Ministry of Health

Palliative Care Training Manual for Home Based Care Volunteers in Malawi

January 2010
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<table>
<thead>
<tr>
<th>Acronym</th>
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<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
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<tr>
<td>CHC</td>
<td>Catholic Health Commission</td>
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<tr>
<td>HBC</td>
<td>Home Based Care</td>
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<td>HBPC</td>
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<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>MOH</td>
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<tr>
<td>MST</td>
<td>Morphine slow release tablets</td>
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<td>NAC</td>
<td>National AIDS Commission</td>
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<td>PACAM</td>
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<td>QECH</td>
<td>Queen Elizabeth Central Hospital</td>
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<td>SSA</td>
<td>Sub Saharan Africa</td>
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<td>TB</td>
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INTRODUCTION

This manual is a training guide for volunteers who have undergone a ten days initial training in community home based care and is aimed at empowering these volunteers in the provision of home based palliative care services in Malawi.

Course description

The five day complementary training package is designed to equip volunteers with additional knowledge, skills and attitudes in the provision of home based palliative care services.

Course objectives

By the end of the course participants should be able to:

- Demonstrate understanding of the concept of palliative care.
- Demonstrate effective communication skills to patient and family
- Provide holistic patient and family care
- Demonstrate the ability to assess and manage pain
- Demonstrate the ability to work in a palliative care team
- Demonstrate the ability to provide nutritional education and counseling to palliative care patient and family
- Demonstrate the ability to provide care to the dying patient
- Demonstrate the ability to advocate to the patient on will writing
Demonstrate the ability to support the family during the period of grief and bereavement.

Demonstrate understanding of the concept of care of carers

**Participant evaluation**
- Pre test
- Post test
- Holistic assessment of patient and family using a checklist

**Course evaluation**
- Evaluation form to be completed by each participant at the end of training.

**Suggested course composition**
- 20 participants
- 4 facilitators.
UNIT 1: INTRODUCTION TO PALLIATIVE CARE

Time allocation: 2 hours

Aim

This unit is intended to equip participants with knowledge, skills and attitudes needed to understand the concept of palliative care.

Learning objectives
By the end of this unit participants should be able to:

- Define palliative care
- Explain the guiding principles and approaches to palliative care
- Describe the models of palliative care
- Explain the roles of volunteers in palliative care

Suggested teaching: Brainstorming, Lecture, discussion,

Learning aids: Flip chart, training manual

Teaching and learning activities
A. Definition of Palliative care

Step 1

Ask participants to brainstorm the definition of palliative care and list the responses on a flip chart.

Step 2

The trainer gives the definition of palliative care as follows:
Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual

B. Aim of palliative care

Step 3

The trainer explains to participants’ aims of palliative care using the following content

- To help people with incurable illness, and their families, live more comfortable, active and hopeful lives
- To provide relief from pain and other distressing symptoms;
- To affirm the patient’s life and to regard dying as a normal process
- To neither hasten nor postpone death;
- To acknowledge the physical, social, psychological and spiritual aspects of the patient’s care
- To offer care and support in order to allow patients to live as actively as possible until their death;
- To offer care and support to the family and guardians during the patient’s illness and in their own bereavement.
- To support the patient and family in their grief.
C. Guiding principles and approaches to Palliative care:

Step 4

Guide participants to discuss the guiding principles, approaches to palliative care by giving examples

Step 5

Using the following information the trainer should give the summary of the discussion:

The following principles should be observed for effective provision of palliative care services;

- Attention to detail: Time spent can bring great relief to the patient
- Honesty and respect: This should be shown at all times and the truth given when asked for, in terms understandable by the patient. False reassurance helps no one.
- A holistic approach: Concern for the emotional, spiritual and social aspects of the patient’s care as well as controlling their physical symptoms
- A patient centered approach: To deal with what the patient thinks is the most important in all aspects of his/her care
- A problem oriented approach: Taking time to deal with each problem in turn, no matter how small

D. Models of palliative care service delivery

Step 6

Ask participants to explain the models of palliative care they know.
There are six models used to deliver palliative care

1. In-Patient Care
2. Home – Based Care
3. Hospital Palliative Care
4. Palliative Day Care
5. Outreach Clinic
6. Road side.

**Step 7**

The trainer should discuss with the participants the following models of palliative care:

**Model 1: In-patient Care**

This takes place in a separate building or it can be a ward in a general hospital that admits palliative care patients. It is ideal for patients who cannot be looked after at home for medical or social reasons. Some units look after children only. The care is provided by trained by Palliative care team.

**Model 2: Home Based palliative care**

Care is provided at home mainly by the family, relatives’, close friends and volunteers. The patient is in the familiar environment.

Trained palliative care team conducts home visits once or more times per week, to help with supportive measures, counselling and pain & symptom control. On each visit the team assesses the patient and provides care holistically. If hospital admission
is indicated the team recommends that the patient be admitted to a hospital for a close follow up. Volunteers play an important role in the provision of day to day care and linking the patient with the team if need arises.

**E. The roles of the Home-Based Palliative Care Volunteer**

**Step 8**
Group Work: Roles of the home based palliative care volunteer

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**Activity**

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The Palliative Home-Based Care Volunteer is a trusted ‘bridge’ between the patient, family, community and the palliative care team.

**The roles are to:**

1. Identify patients who need palliative care.

2. Assess the needs of the patient and family.

3. Refer problems to the nurse, the health care facility, pastoral care, social/community services or other care providers as required.

4. Provide holistic care.
5. Monitoring of drug adherence

6. Follow up of pre ART patients

7. Provision of basic nursing care with emphasis on infection Prevention

8. Record keeping and monthly reporting
UNIT 2 BASIC FACTS AND INFORMATION ABOUT CANCER

Time allocation: 1 Hour

Aim
To equip participants with knowledge on basic facts about cancer

Learning objectives
By the end of this unit participants should be able to:

- Define cancer
- Describe the overview of Cancer burden in Africa
- Describe types and forms of cancer
- State the relationship between HIV/AIDS and cancer

Suggested teaching and learning methods: Brainstorming, Lecture, discussions.

Suggested teaching and learning materials: Trainers manual, Picture of different types of cancer, flip charts, markers, posters.

Teaching and learning activities
The trainer should review basic facts about HIV/AIDS from HBC manual

A. Definition of Cancer

Step 1
Ask participants to define cancer and list responses on a flip chart.
Step 2

The trainer should provide information on definition of cancer

Cancer is an abnormal growth of cells which tend to multiply in an uncontrolled way and, in some cases spreads through the bloodstream and lymphatic system to other parts of the body.

B. Overview of Cancer burden in Africa.

Step 3

The trainer should provide information on Cancer burden in Africa

The World Health Organization (WHO) has estimated that the world cancer burden will increase according to the current trends from 10 million new cases each year in 2000 to 16 million in 2020. 70% will be in the developing world, rising from 5.2 million annually to 8.8 million an increase of ~ 60%. SSA will account for< 1 million of these cases.

In the developing world one third of cancers are potentially preventable and another third are treatable if detected early. Global cancer statistics (2002). In Africa a cure is rare due to the cost and paucity of investigations and curative treatments e.g. surgery, chemotherapy and radiotherapy. Merriman (2006). In 2002, 7.6 million people worldwide died of cancer. This was 13% of the global mortality and more than the number of deaths from HIV/AIDS, TB and malaria combined. (~5.6 million)

NOTE. Early cancer detection and prevention could prevent 100,000 deaths and paediatric cancer treatment programmes could save lives of 5,000 children.
C. Types and forms of cancer

Step 3

Let the trainer divide participants into small groups to list forms and types of cancer they know and present to the larger group.

Step 4

The trainer should summarise discussions on forms and types of cancer using the following information:

Cancer can attack any tissue of the body and can appear in different forms like lesions, and tumors. There are different types of cancer depending on the organ attacked for example Kaposi’s sarcoma, esophageal carcinoma, cervical carcinoma, and breast carcinoma.

D. Prevalence of Cancer

Step 5

The trainer should provide information on the prevalence of cancer using the following information:

The incidence of cancer is set to increase by 400% in the next 50 years (WHO, 2002)

However, incidence and prevalence data on cancer in Malawi is lacking. This is due to a number of factors which affect the accurate collection of statistics. Issues to discuss: how many people have been diagnosed with cancer over a period of one year? How many people have died of cancer-related deaths? According to recent based information, up to 60% of most cancer types are treatable if diagnosed early. 20% of cancers are preventable with right diet and physical exercises while only
20% is terminal. Even in the era of HIV/AIDS, many men with Kaposi's sarcoma have shown strong survival rates if treated early and those with low CD4 if receiving ARVs.

E. Common Cancers in Malawi

Step 6

The trainer should provide information on common cancers in Malawi as listed below:

Kaposi's sarcoma 39%, cervical 21%, esophagus 15%, lymphoma 8%, urinary bladder 5%, breast, liver and prostate 3% conjunctiva 2% and stomach 1%.

Step 7

Let the trainer show participants' pictures of common cancers in children and adults such as lymphomas and Kaposi's sarcoma.
Lymphomas
Karposis Sarcoma
F. Relationship between Cancer and HIV/AIDS

Step 8
Ask participants to describe the relationship between cancer and HIV and write responses on the flip chart.

Step 9
The trainer should summaries discussions using the following information:

- Current data suggest that Kaposi’s sarcoma is the most common cancer in Malawi.
- Cancer and HIV are chronic conditions that are not curable therefore both require palliative care.
- Some cancers are HIV related which develop due to low immunity e.g. Kaposis Sarcoma.
UNIT 3: COMMUNICATION WITH PATIENTS AND FAMILIES

Time allocation: 1 hour 30 minutes

Aim: To equip participants with knowledge, skills and attitudes needed to communicate effectively with palliative care patients and families

Learning objectives
By the end of this session participants should be able to:
- Define communication
- Explain the importance of communication in palliative care
- Demonstrate effective communication skills.
- Explain the qualities and attitudes needed in communication.

Suggested methods: Role play, Facilitated discussion, experiential, Brainstorming, Lecture, Value clarification

Suggested teaching/learning aids: Flip chart, Manual

A. Communication

Step 1
Ask participants to brainstorm their understanding of the term ‘communication’. Put the responses on the chalkboard or flip charts.

Step 2
The trainer should discuss with participants using the following definition:
Communication is the sharing of ideas or information in order to come to a common understanding.

**Communication is the process of sharing information, ideas and experiences from one person to another in order to enhance behavior change**

Communication with patients can make a difference in their lives and they can “start living again”. It is greatly needed while handling a terminally ill patient and his/her family members/carers. Enhance the quality of remaining life of a terminally ill patient and his/her family.

Poor communication on the other hand makes life difficult for a patient and his family and carers because it creates a sense of rejection, confusion, misunderstanding and despair.

Communication starts with ourselves. There is need to be more Self-aware because once we are self aware, we become in charge of our lives and that can influence the way we communicate with others.

**B. Importance of Communication**

**Step 3**

The trainer should lead a discussion on importance of communication using relevant examples and consolidate the points as follows:

- Establish & maintain a relationship
- Promote equality in that relationship
- Gather information
- Provide information
- Facilitate self-expression
- Promote recovery
- Reassure the patient
- Manage & control symptoms
C. Communication Skills

*Step 4*

The trainer should lead the discussion on communication skills and their implications in daily life.

*Step 5*

The trainer should summarise the activity by stating the following skills:

- Listen, speak and act with respect, warmth and empathy.
- Show that you wish to understand and help.
- Always be honest and trustworthy.
- Find out how the person is feeling. Is he or she worried, in pain, or Hungry?
- Reach behind the words for the real message – what is the person really trying to say?
- Notice body language and facial expression.
- Make sure you have understood correctly. Ask questions to clarify.
- Support with hope, always focus on what can be done.
- Do no harm. Do not make the person feel guilty, ashamed or worried.
- Give the person time to make decisions, to think and to feel.
- Help the person find and use his/her strengths.
- Encourage the person to make his/her own decisions.
- Encourage communication between the patient and the family.

D. Qualities and attitudes needed in communicating with patients and Families
Step 6
The trainer should lead a discussion with participants on qualities and attitudes needed in communication with patients and Families

Step 7
The trainer should summarize the discussion under the following headings:

- Desire to help - have an inner urge to help the patient and his/her family members.
- Patience - take time to listen to patients, they are in most cases weak and are not sure of what to say to us.
- Respect for others - handle every patient as an individual. Respect individual beliefs, values and attitudes.
- Genuineness - try to be honest to patients and their family members to be trusted.
- Confidentiality and Privacy - ensure privacy and confidentiality while dealing with each patient and their families.
- Knowledgeable - give accurate and clear Information to clients to enhance trust for future communication with the patient.
UNIT 4: COMMUNICATION AND COUNSELING IN CHILDREN

Time allocation: 1 hour

Aim
To equip participants with knowledge, skills and attitudes needed to communicate effectively with children who are receiving palliative care.

Learning objectives
By the end of this unit participants should be able to:

- Explain principles for effective communication with children
- Identify barriers to communication with children
- Explain different tools & media used in communication with children

A. Introduction:
Step 1

The trainer introduces the session with the following information
Children like adults need the therapeutic support to enable them with challenging circumstances that they face. They have physical, psychosocial and spiritual needs that are different and our responses need to be different from those we would give to adults.

It is always important to have a parent/guardian when dealing with children unless the child requests to be alone

Communication with children needs the use of age appropriate language to facilitate both the passage of information to the child and expression of their feelings
B. Principles in counseling and communicating with children

Step 3
The trainer should ask the participants to brainstorm what they think are principles in counseling and communicating with children and put on flip charts.

Step 4
The trainer should explain to participants the principles by using the following information:

Children are unique… they are not small adults. Communicating and counseling children requires building a therapeutic relationship and creating good rapport that involve the following:

- **Trust** - a trusting relationship between the care giver and the child leads to a successful therapeutic support

- **Privacy** - The counseling environment needs to be safe and quiet to allow free sharing

- **Confidentiality** – Information shared with the child should kept confidential and only shared with their consent.

- **Family focused**- Because children live in families, their families need to be involved in care

- **Honesty** – respect views of the guardian and never lie to a child! A child trust in those who are caring for him. Lies destroys, future care and bring fear and anxiety to children.
Freedom to Express - Allow children to express their worries and anxieties through play, drawing, songs or other activities.

Avoid direct eye contact which is too threatening

Participatory approach - Include children in their care, Speak with the child and not to the child, teach them about their illness.

Patience - Communicating well with sick children takes time; develop patience and make the time you have with the child count.

Respect - Respect children for who they are with a non-judgmental attitude. Do not ignore the child’s viewpoint

C. Barriers to effective communication and counseling in children

Step 5
The trainer should lead a discussion with participants on Barriers to effective communication and counseling in children

Step 6
The trainer should summarize the discussion under the following headings:

- Language: inappropriate age level
- Adult’s failure to come to a child’s level
- Wrong message/wrong information
- Lack of active listening
- The assumption that the child is too small to understand

D. Tools and media for counseling and communicating with children

Step 7

Ask participants to brainstorm tools and media for counseling and communicating with children. Put the responses on the chalkboard or flip charts

Step 8

The trainer should present to participants the following tools and Medias that facilitate effective communication and counseling with children

- Play
- Drawing
- Use of toys
- Telling or story writing
- Music and dancing
- Age appropriate language

ZOWONA ZENIZENI ZA MA ARV

KODI MA ARV NDI CHIYANI?
• Ma ARV ndi mankhwala amene amathandiza kubwezeretsa chitetezo mthupi chomwe chaonongeka chifukwa cha kuchuluka kwa tizirombo ta HIV mthupi
• Mtundu wa ma ARV omwe umagwiritsidwa ntchito kwambiri ku Malawi kuno ndi Triomune. Mu m’bulu umodzi wa Triomune muli mankhwala a mitundu itatu yosiyana.

KAMWEDWE KAKE KA MA ARV

• Triomune amamwedwa piritsi limodzi m’mawa limodzinso madzulo. Masabata awiri oyambilira munthu amamwa mankhwala otchedwa Starter Pack omwe cholinga chake ndikufuna kuliyesa thupi ngati nkwalawoliyanjane nawo kapanayi.

UBWINO WA MA ARV

• Amathandiza kubwezeretsa chitetezo cha mthupi chomwe chinaonongeka chifukwa cha kuchulukana kwa tizirombo ta HIV.
• Amachepetsa kuswana kwa tizirombo ta mthupi kotero munthu amakhala wa mphavu ndi thanzi.

• WOYENERA KUMWA MA ARV NDANI?

• Munthu yemwe walandira uphungu ndikuziyesetsa magazi ake ndipo wapezeka ndi HIV.
• Waonedwa ndi dokotala ndipo watsimikiza za kukula kwa vuto lake.
• Waphunzitsidwa bwino ndipo wavetsetsa za m’mene ma ARV amagwirira ntchito.

• ZINA MWAZOVUTA ZOMWE ZIMABWERA CHIFUKWA CHA MA ARV

  • Dzanzi
  • Kupweteka kwa mutu ndi m’mimba
  • Kupweteka kwa miyendo, kutetha moto, ndi kubayabaya kwa mapazi
  • Mseru kapena kusanza
  • Maso kuchita chikaso komanso ziwengo pa khungu

Munthu akamva zina mwa zovutazi ayenera kupita kuchipatala kuti akathandizidwe moyenera.

ZOYENERA KUDZIWA MUNTHU YEMWE AKUMWA MA ARV

  • Amagwira bwino ntchito ngati amwedwa mitundu ingapo mophatikiza
  • Sachiritsa matenda a Edzi
  • Munthu amayenera kumwa moyo wake onse ngakhale atapeza bwino
  • Akhoza kufalitsa kapena kuonjezera tizilombo ta HIV ngati sagonana modziteteza (kugwiritsa ntchito kondom moyenera nthawi zones)
  • Mkwapafupi kuti thupi lipime ku mankhwalawa ngati amwedwa modukizando kiza
  • Ma ARV sagawana
UNIT 5: TEAM WORK

Time allocation: 1 hour

Aim
To equip participants with knowledge, skills and attitudes required for effective teamwork.

Learning objectives
By the end of this session participants should be able to:
- Define a team
- Describe team work
Describe composition of a Palliative care team
State the importance of team work
Describe characteristics of an effective team

**Suggested methods:**
Brainstorming, Discussion, Lecture, Experiential learning.

**Suggested teaching/learning aids** –
Flip chart, Power-point, Manual, Coloured card

**A. Definition of a Team**

*Step 1*
Ask participants to define team work and put the responses on a flip chart.

*Step 2*
The trainer should summarize give the participants the following definitions

*A team is a group of individuals working together to achieve a common goal.*

**B. Team Work in Palliative Care**

*Step 3*
Guide participants to discuss Team Work in Palliative Care using the following information;

Palliative Care is a team oriented approach and holistic in nature deals with the physical, psychological, social and spiritual needs of patients and families

**C. Composition of a Team in Palliative Care**
**Step 4**

The trainer should ask participants to brainstorm groups of people that make a palliative care team and put responses on the flip chart.

**Step 5**

The trainer to summarize the discussion by describing the following team:

- Patient
- Close family members/community members
- Volunteers
- HSA
- Doctor
- Clinical officer
- Medical assistant
- Nurse
- Social worker
- Chaplain
- Priest/other religious leader
- Chiefs and other leaders

**D. Importance of team work.**

**Step 6**

**Group Work: Team Work**

![Activity]

Divide the class into four groups. Give each group a square which has been cut into pieces. Ask the group to assemble the square in 1 minute.

Ask the group that finished earlier to describe the factors that made them to assemble the square faster and ask the group that failed to describe the factors that made them not to assemble the square in time.
**Step 7**

The trainer to summarize the discussion by explaining that team work is important for Better decision making

- Safer approach to patients and families
- Opportunity for growth and learning, self appraisal – learn from friends
- Supportive environment lessens stress
- More Fun!

**E. Characteristics of an effective team**

**Step 8**

Ask participants to discuss characteristics of an effective team and complement with the following information

- Recognizing the centrality of patient and family needs
- Mutual respect for specific personal contribution of each team member
- Competence of each team member in his/her own discipline
- Competent leadership appropriate to the structure and function of the team and the tasks at hand
- Mutual support
- Good communication
- Early referral
Role of a volunteer in a team;

The volunteer is a team member for the benefit of the patient and should be able to work with the team. This implies that volunteers should understand their competencies and their limitations and they should make efforts to know the important key players in the community. Volunteers should refer patients among members according to the needs; source information and other resources from various team members discussed above to meet the goal.

UNIT 6: HOLISTIC ASSESSMENT OF PATIENT AND FAMILY

Time allocation: 1 Hour 30 Minutes

Aim
To equip participants with knowledge, skills and attitudes needed in holistic patient and family assessment

Learning Objectives
By the end of this session participants should be able to:
- Conduct holistic assessment on patient and family
- Intervene according to the identified problems
- Report/refer patients to the appropriate services
Suggested methods: Brainstorming, Discussion, Lecture, Experiential learning, Case study

Suggested teaching/learning aids – Flip chart, Manual,

A. Holistic assessment

Step 1
The trainer should introduce the session with the following information

Assessing patient and family needs holistically is important to address the physical, psychological, social and spiritual needs of the patient.

The care provider should ask questions, listen and observe carefully.

The checklist should be updated every time the care provider visits the patient.

Step 2

The trainers should ask participants to describe their experiences and or views about assessment of the home and the sick in general, ask them the areas they have been focusing on and put responses on the flip chart

Step 3

The trainer should discuss with participants the ideal assessment as follows

1. Home assessment
During a home visit, the care provider should;
   - Observe the general cleanliness of home surroundings, waste disposal,
Ask about availability of safe water and its utilization
Ask about availability and food utilization in the home

2. A **general assessment of the patient/client should follow to find out the needs of the patient and family.** Assessment should include;

a. **Physical assessment**
   - Observe the general condition of the patient (weak, sick, dehydrated)
   - Ask patient for any problems/complaints by asking the following questions
     - How are you feeling?
     - Do you feel pain? Where?
   - Ask if the patient had sleepless nights, diarrhoea, fever, nausea or vomiting?
   - Ask about feeding pattern and any feeding problems
   - Are if the patient is taking any medications or other remedies? Checking on the treatment/drugs taken, side effects and adherence

b. **Psychological Assessment**
   - Ask if the patient has any worries or concerns
   - Observe if the patient is confused or depressed
   - Ask if the patient has any person whom he/she can talk to when he/she has problems?
   - Ask if the patient is worried about the family – wife/husband, children (who is looking after the children, their needs, understanding of the illness and what is happening, are the children going to school?)

c. **Social – cultural assessment**
➢ Ask if there is someone who helps the patient and what is the relationship?
➢ Ask how the family is managing or coping in terms of finances, food, transport, provision of essential needs?
➢ Ask the patient what he/she thinks is the cause of the illness?

\[ \text{d. Spiritual assessment} \]
➢ Ask if the patient is belonging to any denomination/religious group
➢ Observe if the patient has fears or worries
➢ Ask if the patient is visited by church members or receives support from the church/mosque
➢ Find out if the patient needs prayers? Always refer the patient for pastoral care.

\[ \text{B. What the care provider can do at home} \]

\[ \text{Step 4} \]
(a) The trainer should guide participants to discuss what should be done after assessment as follows. After the assessment the care provider should;

- Help the patient and family identify and describe their problems.
- Help them begin to work out their problems.
- Provide counseling, education and emotional support.
- Respect the abilities and choices of the patient.
- Encourage community and pastoral support
(b) The trainer should review the following basic nursing care skills with emphasis on infection prevention:
- Bed bath
- Wound care
- Oral care
- Pressure area care
- Feeding

C. Reporting and referral

Step 5

The trainer should explain to participants what the provider should report monthly and refer patients to the nurse or health facility or for other services when there is need.

UNIT 7: PAIN ASSESSMENT AND MANAGEMENT

Time allocation: 2 hours 30 minutes

Aim: To equip participants with knowledge, skills and attitudes required for effective pain assessment and management.

Learning Objectives
By the end of this session participants should be able to:
- Define pain.
- Discuss causes of pain.
- Explain pain assessment.
Discuss pain management.
Explain roles of the HBPC volunteers in caring for patients on morphine
Describe other ways of relieving pain

SUGGESTED METHODS: Brainstorming, Discussion, Lecture, Experiential learning, , Case study.

SUGGESTED TEACHING/LEARNING AIDS - Flip chart, Handouts and Drug samples

A. Definition

Step 1
Ask participants to define pain and write on the flip chart

Step 2
The trainer should give the participants the following meaning:
Pain is what the patient says it hurts.

B. Causes of pain.
Step 3
Ask participants to discuss the causes of pain and complement with the following:

- Pain can have many causes: diseases such as cancer and HIV/AIDS,
- Drugs, surgical procedures, trauma, pressure sores and infections
- Pain can be made worse by emotions, loneliness and worries.
C. Pain Assessment

*Step 4*

**Group Work: Pain assessment**

**Activity**

Divide the class into four groups. Give each group a flipchart and a marker. Ask one group to discuss how to assess pain, questions that can help to assess pain and tools they can use to assess pain and present in plenary.

Allow approximately 10 minutes for each group to discuss and 10 minutes to present. Then the trainer presents supplemental information with the following points:

**Important Points to Remember When Assessing Pain**

- Remember that good assessment is the first step in proper management of pain.
- Encourage the patient to talk about his/her pain and problems.
- Remember that most patients have more than one pain e.g. headache, backache.
- Observe the patient for signs of pain or anxiety – such as facial expression, restlessness and posture.
- Ask simple questions and listen carefully to the patient and to the guardian.
- Explain the possible plan of management in relieving the pain.
- Document findings, and report to the appropriate person.
- Reassess at every visit.
Remember every person feels pain differently.

The following questions can help in assessing pain

- Do you have pain?
- Where is your pain?
- How long have you had your pain?
- Is it constant or does it come and go?
- How bad your pain is: mild, moderate or severe (Level 1, 2 or 3)?
- When is your pain worse: at night? In the morning?
- What does it feel like: stabbing, burning, aching, tingling, numbness, etc.
- Do you have other problems associated with your pain?
- What makes your pain worse? e.g. loneliness,
- walking, sitting, eating
- What relieves your pain e.g. rest, activity, food, company
- How does it affect your daily life? (E.g. sleep, appetite, mood, Family)
- What do you think is causing your pain?
- What drugs are you taking and how are they helping?

Some Assessment Tools to be used.

Children may not be able to tell much about their pain. When assessing a child’s pain one may find it helpful to use finger to shows how he or she feels.
Enquire how severe the pain is by showing on your fingers the severity of pain. 0 is no pain and 5 fingers is most severe.

Pain can also be assessed by using stones of different sizes. The child can choose the stone that describes his/her pain best: the smallest stone for a little pain, the biggest stone for severe (big) pain and so on. The volunteers should report findings to the appropriate person.

D. Management of Severe pain

Step 5
The trainer gives a lecture on the management and common drugs used in pain management as follows:

- Pain is managed according to severity (mild, moderate and severe): classification and prescription of treatment is done by the health worker.
- The volunteer’s role is to assess, help the patient, teach, supervise and report.

Common drugs used in pain management:
Mild pain: Paracetamol, Aspirin
Moderate pain: Codeine, Tramadol
Severe pain: Liquid oral Morphine, Morphine Slow Release Tablets (MST)

*Morphine is a drug of choice in managing severe pain.*

**Step 6**

**Group Work: Morphine**

**Activity**

Divide the class into four groups. Show the groups the two kinds of morphine most commonly available at this time.

Allow approximately 10 minutes for each participant to have a chance to see liquid morphine and the slow release tablets. Then the trainer presents supplemental information in the table below;

<table>
<thead>
<tr>
<th>Kinds of Morphine</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Liquid Morphine</td>
<td>Acts quickly, Is taken every 4 hours, It is in two types: the weaker solution is <strong>green</strong> and the stronger solution is <strong>pink</strong></td>
</tr>
<tr>
<td>Morphine Slow Release Tablets (MST)</td>
<td>Act slowly, Are taken every 12 hours, Work best when the pain is already well controlled and the patient is mobile</td>
</tr>
</tbody>
</table>

**E. The role of the volunteer when caring for patients taking morphine**

**Step 7**
The trainer should read the case study below aloud for easy understanding of roles of home based palliative care (HBPC) providers. After reading the case study, ask participants to explain what they will be doing when caring for patients on morphine.

**Case study**

Ensure responses cover the following points and consolidate the role the HBPC volunteer as follows:

- Ensure that the patient has good support from the guardian and family
- Work closely with the guardian and the rest of the palliative care team
- Assess pain at each visit.
- Volunteers are not permitted to administer morphine to patients but may supervise to be sure that drugs are being taken correctly by;
- Check the amount of liquid or number of tablets left in the bottle at each visit to ensure that the patient is taking the correct dose.
  - Check that the bottle is correctly labeled.
  - Make sure that the drug is being stored safely out of the reach of children and in a cool, dry place.
  - Make sure the patient is taking laxatives including other measures to avoid constipation – unless there is diarrhea.
  - Ensure no one else is taking the drugs. They are prescribed for the patient only.
  - Help the patient and guardian find a way to remember to take drugs regularly (by the clock, by the sun, by mealtimes and bedtime, etc).
- Document and report the following;
  - Drowsiness
- Nausea or vomiting (this usually passes in a few days)
- Constipation that is not responding to treatment
- Uncontrolled pain, symptoms or other problems affecting pain

F. pain relieving measures

Step 8

The trainer should let participants brainstorming other ways of relieving pain and put responses on flipchart/chalkboard.

Step 9

The trainer should provide supplementary information and explain to participants other ways of relieving pain using the following information:

Pain can be made worse by lack of sleep, anxiety, loneliness and grief. There are many holistic ways volunteers can help a person who is in pain:

- Advising patient to have enough sleep
- Provide comfort and good basic care: bathing, grooming, positioning, cool/warm compresses, good nutrition, massage, comforting and natural remedies.
- Provide helpful distraction: music, games, conversation, reading, etc.
- Suggest making a memory book or box with photos, stories, pictures or other objects that can then be shared with the children. (A memory box is also a good place to
keep important things such as the health passport book and prescriptions.)
- Provide counseling to help with problems and worries.
- Offer prayer and hope, and ensure that spiritual/pastoral support is offered.
- Help family and friends learn ways to relieve the patient’s pain.

UNIT 8 NUTRITION

Time allocation: 1 hour

Aim: To equip participants with knowledge, skills and attitudes needed to meet nutrition requirements of palliative care patients.

Learning Objectives
By the end of this session participants should be able to:
- Conduct nutrition assessment of palliative care patients
- Provide nutritional education and counseling to the patient and family

Teaching methods: Brainstorming, facilitated discussion

Teaching & Learning aids: Flip charts, markers, training manual
A. Nutrition assessment

**Step 1**

Illness affects a person’s ability to eat and drink properly, the trainers should ask participants to brainstorm the type of assessment that can be conducted to find out condition or factors which can affect the ability of the patient to eat. Then the trainer should write responses on the flip chart and consolidate the responses using the following information;

To ensure that a patient receives enough nutritious foods and fluids, the care provider should assess the following;

- Loss of appetite or refusal to eat.
- Physical symptoms that affect nutrition such as nausea, vomiting, taste changes, chewing or swallowing difficulties, diarrhoea, constipation, weight loss, weakness, failure to thrive in children, poor condition of the skin or hair, oedema
- Fatigue, indigestion, pain, infection or side effects of drugs.
- The ability of the patient or guardian to collect and prepare nutritious foods.
- Knowledge about nutrition and hydration.
- Psychosocial or spiritual problems such as neglect, isolation, depression, abandonment, loneliness or hopelessness.

B. Nutrition Education and Counseling

**Step 2**
Trainer ask participants to be in groups of four and discuss what they can do if they have a patient who has a nutritional problem and ask them to present to the larger group.

**Step 3**

The trainer should summarize the discussion as follows:

- Provide nutrition and hydration education and counseling.
- Take small but frequent meals that can be tolerated from the 6 food groups.
- Take enough fluids in form of water, thobwa, juices etc more than 3 liters per day
- Teach how to make special meals depending on need. For example, the provider can give education on how to make Power Drink Recipe (for boosting energy) 1 cup chopped ginger; 2 cups lemon juice; 3 cups peeled chopped aloe Vera; brown sugar to taste; 2 tablespoons honey; 5 liters of water. Boil for two hours. Take 1 tablespoon 3 times daily, if tolerated, to boost energy.
- Encourage communities to establish communal gardens
- The provider should advise the care givers/ family member:
  - Not to force feed, only feed a patient who is alert and cooperative.
  - Observe carefully for any difficulties with chewing and swallowing.
  - Avoid foods that are not tolerated or wanted by the patient.
  - Follow the patient’s wishes and abilities.
  - Position the patient safely and comfortably for eating
  - If the patient is refusing food or liquids, keep the mouth moist with frequent mouth care, for
example with drops of fluid or a damp cloth and keep lips moisturized with lotion or Vaseline.

- Provide support, comfort and teaching to the family at this difficult time.

- Report / refer any sudden changes in nutritional status or food intake, signs of neglect, depression, psychosocial or spiritual problems, food shortages, hunger, and lack of funds for food. Also report if the caregiver is unable to provide for basic needs or if there are family problems.

*Important note:* Forcing a dying patient to eat or drink can cause choking, suffering and even early death. Dehydration and not eating do not cause suffering at the end of life, always give frequent mouth and lip care.

**UNIT 9: DEATH AND DYING**

**Time allocation:** 1 hour

**Aim:** To equip participants with knowledge, skills and attitudes needed to respond to emotional needs of palliative care patients and families at the end of life

**Specific objectives**

By the end of this session participants should be able to:

- Explain how to respond to patient’s emotional needs
- Explain how to respond to family’s emotional needs
- Discuss how to respond to children’s emotional needs
- Describe the role of the HBPC volunteer in death and dying
Suggested teaching and learning methods - Lecturing, brainstorming and discussion

Suggested teaching and learning materials - Flip charts, markers, training manual

A. Patient needs

Step 1

The trainer introduces the unit with the following information.

At the end of life, a person becomes weaker and may begin to refuse food and/or fluids. This may happen slowly in cancer patients but it is more unpredictable in patients with HIV and AIDS. At this crucial moment, a person may need extra care and support. It is therefore very important to respond to Emotional Needs of the patient and the family at the end of life.

Step 2

Ask participants to brainstorm patients need and list the responses on a flip chart and the trainer should summarise the discussion on the patient needs as follows;

- Listen to the patient’s concerns, wishes and feelings.
- Provide help or counselling as needed.
- Pay attention to the patient’s efforts to communicate – his or her words, facial expressions and body language.
• Answer questions honestly. Make sure you understand what the patient is really asking before you answer.

• Help the patient plan for the support of children and family members.

• Arrange for pastoral care if desired and pray together if asked.

• Respect the patient’s wishes and feelings.

• Try to ensure the atmosphere is calm.

• Do not leave the patient alone if this is possible.

B. Family needs

Step 3

Ask participants to brainstorm family needs and list the responses on a flip chart and the trainer should summarize the discussion as follows:

• Help family members with their needs and concerns.

• Be calm with the family and help them understand what is happening.

• Tell family members the patient can hear and feel touch even if unable to respond – encourage them to communicate with the patient.

• Show the family how to do mouth care, positioning and so on.
• Encourage family members to allow the patient to die peacefully. They may try and close the patient’s eyes and straighten the limbs. Help them understand that this may be causing pain; they can do this later.

• Allow family members to express their grief in their own way as long as it is not upsetting to the patient. Try to ensure the atmosphere is calm for the patient at all times.

**At the Time of Death**

• Respect the family’s feelings and needs.

• Talk to the family gently but honestly to avoid panic.

• The signs of death may be: breathing and pulse stop; eyes are partially open, fixed and glazed; the jaw drops and the mouth is often open; the patient may pass urine or stool; and there is no response to touch or voice.

• Calmly support family members in their grief.

• Respect religious and cultural traditions.

• Handle the body with respect and tenderness.

• Do not judge them in their reactions or forbid them from weeping.

• Offer prayer and pastoral care.

• Offer to assist in caring for the body if the family wishes.
• Pay special attention to the needs of children.

• Offer continuing support to the family.

C. Children needs

Step 4

Ask participants to brainstorm childrens’ needs and list the responses on a flip chart and the trainer should summarize the discussion as follows:

• Children react differently to adults
• Small children see death as reversible and temporary
• Often children do not believe it could happen to them
• Children who see a lot of death may appear as though they do not feel deeply
• Children are often deprived of the attention of family members just when they need it most, as they are grieving too
• Children may think that the person who has died is still alive somewhere
• Helping a child remember the person who has died can be very healing – such as prayers, photos, memories, a story
• Children often grieve in small doses, on and off and often at the most unexpected moments
• Children should be allowed to grieve and express their feelings in their own way
• The person who has died was important to the stability of the child’s life – it is natural that they might be angry
• Anger and grief may show in aggressive play, nightmares, irritability, or other ways
• Anger may be directed at other family members including adults or children
• A child might regress – acting younger than his or her age – demanding food, comfort, cuddling, attention more than usual
• A child may feel that he or she caused the death but not be able to say so
• A child may feel very guilty and blame him or herself
• A child may lose interest in friends, play, daily life and activities
• There may be loss of appetite, sleep, fear of being alone
• A child may imitate the person who has died
• A child may want to join the person who has died
• A child may start to do badly in school or refuse to go to school

Children need special attention when bereaved. They need unconditional love, support and acceptance of their feelings of loss. Simply the presence of a loving person who allows them to experience their grief in their own way may help them heal and travel through the long grieving process back to life. In more complicated grief it may be necessary to find experienced and professional help for the grieving child.

D. Roles of the HBPC volunteer in relation to death and dying
- Provide care according to the needs of the patient, family and children as above
- Report the death to the nurse.
- Refer to community support / pastoral care depending on need or as desired by the family.
- Follow up to assess the needs of the family.

Unit 10: WILL WRITING

Time allocation: 1 hour

Aim: To enable participants acquire knowledge, skills and attitudes in will writing.

Learning Objectives:

By the end of this session participants should be able to:

- Define a Will.
- Explain the importance of will writing.
- Describe the contents of a will.
- State the conditions for changing a will.
Suggested teaching and learning methods - Lecturing, brainstorming, demonstration, experiential learning and discussion

Suggested teaching and learning materials - Flip charts, markers, sample will and training manual

A. Definition of Will

Step 1

Ask participants to brainstorm the definition of a will and list the responses on a flip chart. Then the trainer gives the definition of a will as follows:

A Will is a legal document that states how a person wishes to distribute his or her property after death.

B. Importance of a will

Step 2

Ask participants to brainstorm the importance of a will and list the responses on a flip chart. The trainer should summarize the importance of a will as follows:

It helps and protects dependants, including widows and children, from property grabbing, theft and other kinds of loss of property that can leave them in a state of poverty.

C. How to make a will

Step 3
Ask participants to brainstorm how they can make a will, the contents, custodian of the will and list the responses on a flip chart. The trainer summarizes the information as follows:

- Anyone over 18 years of age and of sound mind may make a will.
- It may be handwritten or done by a lawyer.
- It requires the signatures of two witnesses (also over 18 years of age).
- It must contain the full name and address of the person writing the will as well as the full names of spouse(s), children and other beneficiaries.
- It must include a description of properties owned by the person making the will and how they are to be distributed in the event of their death.
- It should be written in a simple and well known language.

**Contents of the will**

- Name and address.
- The day, month and year on which a will is made.
- List all the properties one owns, the property should be own property not somebody’s.
- Name of spouses, children and parents (a must) and any other beneficiaries.
- How the property will be shared.
- If anybody owned anything (debt), name him/her state what was owned and how to pay him back.
- Guardian of the children if they are young.
- Names of persons who should carry out the wishes as stated in the will. Such person is called executor.
All pages of the will to be signed to prevent forgery. If one cannot write then to use a thumb mark.

When signing the will, two people should witness but are not supposed to read it.

The two witnesses should write their full names, addresses, occupations on the will and then sign it.

Custodian of the will

The will should be kept in a safe place such as the District Commissioner’s office, Copies can also be kept by a trustworthy friend, religious leaders, another trusted individual and traditional leaders.

D. Reasons for changing a will

Step 4

Ask participants to brainstorm the conditions for changing the will, write and discuss the responses in the flip chart. The trainer should summarize the reasons for changing the will as follows:

- When some property is added or lost.
- When the list of beneficiaries changes.
- In case of no will refer to social welfare officer and administrator general.

Conclusion

Encourage your patients to write a will early in their illness to protect their loved ones. Ask a local extension worker or social worker to help your patient make a will.
Time allocation: 1 hour

**Aim:** To equip participants with knowledge, skills and attitudes needed to manage grief and bereavement.

**Learning objectives:**

By the end of this session participants should be able to:

- Define grief, anticipatory grief, mourning and bereavement
- Explain some common grief reactions
- Discuss the role of the volunteer in grief and bereavement
- Discuss how the volunteer can help grieving children

**Suggested teaching and learning methods** - Lecturing, brainstorming and discussion

**Suggested teaching and learning materials** - Flip charts, markers, training manual

**A. Definitions:**

**Step 1**

Ask participants to brainstorm the definition of grief, Anticipatory grief, bereavement and list the responses on a flip chart. Then trainer gives the definitions as follows;

**Grief** is the normal response to any loss, not just death. It is the process of adaptation to the changes that come with loss.

**Anticipatory grief** is the grief that patients and their families feel before a death, when they are anticipating their loss. Attachment, loss and grief are fundamental to life. Grief is not an illness. It is a healthy, even though painful, natural response to loss.

**Bereavement** refers to loss of something dear to a person, family or community. Bereavement to the majority of people means death of a loved one and the grieving and mourning that follows.

People need to grieve their losses in order to move forward in their lives. Listen to them, and give them your support and
attention. Such support may help prevent long-term social and emotional problems.

It is therefore very important that volunteers be equipped with the knowledge and skills to support and counsel grieving families, and to work cooperatively with the people and the structures in the community that already offer support.

**B. Some Common Grief Reactions**

**Step 2**

Ask participants to brainstorm common grief reaction and list the responses on a flip chart. The trainer gives common grief reaction as follows:

*Emotional and psychological*

Shock; denial; anger; sadness; depression; guilt; confusion; worry; fear; constantly thinking about the dead person; thinking about killing oneself.

*Spiritual*

Loss of faith; wanting to join the dead person; asking for answers; turning to God; wanting spiritual support.

*Social*

Avoiding friends and family; secrecy and shame; conflict and blaming someone for the death.

*Physical*

Loss of appetite; trouble sleeping; pain in the chest; difficulty breathing; diarrhoea; crying; sighing; restlessness; fatigue; drinking alcohol to forget, promiscuous sexual behaviour.
C. **Role of the volunteer in grief and bereavement**

The trainer should guide participants to discuss what the provider can do as follows:

The care provider should allow the grieving person to express feelings of pain and grief – listen to their feelings, thoughts and memories.

- Be a friend. Be understanding. Be patient.
- Help family and friends understand that people need to grieve, to talk about the dead person and their pain. It is healthy and necessary. It takes time.
- Help the grieving person to make decisions and solve practical problems.
- Do not encourage hasty decisions.
- Encourage the person to eat well and to take care of him or herself.
- Encourage activities that help heal the pain, such as looking at photos, making a memory book, joining a support group if appropriate, and so on.

**REPORT** if the person has been grieving for a very long time, is unable to manage daily life, is getting drunk or being destructive or suicidal.

**REFER** to a spiritual care provider, a priest, a pastor or imam for spiritual support; to community/social resources for financial or other problems.

D. **Helping Grieving Children**
The trainer should review children’s needs during death and dying

Step 3

The trainer guides participants to discuss that; Children grieve differently from adults. As a result their needs are often neglected. Children may imagine that the dead person has just gone away for a short time. They often think they did something wrong to cause the person to die. They imagine many things and are frightened to speak of them. They may feel abandoned (perhaps because other adults are busy dealing with their own grief) when they need love the most.

Step 4

Ask participants to brainstorm signs and symptoms of grief in children and list them on the flip chart. The trainer should summarise the responses as follows:

Children may show their grief in different ways, such as:

- Being disobedient, angry and aggressive
- Having bad dreams, fear of being alone
- Losing interest in school or friends
- Imitating the person who has died
- Starting to behave like a much younger child.

Step 5
Role play

**Activity**

Ask two volunteers. One participant to be a 10 years old grieving child who has lost the father and mother through the road accident has fear of being alone, some times is disobedient, angry and aggressive. The child is in company of an aunt.

The other participant should be a counselor who is helping the child to go through the grief and bereavement process successfully. While they are role playing the rest of the participants should observe if the provider is loving and has accepted the child, is a good listener, talks honestly and encourage a family member to support the child.

Allow approximately 10 minutes for the role play and 5 minutes for the rest of the group to give role players feedback.

Then the trainer should summarize after the feedback by providing the information;

You can help children by:

- Giving them love and acceptance
- Listening to them and being with them
- Talking to them honestly
Letting them visit and talk to their parent or relative who is dying

Understanding that crying is necessary and normal

Praying with them, making a scrap book, looking at photos, telling a story, letting them draw pictures

Encouraging family members to support the child and to understand the need to grieve

Asking for help if you do not know how to help the child.

Unit 12: CARE FOR CARERS

Time allocation: 45 minutes
**AIM**: To equip participants with knowledge, skills and attitudes required in the provision of care for carers

**Learning objectives**

By the end of this session participants should be able to:

- Describe carers in home based palliative care services
- Describe benefits of being HBPC carer
- Explain challenges faced by home based carers
- Explain how to manage challenges faced by home based carers

**Suggested methods** - Brainstorming, discussion, lecture, experiential learning

**Suggested teaching aids** - Flip chart, manual

**Definitions**

Definition Carers

*Step 1*

Ask participants to define cares and list the responses on a flip chart.

*Step 2*
The trainer should provide information on definition of carers

HBPC carers are informal carers: These include HSAs, relatives, friends, neighbours and volunteers who care for the patient.

*Step 3*

Let trainer divide participants small groups to list benefits of being a carer and challenges faced by carers and present to the larger group.

*Step 4*

The trainer should summarise discussions on benefits and challenges using the following information:

**Benefits of being a caregiver**
- Feeling needed and useful
- A sense of purpose and mission in life
- Positive feelings associated with loving and caring
- A sense of achievement
- Developing skills and knowledge
- Community recognition
- Collegiality with other team members

**Challenges faced by carers**
Caring for a person with a chronic disease leaves little time for self-care. Carers often neglect their own nutrition, sleep requirements, exercise, or social needs. The physical tasks and consequences of care giving for carers act as chronic stressors and lead to health problems and affective disorders amongst carers. Carers may face the following problems:

- **Emotional exhaustion** - which causes the carer to feel depleted, depressed, angry, or resentful.
- **Depersonalization** - carers become impractical or enthusiasm and become detached and negative towards their clients.
- **Loss of personal commitment to their work** - result in lateness, absenteeism, and a feeling of relief when there are no patients in the community.
- **Carers burden resulting in burn out** – This can result in the physical (e.g. susceptibility to cold, tension headaches, or chronic fatigue, decreased social activities), emotional (feeling resentful about care giving, exploited, nervous, or depressed), financial (loss of income, and social problems (disrupts daily routines and social relationships) associated with care-giving.

**Step 5**

Ask participants to discuss management of challenges faced by carers and write responses on the flip chart.

**Step 4**
The trainer should summarize discussions on management of challenges using the following information:

Management of challenges faced by carers
Home-based carers or community health workers are vulnerable because they are likeliest to have the least amount of training and often receive the least support. It is very important to build organizational and personal support into their working conditions. It is also important to remember that people do not necessarily feel ‘called’ to the role of carers, and are simply doing what is needed to care for their families. This lack of choices makes them even more vulnerable to the burdens of care giving.

- Some factors could help to reduce the impact of challenges faced by carers:
- Clear description of their roles and good referral systems:
- Links with other service institutions (public & private, NGOs) and communities for support, and resource mobilization
- Safe work environments where possible
- Realistic work targets
- Built-in flexibility in terms of back up in case of illness
- Participate in social activities in their community to relax their hearts and minds, have a life outside of care giving. Do not neglecting friends, attend social occasions, family events, hobbies, or other pleasurable
activities which will enhance the carer’s ability to cope with stress.

- An environment that encourages self-care
- Team work: Working with others in a team to share both the experiences and the work load reduces the risk of burnout
- Open communication between team members
- Examine the burden of care giving in their own lives to creates awareness and recognize danger signs early. A person can respond appropriately if able to name and understand an experience. To prevent burn out carers should:
  - **Learn to let go** - plan on how much one volunteer can reasonably do.
  - **Care for your health** – **Ensure** healthy lifestyles and these includes getting enough rest/sleep; exercise; not smoking; a balanced eating pattern; and avoiding ‘stress-producing’ foods such as alcohol, excess sugar and salt, and drinks with caffeine. It is most important to pay attention to the body’s messages and attend to illnesses.

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**ZOWONA ZENIZENI ZA MA ARV**

**KODI MA ARV NDI CHIYANI?**
Ma ARV ndi mankhwala amene amathandiza kubwezeretsa chitetezo mthupi chomwe chaonongeka chifukwa cha kuchuluka kwa tizirombo ta HIV mthupi

Mtundu wa ma ARV omwe umagwiritsidwa ntchito kwambiri ku Malawi kuno ndi Triomune. Mu m’bulu umodzi wa Triomune muli mankhwala a mitundu itatu yosiyana.

KAMWEDWE KAKE KA MA ARV

• Triomune amamwedwa piritsi limodzi m’mawa limodzinso madzulo. Masabata awiri oyambilira munthu amamwa mankhwala otchedwa Starter Pack omwe cholinga chake ndikufuna kuliyesa thupi ngati nkwalawoliyanjane nawo kapenayi.

UBWINO WA MA ARV

• Amathandiza kubwezeretsa chitetezo cha mthupi chomwe chinaonongeka chifukwa cha kuchulukana kwa tizirombo ta HIV.
• Amachepetsa kuswana kwa tizirombo ta mthupi kotero munthu amakhala wa mphavu ndi thanzi.

WOYENERA KUMWA MA ARV NDANI?

• Munthu yemwe walandira uphungu ndikuziyesetsa magazi ake ndipo wapezeka ndi HIV.
• Waonedwa ndi dokotala ndipo watsimikiza za kukula kwa vuto lake.
- Waphunzitsidwa bwino ndipo wavetsetsa za m’mene ma ARV amagwirira ntchito.

- **ZINA MWAZOVUTA ZOMWE ZIMABWERA CHIFUKWA CHA MA ARV**

  - Dzanzi
  - Kupweteka kwa mutu ndi m’mimba
  - Kupweteka kwa miyendo, kutetha moto, ndi kubayabaya kwa mapazi
  - Mseru kapena kusanza
  - Maso kuchita chikaso komanso ziwengo pa khungu

Munthu akamva zina mwa zovutazi ayenera kupita kuchipatala kuti akathandizidwe moyenera.

**ZOYENERA KUDZIWA MUNTHU YEMWE AKUMWA MA ARV**

- Amagwira bwino ntchito ngati amwedwa mitundu ingapo mophatikiza
- Sachiritsa matenda a Edzi
- Munthu amayenera kumwa moyo wake onse ngakhale atapeza bwino
- Akhoza kufalitsa kapena kuonjezera tizilombo ta HIV ngati sagonana modziteteza (kugwiritsa ntchito kondom moyenera nthawi zones)
- Mkwapafupi kuti thupi lipime ku mankhwalawa ngati amwedwa modukizadukiza
- Ma ARV sagawana
ENA MWA ANTHU OMWE AMAYENERA KUWONANA NDI ADOKOTALA KUTI ALANDIRE MA ARV

- Omwe agwirilidwa
- Amayi oyembekezera omwe ali ndi HIV
- Ana omwe abadwa kwa mayi yemwe ali ndi HIV
- Anthu omwe abayidwa kapena kuchekedwa ndi zida zomwe zimagwiritsidwa ntchito pa munthu yemwe ali ndi HIV.

Appendix 1:

TIME TABLE
<table>
<thead>
<tr>
<th>TIME</th>
<th>MONDAY</th>
<th>TUESDAY</th>
<th>WEDNESDAY</th>
<th>THURSDAY</th>
<th>FRIDAY</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00 - 8:30 AM</td>
<td>Registration Opening prayer Introductions</td>
<td>Recap</td>
<td>Recap</td>
<td>Recap care of the carer</td>
<td>Recap</td>
</tr>
<tr>
<td>8:30 – 10:00 AM</td>
<td>Administrative announcements Workshop objectives and modalities Official opening Pre-test</td>
<td>Communication &amp; counseling in children</td>
<td>Nutrition</td>
<td>Home visits</td>
<td>Post Test Training evaluation</td>
</tr>
<tr>
<td>10:00 to 10:30 AM</td>
<td>B</td>
<td>R</td>
<td>E</td>
<td>A</td>
<td>K</td>
</tr>
<tr>
<td>10:30 – 12:00 PM</td>
<td>Basic facts about cancer</td>
<td>Holistic patient and family assessment</td>
<td>Death and dying</td>
<td>Writing field visit report</td>
<td>Pre &amp; post test feedback Closing</td>
</tr>
<tr>
<td>Time</td>
<td>Activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------</td>
<td>--------------------------------------------------------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12:00 – 1:00 PM</td>
<td>L</td>
<td>U</td>
<td>N</td>
<td>C</td>
<td>H</td>
</tr>
<tr>
<td>1:00 – 3:30 PM</td>
<td>Introduction to palliative care</td>
<td>Pain assessment &amp; management</td>
<td>Will writing</td>
<td>Report presentation</td>
<td>Facilitators meeting</td>
</tr>
<tr>
<td>3:30 – 4:00 PM</td>
<td>B</td>
<td>R</td>
<td>E</td>
<td>A</td>
<td>K</td>
</tr>
<tr>
<td>4:00 – 5:00 PM</td>
<td>Communication with patients &amp; families</td>
<td>Team work</td>
<td>Grief &amp; bereavement spiritual support</td>
<td>Report presentation</td>
<td></td>
</tr>
<tr>
<td>5:00 – 5:30 PM</td>
<td>Facilitators meeting</td>
<td>Facilitators meeting</td>
<td>Facilitators meeting</td>
<td>Facilitators meeting</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 2:

GUIDE TO FIELD VISIT

Upon completion of content for theory participants should conduct a field visit.

Purpose

The purpose of the field visit is to assist participants understand the practice of Home Based palliative Care in the actual setting.

- The Training coordinator should organize a visit to the nearest community where home based palliative care services are provided. Participants should meet palliative care team leader/community leaders, fellow home based palliative care providers, family members and the patient. Specific objectives of the field visit are:
  - To discuss how HBPC services are provided
  - Describe key roles of different team members in the community home based palliative care program (volunteers, health workers, community members, social workers, spiritual leaders, family members etc)
  - Conduct a home assessment
  - Conduct holistic patient assessment
 Provide basic care skills required as per assessment
 Provide patient education and counseling
 Mentor fellow community home based care providers by reviewing skills and engage in discussion on documentation
 Provide peer guidance / advise to fellow community care provider as required

1. Instructions:
2. Visit a FBO/CBO that runs a HBPC programme
3. Identify a household with a patient under the CBPC programme.
4. Identify the model used to deliver palliative care
5. Conduct a home & patient assessment and intervene as appropriate.
6. Observe the skills provided by home based palliative care volunteers.
7. Identify challenges encountered by the volunteer and other providers in delivering palliative care services.
8. Identify referral system used by the HBPC volunteer
9. Reflect and analyze the care given to this client
10. Prepare a presentation for the group upon returning from the field visit.
Appendix 3:

PRE AND POST TRAINING TEST FOR HOME BASED PALLIATIVE CARE PROVIDERS

1. Give the meaning of the following:

1. HIV:__________________________________________

2. AIDS:________________________________________

(2 marks)

2. Define the following terms?

i) Palliative Care:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

ii) Communication:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

iii) Will:
________________________________________________________________________
iv) Community home based care Kit:

v) Cancer:

(10 marks)

3. Mention three ways in which HIV may be transmitted

i) 

ii) 

iii) 

(3 Marks)

4. Mention three ways in which HIV is not transmitted

i) 

ii) 


iii) ________________________________

(3 Marks)

5. Mention three models of palliative care
   i) ________________________________
   ii) ________________________________
   iii) ________________________________

(3 Marks)

6. What are the basic nursing care skills required in community home based Palliative care?
   (i) ________________________________
   (ii) ________________________________
   (iii) ________________________________
   (iv) ________________________________

(4 Marks)

7. Describe 2 important points in the management of the following symptoms at home.
   Fever  (i) ________________________________
               (ii) ________________________________

   Vomiting
   (i) ________________________________
       (ii) ________________________________

   Diarrhoea (i) ________________________________
               (ii) ________________________________
Pain (i) __________________________________________

(ii) ___________________________________________

(8 Marks)

8. What drugs and supplies are found in the home based care kit? List 5

(i). ______________________________________

(ii). ______________________________________

(iii).____________________________________

(iv). ______________________________________

(v). ______________________________________

(vi). ______________________________________

(6 Marks)

9. Give five examples of drugs for pain relief in palliative care

(i) __________________________________________

(ii) __________________________________________

(iii) __________________________________________

(3 Marks)

10. What tools are used when communicating with children who are on palliative care?

i. __________________________________________

ii. __________________________________________

iii. __________________________________________
11. Mention four areas which the provider should focus on when conducting general assessment of the patient to find out the needs of the patient and family.

i. ________________________________

ii. ________________________________

iii. ________________________________

iv. ________________________________

(4 Marks)

50 MARKS
Appendix 4:
PRE AND POST TEST ANSWER GUIDE FOR HOME BASED PALLIATIVE CARE PROVIDERS

1. Give the meaning of the following acronyms:
   i. HIV: Immuno defienciency virus
   ii. AIDS: Acquired immuno defienciency syndrome

   (2 marks)

2. Define the following terms?
   i) **Palliative Care:**
      Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual
   
   ii) **Communication**
      Communication is the sharing of ideas or information in order to come to a common understanding
   
   iii) **Will:**
      A Will is a legal document that states how a person wishes to distribute his or her property after death
   
   iv) **Community home based care Kit:**
      Contains drugs and supplies designed to support the needs of the chronically ill patient in the community
V) **Cancer:**

*Cancer* is an abnormal growth of cells which tend to multiply in an uncontrolled way and, in some cases spreads through the bloodstream and lymphatic system to other parts of the body.

(10 marks)

3. **Mention three ways in which HIV may be transmitted**

Unprotected sexual intercourse with an infected person
Getting in contact with infected blood & blood products
Infected mother to child during pregnancy, birth and breastfeeding

(3 Marks)

4. **Mention three ways in which HIV is not transmitted**

Being bitten by mosquitoes
Using the same eating utensils
Sharing toilets
Playing with an infected person
Chatting with an infected person
Shaking hands

(3 Marks)

5. **Mention three models of palliative care**

In-Patient Care
Home – Based Care
Hospital Palliative Care
Palliative Day Care
Outreach Clinic

(3 Marks)
6. What are the basic nursing care skills required in community home based Palliative care?

Assisting the patient with a bath
Assisting the patient with mouth Care
Pressure area care
Assisting in feeding the patient
Wound care
Counseling

(4 Marks)

7. Describe two important points in the management of the following symptoms at home.

**Fever**  
i) Remove unnecessary clothing /blankets

ii) Drink plenty of fluids like water, juices

**Vomiting**  
(i) Advise patient to wash mouth and suck lemon

Assist patient to take small frequent meals
Watch for signs of dehydration

(ii) Keep patient clean, dry and comfortable

**Diarrhea**  
(i) Keep patient clean, dry and comfortable

(ii) Prepare ORS and give patient a cupful after each loose stool

**Pain**  
i) Advise patient to take a warm bath, Change positions in bed or move about frequently

(ii) Assess patient’s pain, help and teach the patient to take prescribed drugs,

Supervise and report how the patient is taking drugs

(8 Marks)
8. What drugs and supplies are found in the home based care kit? List 5

(i). Panadol / asprin
(ii). Albendazole
(iii). Multivitamin
(iv). Ferrous sulphate, eye ointment
(v). Magnesium trisillicate
vi). Cotton wool /Plaster, ORS, gauze, Bandages scissors

(6 Marks)

9. Give five examples of drugs which are used for pain relief in palliative care

(i) Panadol, asprin , ibuprofen
(ii) Codeine, Tramadol
(iii) Morphine , Amitriptylline

(3 Marks)

10. What tools are used when communicating with children who are on palliative care?

i. Play
ii. Drawing
iii. Use of toys
iv. Story telling or writing
v. Music and dancing
vi. Age appropriate language

(4 Marks)
11. Mention four areas which the provider should focus on when conducting general assessment of the patient to find out the needs of the patient and family.

i. Physical assessment
ii. Psychological Assessment
iii. Social – cultural assessment
iv. Spiritual assessment

(4 Marks)

TOTAL: 50 MARKS
Appendix 5

TRAINING EVALUATION QUESTIONNAIRE

Question 1

You are required to give your opinion of the relevance or importance of the following topics by ticking in the appropriate column.

<table>
<thead>
<tr>
<th>Topics covered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basic facts and information about CANCER</td>
</tr>
<tr>
<td>Introduction to Palliative Care</td>
</tr>
<tr>
<td>Communication with patients and families</td>
</tr>
<tr>
<td>Communication and counseling in children</td>
</tr>
<tr>
<td>Team work</td>
</tr>
<tr>
<td>Holistic patient and family assessment</td>
</tr>
<tr>
<td>Pain assessment and management</td>
</tr>
<tr>
<td>Nutrition</td>
</tr>
<tr>
<td>Death and dying</td>
</tr>
<tr>
<td>Will writing</td>
</tr>
<tr>
<td>Grief and bereavement</td>
</tr>
<tr>
<td>Care of the carer</td>
</tr>
</tbody>
</table>
2. Using letters (a) to (k) for the topics covered above, give your own assessment of how you generally understand these topics by writing the numbers of the relevant topic from the table in question 1 on the appropriate space below. (e.g. d = Nutrition)

A. Five topics which you understood easily.

(i) ..............................................................

(ii) ..............................................................

(iii) ..............................................................

(iv) ..............................................................

(v) ..............................................................

B. Five topics which you would like to be repeated.

(i) ..............................................................

(ii) ..............................................................

(iii) ..............................................................

(iv) ..............................................................

(v) ..............................................................
**Question 2**

For each statement below tick the answer which best describes how you feel about this training. Give your reasons by making brief comments in the space provided:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>The objectives of the workshop were clear</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The teaching/learning materials used were appropriate</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The length of the workshop was enough to cover the number of topics/units.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The presentation and explanation of the information and skills by the facilitators were generally good.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The facilitators were very helpful</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The arrangements made for the workshop were good (transport, meals, practical work, timetable, accommodation, health issues, etc)

This workshop was participatory, involving the participants adequately

3. General Comment

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
Reference


