   (iv) Number and percent of community and family care givers trained.

Who are involved?
A team of evaluators composed of representatives of the stakeholders in the project, namely:
   • A representative from funding agency if the project if funded from other sources.
   • The MOH
   • The participating NGOs
   • The participating DHMTs
   • Representatives of PLHA
Usually in HBC, MoH through NACP will provide administrative support to the Annual evaluation. A consultant (s) may be contracted to conduct the evaluation.
UNIT 16:

PRINCIPLES AND THE CONCEPT OF TEACHING AND LEARNING

INTRODUCTION
This unit will enable the trainee to train the CHBC Providers, home care takers, and the patient on care of the patient at home. During the training the trainee will prepare lesson plans and conduct microteaching before field practice.

OBJECTIVES
By the end of this unit the trainee will be able to:

• Describe principles of learning and teaching
• Explain how learning can be promoted by the facilitator
• Describe different teaching methods/aids
• Utilize the principles of teaching and learning when giving health education.

TEACHING METHODS
• Lecture/Discussion
• Plenary sessions
• Microteaching

SUMMARY OF CONTENTS
• Principles of learning and teaching
• How learning can be promoted by the facilitator
• Teaching methods
• Teaching Aids

CONTENT
TEACHING AND LEARNING
• Review principles and concepts of teaching and learning.
• Review the three domains of learning i.e. Knowledge, Altitude and Skills.
• Motivation.
• Motivation accelerates learning especially self-motivation person learns faster than the one who is motivated.
• Readiness to learn.
• General Education background, intellectual ability and individual attitude makes one ready to learn and accept responsibility.
• Age of the trainee (too young or too old) will affect learning.
• Setting or realistic goals.
• Realistic goals, which are achievable, enhance effective and efficient learning.

Learners capacity to learn
• Learners learn in different ways and at different rates and speed. (Always consider individual differences when teaching)
• Learning situation

PRINCIPLES OF LEARNING
• Learning takes place at different paces in different individuals
• Learning must be rewarded or reinforced
• People learn by selective perception
• Active participation promote learning
• Practice/repetition are essential
• Things are learnt better if they are sequenced from simple to complex or known to unknown
• Objectives are essential for effective learning
• Feedback on performance is important in learning.

HOW THE FACILITATORS CAN PROMOTE LEARNING
• Establish good facilitator/participant relationship
• Consider participant as individual with different needs and abilities
• Give feedback to participant
• Motivate participant by providing a conducive physical and social environment
• Help participants to learn relevant materials
• Organize what is to be learned systematically
• Use different teaching methods/skills which make the learner be active

QUALITIES OF AN EFFECTIVE FACILITATOR
• Must have a command of theoretical knowledge about learning and human behaviour
• Display of attitude that foster learning and genuine human relationship
• Command of knowledge in the subject matter to be taught
• Control of technical skills of teaching that facilitate learning

TEACHING METHODS
The following is a description of the commonly used teaching methods in the training of HBC providers.

LECTURE DISCUSSION
A discussion is a learning activity where a teacher and his students talk together in order to share views, ideas and information about a topic or problem. They talk together in order to solve a particular problem. The discussion can be a guided one where the teacher uses a number of questions related to the topic under discussion in order to control its direction. This method allows the teacher to give room to the students to take part in a lesson through sharing ideas and points of view on a particular topic.

DEMONSTRATION
This is a teaching method where by a teacher performs an instructional activity in the presence of his students in order to show them how to do it, for example positioning a patient.

ROLE PLAY
It is a teaching method involving a spontaneous portrayal of a situation, condition or circumstances by selected members of a learning group. Example role-play to show community participation.

CASE STUDY
Is a planned learning activity dealing with solving an actual problem whereby the learner is involved in studying the problem or the actual situation in depth.
It is documented that learners can learn more effectively when actively involved in the learning process.
SIMULATION
Simulation can be defined as placing an individual in setting that imitates some aspect of similarity and designing a problem around that setting which requires the learners participation in initiating and carrying out through inquiry sequential actions.
Simulation refers to the act of closely approximating and controlling some aspects of practical realities of health care for the purpose of accomplishing specific instructional objectives or evaluating specific competences.

TEACHING AND LEARNING AIDS
These are materials which a teacher uses in order to help him teach effectively. They also help students to understand what they are being taught.
There are many different types of teaching aids. The following are some examples:
- Chalkboard
- Flip chart
- Posters
- Overhead projector and slide projector.

Effective teaching and learning aids should be:
- Accurate and relevant
- Appropriate for a particular age group
- Attract so that they can attract learners attention.
- Brief, clear and simple.

Categories
- Visual aids
- Audio aids
- Audio-visual aids

THE IMPORTANCE OF TEACHING AND LEARNING AIDS
- They arouse student curiosity and motivation and at the same time sustain student’s attention throughout the lesson.
- They help the teacher to clarify points
- They reinforce memory
- Aids help students in acquiring listening and observational skills.
UNIT 17:

FIELD WORK REVISION AND EVALUATION

The third and fourth week of training is allocated to field practice on HBC in patient’s homes.

OBJECTIVES

By the end of this unit the trainee will be able to:

- Utilize the home caring model for care provision in patients homes
- Provide feedback of the HBC field practice

SUMMARY OF CONTENTS

- Review of the home based caring model
- The art of home visiting
- Introduction to field work practice including field work practice objectives
- Planning for individual and group feedback
- Presentation and discussion of field work reports

CONTENTS

- The process of caring model will be reviewed before the field practice
- Trainees will be introduced on the art of home visiting
- Clinical objectives will be prepared by the trainer and given to each trainee before they depart to the fieldwork
- Daily work plans, objectives and daily diary will have to be prepared by each trainee.
- Guidelines for report writing should be given to trainees to guide them with report writing.
- Report presentations and discussions will be done at the end of fieldwork.
- During the fifth week, the trainees will report back to the training center ready for revision and a post-test will be administered at the end of training period.
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