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MINISTRY OF HEALTH

**NATIONAL PALLIATIVE CARE  
TRAINING CURRICULUM FOR HIV  
& AIDS, CANCER AND OTHER LIFE  
THREATENING ILLNESSES**

**TRAINEES MANUAL**

2013

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# Acknowledgement

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Kenya Hospices and Palliative Care Association would like to thank all those who tirelessly worked to develop the National Palliative Care Training Curriculum for HIV&AIDS, Cancer and other Life Threatening Illnesses.

This Manual will complement the efforts undertaken towards initiation of palliative care services for patients with HIV&AIDS, cancer and other life threatening illnesses and their caregivers.

Our most sincere appreciation goes to the Ministry of Health (MOH); National AIDS and STI Control Program (NASCO); the Nairobi Hospice; University of Nairobi; Kenya Medical Training College (KMTC) and other stakeholders for their active participation in developing the curriculum. Special acknowledgment goes to Diana Princess of Wales of Wales Memorial Fund, UK; CHF Kenya; CDC Regional office Nairobi; CRS SAIDIA Project who supported this initiative both financially and technically.

# Forward

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In response to shortcomings in medical and nursing care at the end of life and growing recognition of the unmet needs of patients and their families who confront serious life-threatening/limiting and terminal illnesses, palliative care has globally been growing in importance in recent years. Non-Communicable diseases like cancer are on the increase in our community, while HIV&AIDS continues to affect many Kenyans. Despite communicable diseases like HIV&AIDS posing the biggest challenge, the incidence of non communicable diseases like cancer, diabetes, hypertension and cardiovascular diseases are on the increase and cancer ranks third as a course of death in the country, after infectious diseases like HIV&AIDS. With the number of people suffering from life threatening illnesses rising to alarming heights, this calls for an urgent need to integrate palliative care services in our health care system. Palliative care focuses on quality of life; control of pain and other distressing symptoms; attention to the psychosocial, emotional and spiritual needs of the patient.

Palliative Care is an area of Health care, which for many years has been sidelined. The purpose of the National Palliative Care Training Curriculum for HIV&AIDS, Cancer and Life Threatening Illnesses is to equip health care professionals with the knowledge and skills needed to provide the best possible care to patients living with Life threatening illnesses and their families. This Manual will go a long way in advancing effective palliative care services and improving the awareness of the various aspects of palliative care in this area.

Appreciation and recognition goes to all who spared time from their busy schedules to help in the realization of the production of this Manual.

**James W. Macharia**  
**Cabinet Secretary,**  
**Ministry of Health**

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 (WHO 2002)

Emerging and re-emerging diseases that compromise the patient's quality of life are on the increase in Kenya due to lifestyle and environmental changes. This has led to overcrowding of patients in both Government and Private health institutions requiring palliative care. Despite this, access to culturally appropriate holistic palliative care is at best limited and at worst non-existent for majority of the patients with life threatening illnesses. In 2005, the WHO projected that Africa will experience the largest increase in death rates from cardiovascular diseases, cancer, respiratory diseases and diabetes by 2015. Majority of patients present late and cure is not possible hence the need for palliation

The existing curricula for health care professionals focus on the medical models which are geared towards cure without much emphasis on palliative care. The national palliative care curriculum seeks to address the gaps in palliative care.

### **Back ground**

Since 2008, with support from CDC, the organizations CHF and CRS have been supporting Kenya Hospices and Palliative care Association (KEHPCA) to develop a national palliative care curriculum as a guide for use in training of health care professionals in palliative care. KEHPCA has been keen to harmonize palliative care service provision as well as ensuring provision of proper guidance in training of both health care professionals and non-health care professionals in Kenya.

### **Why a National Curriculum is needed:**

- To provide a definition for palliative care services and established levels of care and service delivery for palliative care providers
- To standardize materials used by various implementing partners in health care facilities
- To provide a framework for the evaluation of palliative care programs
- To provide a way forward for the indicators that currently lack from most of the data collection tools.

**The curriculum development process:**

The process of the national palliative care curriculum development began with a consultative meeting for major stakeholders including the Ministry of Health, University of Nairobi, NASCOP, Nursing Council of Kenya, Hospices, Kenya Medical training College, Centre of Disease Control, KEHPCA and CHF International Kenya was held. The stakeholders agreed that a national curriculum was very important and came up with a proposed team of experts to actualize the task. The task force brought together experts with different fields in the different areas of palliative care and on different areas which needed to be covered in the curriculum.

The selected task force members held several workshops in consultation with KEHPCA and expert consultants on the different specific tasks. This process has been done in consultation with the Ministry of Health, NASCOP and other stakeholders.

**Curriculum design**

The five phases involved in curriculum development as listed were tackled; Analysis, design, development, implementation and evaluation. Following the discussions of the design of the curriculum, the members agreed that it will be done in modular format. The list below outlines the modules in the curriculum and three main documents were developed; a national palliative care curriculum, a trainer's manual and a participant's manual.

1. Aspects of palliative care
2. Clinical Assessment of palliative care
3. Nutrition
4. Psychosocial aspects
5. Pediatric palliative care
6. System strengthening
7. Practicum

**Overall goal**

To equip health care service providers with appropriate knowledge, skills and attitudes on palliative care that will enable them to provide quality, holistic services to patients, families and communities faced with cancer, HIV & AIDS and other life threatening illnesses.

This national palliative care curriculum will guide the training and capacity building for professionals in health as the Ministry of Health (MoH) continues with the effort of having palliative care established and fully integrated in the health system in Kenya in order to ensure that services offered are standard with an eventual aim of improving the quality of life of patients and families faced by life threatening illnesses.

**Dr. Francis Kimani**  
**Director of Medical Services**  
**Ministry of Health**

**Dr. S. K. Sharif**  
**Director of Public Health & Sanitation**  
**Ministry of Health**

# Acronyms & Abbreviations

1.	<b>AIDS</b>	Acquired immune deficiency syndrome
2.	<b>ART</b>	Anti-retroviral therapy
3.	<b>ARV</b>	Anti-retroviral
4.	<b>APCA</b>	African Palliative Care association
5.	<b>BTA</b>	Breakthrough administration of pain medication
6.	<b>BMI</b>	Body mass Index
7.	<b>CDC</b>	Centre for Disease Control and Prevention
8.	<b>DRH</b>	Division of Reproductive Health
9.	<b>GOK</b>	Government of Kenya
10.	<b>HB</b>	Haemoglobin
11.	<b>HCW</b>	Health Care Worker
12.	<b>HIV</b>	Human immune deficiency virus
13.	<b>KEHPCA</b>	Kenya Hospices and Palliative Care Association
14.	<b>Kcal</b>	Kilo Calories
15.	<b>M, E &amp; R</b>	Monitoring and evaluation
16.	<b>MOH</b>	Ministry of Health
17.	<b>MUAC</b>	Mean Upper Arm Circumference
18.	<b>NASCOP</b>	National AIDS and STD Control Program
19.	<b>NGO</b>	Non-government organization
20.	<b>NSAID</b>	Non Steroidal Inflammatory Disease
21.	<b>OIs</b>	Opportunistic Diseases
22.	<b>SGDs</b>	Small Group Discussions
23.	<b>STI</b>	Sexually Transmitted Infections
24.	<b>TB</b>	Tuberculosis
25.	<b>TOT</b>	Training of Trainers
26.	<b>PASCO</b>	Provincial AIDS and STI Coordinator
27.	<b>PLWHA</b>	People Living With HIV&AIDS
28.	<b>VCT</b>	Voluntary counselling and testing
29.	<b>WBC</b>	White Blood Count
30.	<b>WHO</b>	World Health Organization



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## Introduction and General Background

Kenya Hospices and Palliative Care Association (KEHPCA) in 2006 carried out a needs assessment survey in the centers providing palliative care, and found that there is definite limited skill resource in terms of numbers of service providers and even the level of skill. There is also a lack of awareness on HIV&AIDS Palliative care and inadequate training of both health care providers and non health care providers in HIV&AIDS palliative care. This has resulted in the unmet need for palliative care for those who are already affected and infected by HIV&AIDS, Cancer and other Life threatening diseases. The number of service providers was also found to be low with limited resources to support Palliative Care Services.

The report recommended training on Palliative Care especially for HIV&AIDS and cancer.

## Cancer and Other Conditions

Cancer is a disease that results from failure of the mechanisms that regulate normal cell growth and cell death leading to uncontrollable proliferation of cells, destruction of neighbouring tissues and spread of the disease to other parts of the body. Owing to its nature, cancer is difficult to treat, and cannot be eradicated. However, it is possible to significantly reduce the effects of cancer on the society if effective measures are put in place to control risk factors associated with cancer, detect cancer cases early and offer good care to those with the disease.

In Kenya, cancer ranks third as a cause of death after infectious diseases and cardiovascular diseases. The country has no data on the real cancer burden, but it is estimated that over 18,000 Kenyans die of cancer annually. The incidence of cancer in Kenya has progressively increased over the years mainly as a result of increased exposure to preventable risk factors. These risk factors include the adoption of unhealthy life styles such as consumption of unhealthy diet, physical inactivity, tobacco use and harmful use of alcohol. Other risk factors are exposure to environmental carcinogens, viral infections such as HIV, Hepatitis B & C and Human Papilloma Virus; bacterial infections such as *Helicobacter Pylori*; and parasitic infestations such as schistosomiasis. The most common types of cancer in Kenya are cancers of the cervix, breast, oesophagus and prostate. Other cancers include those of the head and neck, colon and rectum, stomach and liver, lymphomas and sarcomas.

## Overall Goal

To equip health care service providers with appropriate knowledge, skills and attitudes on palliative care that will enable them to provide quality, holistic services to patients, families and communities faced with cancer, HIV & AIDS and other Life threatening illnesses.

## The Objectives of the Course

1. To explain the concepts of palliative care.
2. To discuss clinical palliative care concepts.
3. To demonstrate appropriate clinical palliative care skills.
4. To describe psychosocial concepts in palliative care.
5. To demonstrate appropriate understanding of psychosocial aspects in the provision of palliative care services.
6. To discuss programmatic issues in palliative care.

## Facilitators

The facilitator will need to:

1. Obtain a copy of the National Palliative Care curriculum for health care service providers, facilitator's and the syllabus, and familiarize herself/himself with the layout and content of the modules.
2. Plan for the time allocated for the modules of the course.
3. Prepare the teaching materials for the course including pre/post tests.
4. During the teaching/learning sessions, begin each module by presenting the objectives of each module.

## Target Audience

These materials can be used in training sessions for all health care professionals, social workers and other palliative care practitioners. This manual can also be used by health care trainers, managers and policy makers interested in palliative care.

## Teaching Learning Methods

Each module follows the same format, and clearly indicates the methods deemed most appropriate for teaching the content of the module. However, the trainers must feel free to use other methods depending on different circumstances.

The emphasis is on use of methods appropriate for adult learners. Such methods emphasize involvement and active participation and include overview lectures, small group discussions, small group activities, role plays, brainstorming, demonstrations, practical sessions, classroom exercises and field visits.

References and recommended readings are indicated for each module and facilitators will need to draw the attention of the participants to them.



## Course Duration

Ten days residential training

## Participant Selection Criteria

A class of 25 participants shall be appropriate.

Healthcare service providers interested in providing palliative care

## Certification

Certificate shall be provided to participants upon successful completion of the course by recognized certified training institutions or organizations

## Course Organization

This course is organized into 7 modules

## Modules in Palliative Care Curriculum

1. Aspects of palliative care
2. Clinical Assessment of palliative care
3. Nutrition
4. Psychosocial aspects
5. Pediatric palliative care
6. System strengthening
7. Practicum

## Training and Facilitation

This course will be taught using methods appropriate for adult learners. The methods will include, overview lectures, brainstorming, small group discussions, small group activities, class exercises, case studies, case scenarios, demonstrations, field practical and role-plays.

A minimum of five trainers who have trained as TOTs in palliative care will facilitate the course.

## Performance Assessment

Pretest and post tests are recommended for the course. Trainers will use continuous assessment tests, by the way of question and answer sessions. Class exercises, and assignments will also be given and participants will be expected to make decisions based on the information given to them. Full course attendance will be mandatory.

## **Course Implementation**

Facilitators for the course will be drawn from among qualified healthcare providers who have had experience and training as trainers of facilitators (TOFs) in palliative care. Palliative care providers and other professionals may also be invited to facilitate in the course as may be determined from time to time by the organizers of the course.

## **Course Review and Change**

Each course will be evaluated by the participants and records kept. However, appropriate changes will be made to improve the course, on the basis of the evaluations. After 5 years of course implementations, the course will be reviewed by the stakeholders and appropriate changes made.

## **References and Recommended Readings**

References and recommended readings are reflected in detail at the end of each module.



# Aspects of Palliative Care

## Module 1



**Time: 3 Hours**

### **OBJECTIVES:**

By the end of this module participants will be able to:

1. Discuss the concept of palliative care
2. Explain the interdisciplinary team approach in palliative care
3. Discuss the ethical-legal issues in palliative care

### **Content Outline**

- Definition of palliative care
- Concept of palliative care
- History and evolution of palliative care
- The role of palliative care in HIV&AIDS management
- Interdisciplinary team approach in palliative care
- Ethical legal issues in palliative care

## UNIT 1.1: CONCEPT OF PALLIATIVE CARE



**Time: 1 hour**

### **OBJECTIVES:**

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

1. Define palliative care
2. Outline the public health approach to palliative care
3. Describe hospice care
4. Describe palliative care vs hospice care
5. Outline the role of palliative care in HIV&AIDS management
6. Discuss the history of palliative care in Kenya

## COURSE NOTES

### 1.1.1 Definition

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, 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 (WHO, 2002)

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family (WHO, 2002).

#### **Palliative care;**

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;

- Offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated;
- Will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complication

Components of Palliative Care	
Physical	Nursing, treating, prescribing
Psychological	Listening, counseling, being there
Social	Help with finances, housing, family support
Spiritual	Prayer, counseling, carrying out rituals or rites.

## 1.1.2 The Public Health Approach to Palliative Care

### Why a Public Health Strategy?

Palliative care relieves suffering and improves quality of life for both patients and families throughout an illness experience, not just at the end of life. Today, there is the knowledge to relieve much of the unnecessary suffering. Tragically, however, palliative care is only reaching a fraction of the people who need it. A Public Health Strategy (PHS) offers the best approach for translating new knowledge and skills into evidence-based, cost-effective interventions that can reach everyone in the population. For public health strategies to be effective, they must be incorporated by governments into all levels of their health care systems and owned by the community. This strategy will be most effective if it involves the society through collective and social action.

### The Need for Palliative Care

Globally, there is a very significant unmet need for palliative care: Of the 58 million people dying annually (45 million in developing countries, 13 million in developed countries), it is estimated that at least 60% (35 million) will have a prolonged advanced illness and dying and would benefit from palliative care. Already, there are 600 million people 60 years of age or older. With at least two family members involved in each patient’s care, palliative care could improve the quality of life of more than 100 million people annually worldwide. Palliative care is particularly important for patients with cancer and AIDS, as the burden of issues that cause suffering is particularly high for

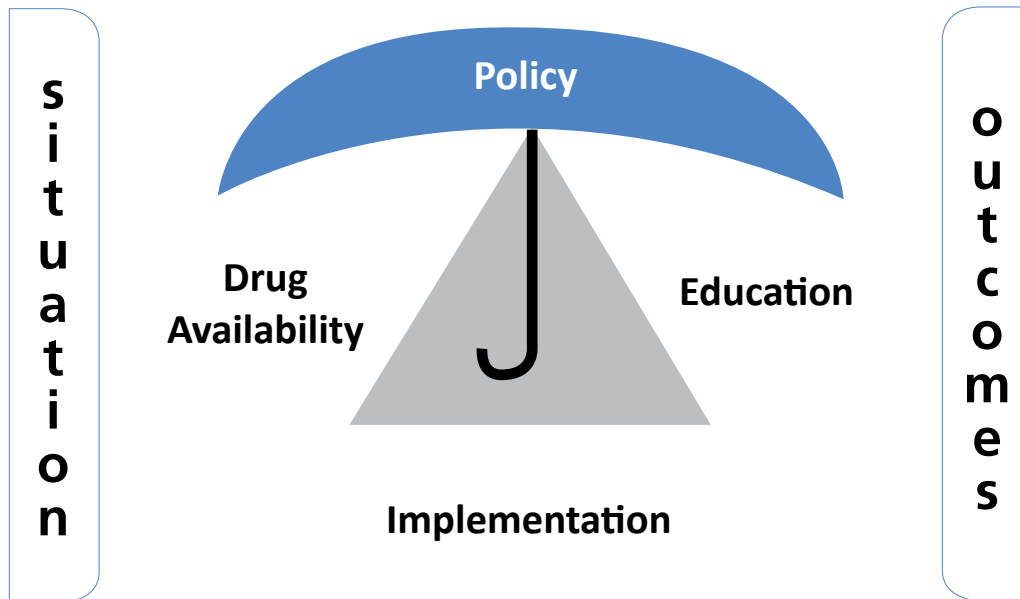
these patients: Two-thirds (seven million) of the 10 million new patients with cancer each year are not cured and die within a year of their diagnosis. Of those living with cancer, 60% will experience significant pain. Already, three million patients die annually from AIDS. With the rapidly aging world population and the associated increase of multiple “non-communicable” diseases, the need for palliative care will increase dramatically over the next 50 years: By 2025 there will be 1,200 million people 60 years of age or older; by 2050 the number will increase to 2,000 million. The incidences of cancer will more than double to an estimated incidence of 24 million new cancers per year by 2050. If preventative measures don’t work, annual mortality from AIDS will increase to four million in 2015 and six million by 2030.

Throughout the world, many patients present late to their health care system with advanced disease. Therapies to control their disease are frequently ineffective, associated with multiple side effects that cause increased suffering and are expensive. For these patients, palliative care, if available, would give the greatest benefit during their limited life expectancy for the least cost. Even in the developed world, when patients present earlier to the health care system and there is a greater chance that their disease is curable, a comprehensive approach to their care that integrates palliative care throughout their illness experience will provide them with better quality of life. Unfortunately, although the knowledge and experience to control pain and diminish suffering exist, the tragedy for most of the world’s population is that palliative care is not available to them. In fact, the greatest need is in developing countries, where 45 million of the deaths occur and health care resources are the scarcest.

## **A WHO Public Health Model**

In 1990, the WHO pioneered a PHS to integrate palliative care into existing health care systems. This included advice and guidelines to governments on priorities and how to implement national palliative care programs and national cancer control programs where palliative care will be one of the four key components (pillars) of comprehensive cancer care. Based on experience with this model and the process to implement it, an enhanced Public Health Model (the Model) has emerged (Fig. 1).

Fig. 1. WHO Public Health Model



To effectively integrate palliative care into a society and change the experience of patients and families, all four components of the WHO Public Health Model must be addressed.

There must be

- 1) Appropriate policies,
- 2) Adequate drug availability,
- 3) Education of health care workers and the public, and
- 4) Implementation of palliative care services at all levels throughout the society.

This process is always implemented within the context of the culture, disease demographics, socioeconomics, and the health care system of the country. For each component there are short, intermediate, and long-term outcomes that must be measured.

Developmental Steps	
<b>Step 1:</b>	<b>Engage Opinion Leaders</b> Start by gaining access to key governmental and nongovernmental opinion leaders for the country. An ideal way (for external international experts) to access these leaders is a combined approach in collaboration with the Minister of Health and local/regional WHO representatives.
<b>Step 2:</b>	<b>Situational Analysis</b> After engaging with national opinion leaders, perform an analysis of the situation and needs within the country



**Step 3: Develop an Action Plan**

After completing the situational analysis, the next step is a workshop of key national political and clinical opinion leaders, nongovernmental organizations, and international expert facilitators. Based on the results of the detailed situational analysis and needs assessment, the goal of this national workshop is to produce a consensus-based report and action plan with a timeline for addressing each of the four components of the model and outcome indicators for each component (review a sample report and action plan online)

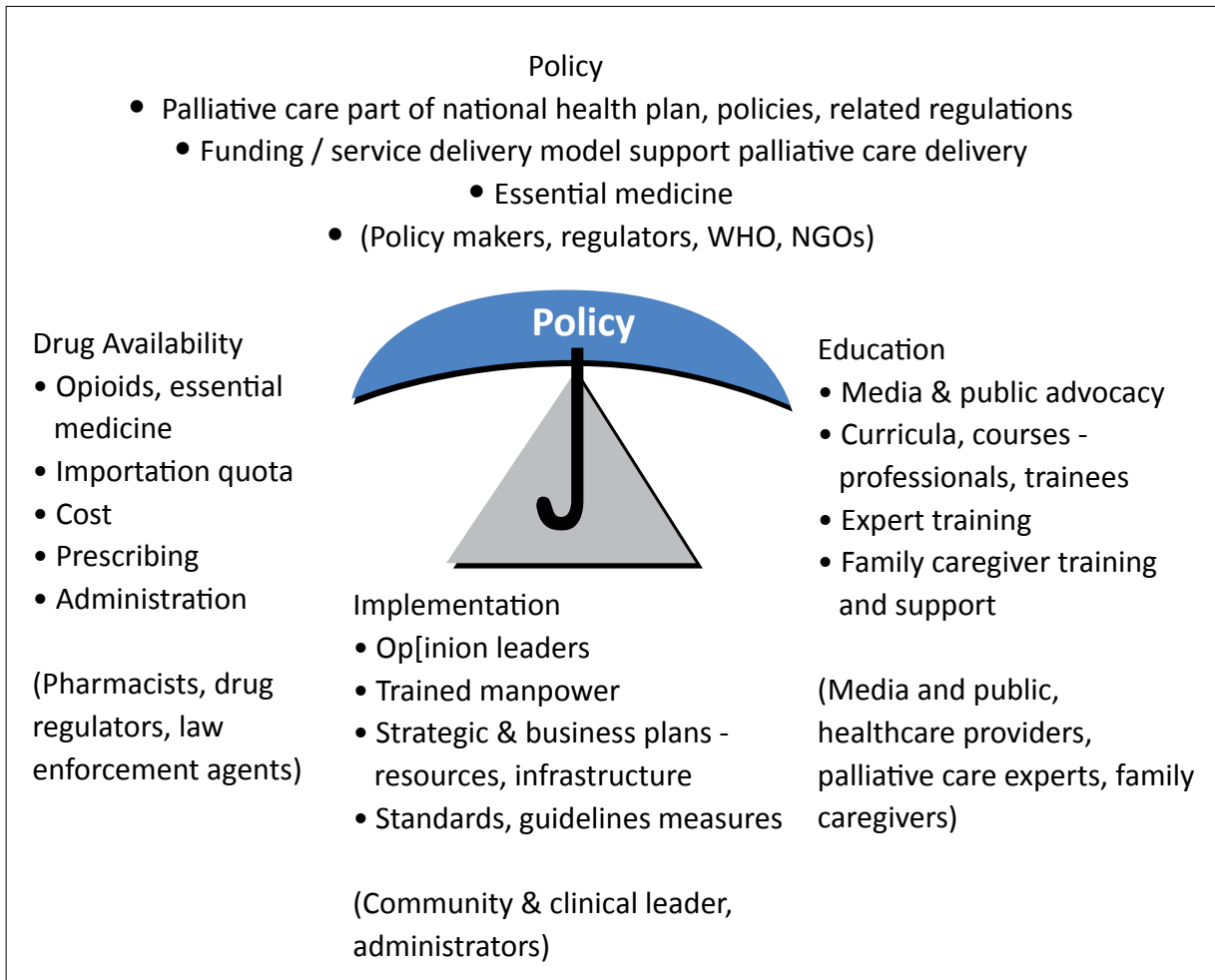
**Step 4: Establish a National Steering Committee**

Once an action plan is in place, establish a national steering committee of key stakeholders to coordinate the overall process in collaboration with international expert facilitators. This committee is typically chosen from workshop participants and includes key politicians, regulators, clinicians, educators, administrators, and the public.

**Step 5: Develop the Components of the Model**

Details of the model are presented in Fig. 2. Before embarking on extensive education and implementation strategies, ensure that policies and drug availability issues are addressed and are in place. These are inextricably linked as it is not realistic to import opioids unless appropriate prescription rules are in place and bedside-training courses can be guaranteed. Do not embark on training without appropriate policies and drug availability. It will only frustrate clinicians, patients and families, and the public.

**Fig. 2. Detailed WHO Public Health Model.**



**Policy**

Start by identifying key policy stakeholders. These frequently include both national and regional government policy makers and regulators. Review national health policies and related regulations to establish whether they incorporate the relief of pain and palliative care as priorities. If they do not, advocate for incorporation of both of these concepts as priorities into the National Health Plan, legislation, and regulations as they evolve. Review existing funding and service delivery models for providing care within the country. Determine how they might support the delivery of palliative care both at the community level and within existing acute and long-term care organizations through home care and consult services, and palliative care units. Review how doctors and other health care professionals providing palliative care are reimbursed.

Establish if the country has an essential medicines policy. If they do, include opioids and other palliative care medicines in the policy.

## Drug Availability

Identify Leaders. Start by identifying national opinion leaders responsible for drug availability, e.g., drug regulators, pharmacologists, pharmacists, and law enforcement officials. Ensure that they are all engaged in the process and willing to review and improve drug availability policies and practices. Estimate Opioid Need. Use a simple strategy to estimate the annual opioid need for the cancer patients. Assume that 60% of patients with advanced cancer will be the principal consumers and that they will each use an average of 100 mg morphine per day for the last 100 days (three months) of their lives, i.e., a total of 10 g of morphine per patient. This technique will estimate only a portion of the total opioid need for the country. As an example, for a country with five million people and 3,500 new diagnoses of cancer per year, two thirds of which present with stage III or IV cancer, if 60% of these patients (2,100) have pain and need 10 g of morphine each before they die, that country will need 21 kg of morphine per year just to manage these cancer patients' pain. Ensure an Affordable Supply. Request a reasonable opioid quota from the International Narcotics Control Board (INCB) well before it is needed. Base this request on the previous years' actual usage and a reasonable estimate of increased usage for the coming year. As long as there is a timely system to review usage and the available supplies, if consumption exceeds the request quota, a revised request for an increased quota can always be submitted to the INCB during the year. Ensure that there is a national policy to guide the importation of affordable, "equally efficient" generic morphine and other opioids formulations. Most patients' pain will be easily managed if the country ensures that they have a supply that includes 30% immediate-release morphine, 60% slow-release morphine, 5% parenteral morphine, and 5% other opioids.<sup>18,19</sup> To date, the least expensive formulation is oral morphine solution. Establish an appropriate distribution, dispensing, and accountability system based on the eight steps developed by WHO and INCB.<sup>20</sup> To minimize the burden for patients and families, opioids will need to be available in the communities where patients receive their care, not just in a single pharmacy in the country's capital city, e.g., in the National Cancer Center. Facilitate Appropriate Prescribing. Ensure that opioid prescribing laws and regulations allow the appropriate management of pain and shortness of breath. All doctors, in any setting, should be able to prescribe the quantity that will be required for a reasonable period of time.

**Education:** Identify Leaders. Start by identifying national opinion leaders responsible for education e.g., clinical and education experts, deans of medical, nursing, pharmacy, and social work schools. Ensure that they are all engaged in the process and willing to change existing educational curricula and courses and develop new ones. Identify Target Audiences. To implement palliative care effectively across the country, there will be many different target audiences who will require education to increase their awareness and change their attitudes, knowledge, and skills related to palliative care.

Typically these include the media and public, medical, nursing, social work/psychology, and pharmacy health care professionals and trainees, experts training in palliative care, spiritual leaders, and patients and families.

**Media and Public Advocacy:** Develop an educational intervention and advocacy tools to engage the media and heighten public awareness of the need for and benefits of palliative care for patients at any time during an illness experience.

**Curricula, Courses:** Education in health care is intended to change the experience of illness for patients and families. To this end, educational interventions increase awareness; change attitudes, increase knowledge and skills, and change behaviors most effectively if courses and conferences are accompanied by bedside training during which students are mentored by skilled palliative care practitioners. Incorporate the core competencies of palliative care into undergraduate and postgraduate curricula and continuing education courses for practicing professionals. To facilitate uptake of palliative care education and highlight its importance, include questions on palliative care in undergraduate and postgraduate examinations that are required for certification and licensure.

**Palliative Care Experts:** Develop a specialized program to train and recognize palliative care experts who will staff the national centers of excellence and provide consultation, education, and support to primary and secondary level practitioners. At the outset, this may need to include out-of-country education of selected individuals to develop their expertise. With time, as sufficient palliative care experts are available locally, these specialized training programs can be developed in country.

**Family Caregivers:** As patients will primarily receive their care from family members and friends, develop educational interventions and tools to enhance the knowledge and skills of family caregivers.

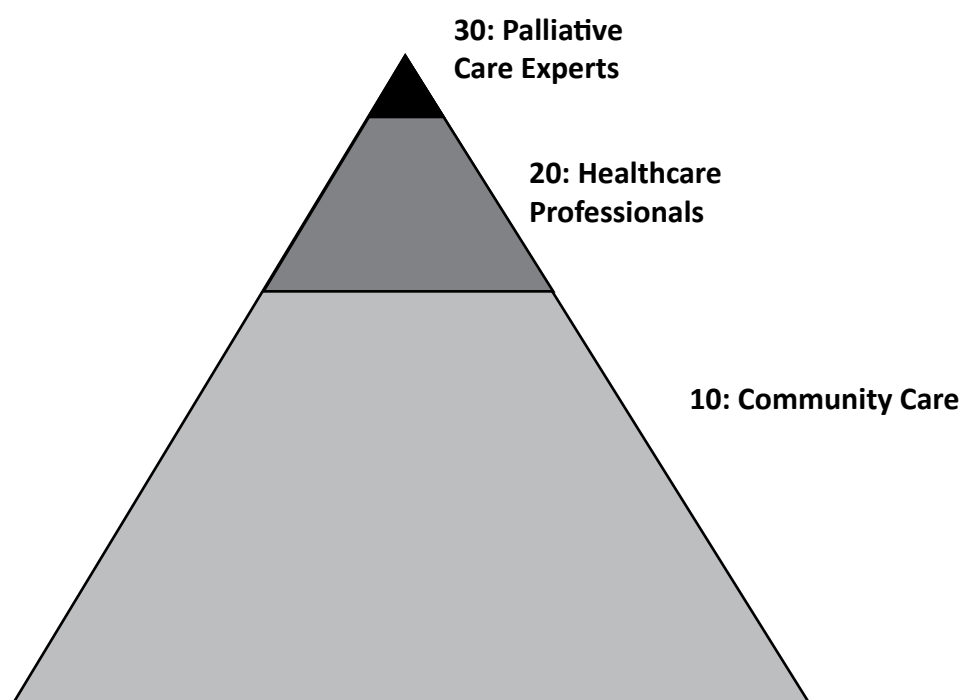
## Summary

Millions of patients around the world are experiencing unnecessary suffering and dying without access to palliative care. In light of the new knowledge and the skills that we now have to manage the suffering and ensure safe and comfortable dying, this is a major public health issue worldwide. The enhanced WHO Public Health Model has demonstrated that it provides an effective strategy for integrating palliative care into a country.

## Summary cont'd

By customizing the process for the situation in each country, addressing all of the elements in the strategy, implementing quality palliative care services, and realizing all of the planned outcomes, population-based coverage will be assured. The final outcome will be adequate relief of suffering and improvement of quality of life for all patients living with advancing illness and their families

**Fig. 3. “Palliative Care for All”**



### 1.1.3 Hospice care

#### Definition:

**Hospice:** A program or facility that provides special care for people who are near the end of life and for their families. Hospice care be provided at home, in a hospice or another freestanding facility, or within a hospital. Hospice care is a program of medical, nursing and emotional care for the terminally ill; a special concept of care designed to provide comfort and support to patients and their families when a life-limiting illness no longer responds to cure-oriented treatments.

## **A More Extensive Definition:**

A care program that provides a centralized program of palliative and supportive services to dying persons and their families, in the form of physical, psychological, social, and spiritual care; such services are provided by an interdisciplinary team of professionals and volunteers who are available at home and in specialized inpatient settings.

The word Hospice originates from a lodging for travelers, especially one kept by a monastic order. It is a place of shelter, for the weary and sick travelers returning from religious pilgrimages. Hospice services provide palliative care to individuals with a life expectancy of six months or less. Most hospice care is provided in the home, but may take place in a hospice home or a hospice/palliative care area within a medical facility. Requesting hospice care may be the first time that individuals, or their families, acknowledge that their condition is not treatable. It may be the first time that they have to deal with their death as a reality taking place within a few months. The emotional journey to be able to deal with these issues may take a while, and therefore may delay the time when the person begins to receive hospice care.

The focus of hospice is not on treatment, but on pain and symptom management, comfort measures, acknowledging that the individual will die, supporting the family, and trying to provide the best quality of life for the time remaining. Hospice functions under the philosophy that although some terminally ill patients may no longer receive treatment, they still require and deserve care.

Hospice care is interdisciplinary in nature, providing the services of physicians, nurses, social workers, physical, speech, or occupational therapists, clergy or other spiritual guides, health care aides, and volunteers. Home hospice care relies on the family and friends of the patient to provide most of the daily care. Nursing and other services are provided daily or weekly, but with 24 hours, 7 days a week on-call access. Addressing the spiritual needs of the hospice client is a fundamental aspect of hospice care.

### **1.1.4 Palliative Care versus Hospice Care**

#### **Definition**

Palliative care is specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support.

It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

## **Relieves Suffering, Improves Quality of Life.**

Palliative care treats people suffering from serious and chronic illnesses including cancer, cardiac disease such as Congestive Heart Failure (CHF), Chronic Obstructive Pulmonary Disease (COPD), kidney failure, Alzheimer's, HIV/AIDS and Amyotrophic Lateral Sclerosis (ALS). Palliative care relieves the symptoms of these diseases, such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping. It helps one gain the strength to carry on with daily life. It improves your ability to tolerate medical treatments. And it helps you have more control over your care by better understanding your choices for treatment options.

The point of palliative care is to relieve suffering and provide the best possible quality of life for both the patient and their family.

## **A Partnership of Patient, Specialists and Family**

Palliative care is a partnership of patient, medical specialists and family. Usually a team of experts, including palliative care doctors, nurses and social workers, provides this care and works together with your own doctor. Chaplains, massage therapists, pharmacists, nutritionists and others may also be part of the palliative care team. The palliative care team of specialists provides spends as much time as necessary with you and your family. The team supports you and your family every step of the way, not only by controlling your symptoms, but also by helping you to understand your treatment options and goals. Working with your doctor to provide an extra layer of support, the palliative care team provides:

- Time for close communication
- Expert management of pain and other symptoms
- Help navigating the health care system
- Guidance with difficult and complex treatment choices
- Emotional and spiritual support for you and your family

## **What is End of Life Care?**

End of life care is an important part of palliative care, and usually refers to the care of a person during the last part of their life, from the point at which it has become clear that the person is in a progressive state of decline.

“You matter to the last moment of your life, and we will do all we can to help you not only to die peacefully, but also to live until you die.”

### **Dame Cicely Saunders**

End of life care is usually a longer period than the time during which someone is considered to be “dying”. In the UK it is mainly health care professionals who use the term end of life care, whereas patients and their families are more likely to refer to terminal illness and terminal care. Whether you call it end of life care, or terminal care, or you refer to it in some other way, how do you know when someone is dying?

Some people take the view that everyone effectively starts to die from the day they are born. The reality of course is that it is never known exactly when someone is going to die from a life-threatening disease. Taking the approach of equating terminal care with “dying”, some medical organizations define someone as being terminally ill when it is expected that there is only a short period of time, perhaps a few days or weeks, or at most a month or two, before the person is expected to die.

When someone is terminal ill, they may be cared for in hospital, they may be at home with home based care, or they may spend some time in a hospice that has in patient services. The aim of hospice care is to provide the best possible quality of life, and to relieve pain and other symptoms during the final days of a person’s life, at a time when the underlying disease can no longer be treated or cured.

Hospice care is a philosophy of care which has been described as follows:

“You matter because you are you. You matter to the last moment of your life, and we will do all we can to help you not only to die peacefully, but also to live until you die.”

Dame Cicely Saunders, founder of the hospice movement.

Hospice care is no longer provided only in buildings known as hospices, but many hospices now provide a “hospice at home” service. The difficulty with the word “hospice” can be the same as that of palliative care more generally, which is that when people go into a hospice, it is very often perceived by both the patient and their family, that it is not going to be long before they are going to die.

### **What is Supportive Care?**

Supportive care is another term that, like palliative care, has a number of different definitions.

If palliative care is defined as being only about pain and other symptom control, then supportive care may include palliative care as well as a range of other cares that could be provided to support a person (and their family) with a life-threatening disease.

Supportive care usually refers to the care that is provided to a patient and their family from pre-diagnosis, to treatment, to death, and into bereavement.



## Difficulties Caused by Different Definitions

Having a number of different definitions of both supportive care and palliative care has resulted in a considerable degree of confusion, not only for health professionals but also for patients. Not only are many people unsure about what palliative care is, and when it should be provided, but palliative care is in some circumstances part of supportive care, and in other circumstances it is the other way round with supportive care being part of palliative care.

Many people have only heard about palliative care as something that is provided in hospices for people who are dying. So another difficulty that can arise concerns people being offered palliative care early on in the course of a disease.

Some people turn down the offer of palliative care believing that to accept will mean that they are terminally ill and going to die. They may also believe that they will no longer be offered any disease modifying or curative treatment.

Whatever you call it, the time at the end of life is different for each person, and each person has unique needs for information, support and care.

### 1.1.5 Palliative Care and HIV/AIDS

At the start of the AIDS epidemic in the 1980s, palliative care was primarily regarded as the care of the dying, and for people in the last stages of AIDS. It was the approach to be adopted when there was no longer any possibility of treating the underlying disease and when further medical treatment would be inappropriate. There was an emphasis on pain and other symptom control, and on psychological, emotional and spiritual care.

When antiretroviral (ARV) treatment became available in high-income countries in the mid 1990s, it had a dramatic effect on the number of people dying from AIDS. HIV/AIDS started to be seen as a chronic condition with little need for palliative care. Many people viewed any talk of death and dying as being unduly negative.

Today, the long term outlook for people currently taking ARV treatment is still relatively unknown. Drug resistance still develops in people living with HIV and long term survival is often associated with an increased incidence of AIDS-related malignancies. Not everyone responds well to ARV treatment, with some people unable to tolerate it, and others diagnosed at a late stage when it's less likely to work. In addition, in many low- and middle-income countries access to antiretroviral treatment is still low for many of those who need it, and therefore for some time there will continue to be people with advanced HIV disease or AIDS, who will benefit from palliative care.

At the same time, palliative care has also evolved, as it has been realized that palliative care should not necessarily be only for those people who are dying and who are

approaching the end of their life. Many people now accept that some aspects of palliative care are applicable earlier in the course of a disease, and that it can often be integrated with acute care for HIV/AIDS. Palliative care is not only for those in the last stages of AIDS.

### **1.1.6 History of Palliative Care in Kenya**

Kenya was the third country in Africa to offer affordable palliative care with morphine. In 1989 the country did not have affordable morphine for use in the home. Codeine could be bought, but it was too expensive for most families. Powdered morphine was obtained by 1990, and the first palliative care service and teaching program commenced. Nairobi Hospice, established in 1990, was designed to reach all in need. From the beginning, the hospice's inspiration came from the vision of Ruth Woodridge, the wife of a BBC correspondent and a nurse herself. Ruth, together with Jane Moore (a British nurse living in Kenya then) and the late Professor Edward Kasili formed a trust fund, which allowed the hospice to open in 1990. The Nairobi Hospice not only delivered services to patients and their families, but also focused on advocacy and training of both health care and non health care providers.

The training and advocacy activities at the Nairobi Hospice have resulted in the establishment of hospices and palliative care services in various parts of the country, improving access to palliative care services to patients and families who would otherwise not have accessed it. The expansion in palliative care service centres is ongoing and although there are only fourty four hospices and five palliative care centres/units in the country, this number is expected to increase with time.

With the rapid expansion of palliative care services in the country, it is important to ensure that high quality standards of care are maintained during the delivery of such services. To accomplish this, high quality training of palliative care providers, facilitative supervision and monitoring and evaluation mechanisms must be put in place and utilized effectively. This will require standardized training of all providers. It is this context that KEHPCA initiated the development of this learning resource package that will ensure delivery of high quality and standardized palliative care training in Kenya.

This curriculum has a pediatric module (5) and all the other pediatric contents are highlighted/coloured blue.

## UNIT 1.2: INTERDISCIPLINARY TEAM APPROACH AND ETHICAL-LEGAL ISSUES IN PALLIATIVE CARE



**Time: 2 hours**

### **OBJECTIVES:**

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

1. Explain interdisciplinary team approach in palliative care
2. Discuss the ethical-legal issues in palliative care

## **COURSE NOTES**

### **1.2.1 Interdisciplinary Team Approach in Palliative Care**

The provision of comprehensive palliative care requires the input of many people, ranging from family members to health professionals, and from community members, including traditional healers, to non-governmental organizations (NGOs) or community-based organizations (CBOs), so as to create a continuum of services through all stages of illness: diagnosis to progression through end of life and bereavement. It is this provision of comprehensive care across the continuum from home care and community support to institutional services (primary, secondary, and tertiary), social services, and back that will ensure the needs of patients and their families are met. In settings where palliative care is well established and well resourced, it is often carried out by a multidisciplinary/interdisciplinary team, which may consist of doctors, nurses, social workers, counselors, spiritual leaders and others. However, in most settings there may be only a handful of people to help, or perhaps only one provider. There is need to build a team because one cannot provide palliative care on her/his own. An interdisciplinary team involves care that is:

- **Physical** – The role of the health care professionals (nursing, treating, prescribing)

- **Psychological** – The role of the counselor (listening, counseling, being there)
- **Social** – The role of the social worker (the help with finances, housing, family support)
- **Spiritual** – The role of a spiritual leader (prayer, counseling, carrying out rituals or rites)

Volunteers who help the patient with basic needs like assisted walking or feeding and improve the patients' comfort.

## Teamwork

A team does not have to be big to be effective – two people can be a team – but the way they work together is important. Building a team requires mutual respect, support and good communication. Recognizing the importance of team members' different contributions and verbalizing it is vital, i.e. noticing when someone has done something well and appreciating their hard work. Palliative care can be emotionally draining and there is need for providers to support one another, noticing when one is exhausted and sharing their load.

### 1.2.2. Ethical-Legal Issues

In recognizing the importance of human rights within the health field, the Kenyan Patients' Rights Charter states that every patient has the right to:

- A healthy and safe environment
- Participate in decision making
- Access to health care
- Knowledge of one's health insurance/medical aid scheme
- Choice of health services
- Be treated by a normal health care provider
- Confidentiality and privacy
- Informed consent
- Refuse treatment
- Be referred for a second opinion
- Continuity of care
- Complain about health services

Protecting the human rights of people living with HIV&AIDS has been a necessary part of AIDS policy since the beginning of the epidemic because of the issues of discrimination and stigma. The Human Rights Approach applies also to patients with cancer and other life threatening illnesses.

### 1.2.2.1 Palliative Care Principles

- Ethical principles in palliative care centre around **autonomy, beneficence, non-maleficence** and **justice**.
- However, these principles are sterile if they are not applied within a compassionate environment, by wise, charitable and moral practitioners.
- What is particularly needed is the virtue of prudence, understood as 'practical wisdom'. Prudence plays a key role in disclosing the way in which the different classical ethical principles should be applied in individual situations.

### 1.2.2.2 The Ethical Framework for Palliative Care

#### Autonomy

- Autonomy is about the respect for a person's right to make decisions concerning their care. Autonomy promotes the development of a trusting relationship between a health care worker and a patient.
- It also means the patient becomes an active member of the management team, which restores a sense of control in the face of an illness that has deprived that person of control.
- In order to give due attention to this principle, several matters are involved, and these are set out next.

#### Communication

- The patient has a right to know about the diagnosis, the treatment that is proposed, its effects and any side effects.
- It is the responsibility of the health care worker to ensure that the patient is fully informed.
- This will involve an assessment by the health care worker both of the patient's understanding and of how much the patient wants to know.
- Failure to communicate honestly with the patient can isolate the patient, preventing a therapeutic sharing of the patient's fears, anxieties and other concerns.
- In the case of a child patient, especially an older child, opinions and concerns are often not sought. This increases the child's pain.
- The child can be left to feel responsible for their illness and even for their parents' suffering.
- It is most important for the health professional to include the child in communications with the family about the illness and in decision-making.

**Consent**

- Once the patient is given sufficient information, they have the prerogative to accept or not accept the care or treatment offered.

**Confidentiality**

- Confidentiality protects the autonomy of the patient by allowing them to control information about themselves.

**Privacy**

- Central to a respect for personal autonomy is the concept that the privacy of the individual must be respected.
- The principle of non-maleficence is not absolute, and must be balanced against **Beneficence**
- To 'do good', health professionals should reflect on patient care decisions with this question in mind: 'Will this treatment benefit the patient?' This requires considering risks versus benefits and deciding whether the benefits outweigh the risks.
- Often, families will not want a patient to know their diagnosis, or perhaps want the patient cared for in hospital rather than at home. The healthcare worker needs to be familiar with both the patient and their situation in order to make a good assessment and so guide the patient and family.
- Knowing the patient's wishes is essential in deciding what will benefit them.
- The patient needs truthful information from the health professional in order to make his or her own decisions.
- Although palliative care is concerned with the care of both the patient and the family, the healthcare worker must be careful not to subordinate the interest of the patients to the anxieties of relatives.
- It is often the case that family members want 'everything' done for their patient, not appreciating that, in fact, prolonging the patient's life with artificial hydration or other measures only acts to prolong their suffering.
- Families need to be informed about the consequences of different treatments and they also need to be encouraged to listen to what the patient wants.
- With regard to children, parents are presumed to have the ability to make decisions regarding a child's 'best interests'.
- In general, the best interests of a child are presumed to be life preserving, but in the face of irreversible illness this presumption requires careful exploration. 'Best interests' may require a plan that focuses on the child's need for comfort and symptom relief to ease the process of dying in a way that promotes the safety, comfort and dignity of the child.
- Palliative care is neither about shortening life nor prolonging the dying period.

- It is of great importance that the health care professional establish, with the patient and the patient's family, the clinical goals at which they are aiming.
- One patient may desire only to die comfortably without pain, while another may want to live long enough to witness a particular event, a wedding, a birth etc. These different goals help the health worker to determine the best treatment decision to make in the case of each patient.
- In order to 'do good', it is essential that the healthcare worker have the necessary degree of competence to address the various components of human suffering.
- Health workers engaged in palliative care need to keep up-to-date with current knowledge in their field to be able to make judgements about the risks of interventions versus the benefits.

### **Non-maleficence**

- To 'do no harm', a health worker needs to have adequate education and knowledge to ensure that the treatment they offer will not harm or endanger a patient.
- In practice, many treatments carry some risk of harm and it is up to the health worker to weigh the risks versus the benefits.
- The principle of non-maleficence is not absolute, and must be balanced against the principle of beneficence (doing good – see above).
- In essence, the intended effect of treatment must be a good one. For instance:
  - Artificial hydration at the end of life may appear to families to be good for a patient who is no longer taking oral fluids, whereas in fact it can cause great distress since the patient's body can no longer cope with these fluids.
- The principle of 'double effect' forbids the achievement of good ends by wrong means. It forbids doctors to relieve the distress of a dying patient by killing them, but it permits the use of drugs that relieve the distress of dying even when they may hasten death.

### **Justice**

- Justice is concerned with the correct use of resources, and this is particularly pertinent when working in resource-poor settings such as in many areas of Africa.
- It is the principle by which competing claims may be decided in fairness and is concerned with fair distribution of resources. Here are two examples:
  - If a family has very limited resources, should the terminal patient be prescribed expensive treatment that will cause financial hardship for the rest of the family? In the days before antiretrovirals became free or more affordable, individuals sometimes sold all the families

- property to buy drugs for a limited period of time. The family was eventually left impoverished.
- o Should patients with terminal cancer be started on ART? This is often seen with HIV-positive women being started on ART when they have advanced cancer of the cervix. In places where ARVs are scarce, this is a case where drugs would be better used for patients who have a longer prognosis. This is also an example of futile treatment: ART is not going to have any curative effect on the cancer and in fact may prolong the woman's suffering without just cause.
  - Prolonging the dying process may be justifiable if the patient and the family need that extra time to achieve important personal goals. However, the availability of medical technologies is not of itself an ethical command that these technologies be used.

## **Power Imbalance and HIV&AIDS, Cancer and Other Life Threatening Illnesses**

### **Overcoming Inequality**

Sexual inequality can be overcome through interventions such as:

- Recognizing, understanding, and publicly discussing the ways in which the power imbalance in gender and sexuality fuels the HIV&AIDS epidemic and other STIs.
- Ensuring that imbalances are not allowed to reinforce damaging gender and Sexual stereotypes.
- Promoting gender-neutral programs. This includes using prevention education messages not targeted to one sex, such as 'be faithful' or 'stick to one partner,' empowering and providing care services that make no distinction between the needs of women and men.
- Working with couples as the unit of intervention, rather than with individual women or men.
- Empowering women by improving their access to information, skills, services and technologies, and by encouraging participation in decision making and creating a group identity.

### **Special Considerations in HIV&AIDS**

- Many ethical issues are particularly important in relation to patients with HIV or AIDS. Such as the right to confidentiality about HIV status, the concerns of the public and the fears of the health professionals.
- Disclosure of a person's HIV status, even to another health professional, must be on a legitimate 'need to know' basis.



## Important Note

- Ethics in palliative care is a matter of practical reasoning about individual patients, specific cases and unique situations.
- What may be ethical in one case may be unethical in another.
- A health professional at the bedside must understand the clinical situation in all its subtle medical and human complexity.

The fundamental moral attitudes orienting the contemporary practice of palliative care are an unconditional respect for the dignity of each person and the acceptance of finitude

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# Clinical Aspects In Palliative Care

## Module 2



**Time: 10 Hours**

### **OBJECTIVES:**

At the end of this module the participants will be able to:-

1. Outline the principles of clinical assessment of patients with life threatening illnesses
2. Outline the principles of pain assessment
3. Discuss the various aspects of pain management
4. Discuss the management of common symptoms in patients with life threatening illnesses
5. Explain the role and complications of various therapies in patients with life threatening illnesses
6.
  - a) State the common complications in patients receiving palliative therapy
  - b) Explain drug interactions in patients receiving palliative therapy
7. Discuss assessment and management of common mental illness
8. Describe the principles of wound, skin and mouth care
9. Discuss the management of palliative care emergencies
10. Discuss various aspects of end of life care

## Content Outline

- Principles of clinical assessment of patients with life threatening illnesses
- Principles of pain assessment
- Aspects of pain management
- Management of common symptoms of patients with life threatening illnesses
- The role and complications of various therapies in palliative care
- Common complications, drug interactions and adverse effects of therapy in patients with life threatening illnesses
- Assessment and management of common mental illnesses
- Principles of wound, skin and mouth care
- Management of palliative care emergencies
- End of life care

## UNIT 2.1: PRINCIPLES OF CLINICAL ASSESSMENT IN PALLIATIVE CARE

**Time: 1 hour**

### **OBJECTIVES:**

At the end of this unit the participants will be able to:

1. To outline principles of clinical assessment of patients with HIV, cancer and other life threatening illnesses
2. To outline principles of nutritional, psychosocial and spiritual assessment of a patient in palliative care

## COURSE NOTES

### **2.1.1 Principles of Clinical Assessment of Patients with Life Threatening Illnesses**

Comprehensive assessment of patients in palliative care is the basis of quality and holistic care.

- History
- Physical Examination
- Investigations

### **2.1.2 Principles of Nutritional, Psychosocial and Spiritual Assessment**

#### **Nutritional Assessment**

- Anthropometric measurements
- Adequate intake of essential food groups
- Adequate fluid intake
- Functional ability



## Psychosocial Assessment

In general it is necessary to listen to patient's story and encourage narrative in terms of;

- **Emotional issues:** identifying losses, anxiety, fear, guilt, anger, sorrow and coping mechanisms such as how the patient has coped with stressful incidents in the past
- **Genogram:** it is a useful tool to discuss family relationships and identify close supportive relationships, conflictual relationships, and unfinished business
- **Financial issues:** explore income or other financial support
- **Food security:** Finding out whether the patient has access to food

## Spiritual Assessment;

A commonly used spiritual assessment tool comprises of;

<b>F:</b>	Faith or beliefs that the patient subscribes to
<b>I:</b>	Importance and influence of the illness towards faith and vice versa
<b>C:</b>	Community that the patient may belong to in terms of his/her faith
<b>A:</b>	Address/Action that the healthcare worker needs to take note of in relation to the patient's faith

## UNIT 2.2: PAIN AND PAIN ASSESSMENT



**Time: 2 hours**

### **OBJECTIVES:**

At the end of this unit the participant will be able to:

1. Describe pain
2. Describe physiology of pain
3. Describe the Pathophysiology and Types of pain and pain syndromes in life threatening illnesses
4. Describe the types of pain and pain syndromes in HIV, cancer and other life threatening illness
5. Describe pain assessment in HIV, cancer and life threatening illnesses

## COURSE NOTES

### 2.2.1 Definition and Physiology of Pain

#### **Definition**

Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.

*(International Association for the Study of Pain (IASP), 1994)*

Pain has also been defined as “what a person says it is and existing whenever the person says it does”. (McCafferey and Passero)

Pain is associated with actual or potential tissue damage, or described in terms of such damage. It is frequently inadequately treated, resulting in unnecessary suffering. The aim of palliative care is to allow patients to be pain free or for the pain to be sufficiently controlled that it does not interfere with their ability to function or their quality of life.

## 2.2.2 Pathophysiology of Pain and Types of Pain

### Introduction

- Pain, although unpleasant, is essential for survival as it tells us when something is wrong.
- Pain is an important bodily response to stimuli that have the potential to cause damage.
- Understanding the physiology and classification of pain will help in the assessment and management of pain, i.e. determining the type of pain helps to determine its treatment.
- Stimuli that activate the nociceptors are perceived as pain.
- Pain is influenced by many different factors and therefore total pain encompasses physical, psychological, cultural, social and spiritual factors.
- Psychological factors are as important in dealing with pain as the physical cause of the pain.
- Pain can be caused by a disease (e.g. cancer), its consequences (e.g. opportunistic infections), treatment (e.g. chemotherapy) or concurrent disorders (e.g. arthritis).
- Children (including newborns) suffer pain as much as adults. Younger children experience higher levels. Fear of treatment may prevent them expressing pain.
- Repeated painful procedures may cause children increased anxiety and pain perception.

### Pain in Palliative Care

- Pain is a common and often feared symptom experienced by those with life-threatening illnesses, such as HIV/AIDS and cancer.
- Seventy-five per cent of patients with cancer endure significant pain throughout the course of their illness.
- Pain levels are similar for patients with HIV/AIDS and are associated with significant psychological and functional morbidity.
- Most patients in pain will receive treatment for their pain in the home setting.

### Impact of Pain on the Patient

- Reduced quality of life
- Induce depression
- Exacerbated anxiety
- Interfere with social performance and impair the quality of relationships

- Impact negatively on physical capability
- Prevent work and reduce income
- Challenge existence belief

### Causes of Pain

- The illness itself, e.g. bony, visceral or soft-tissue involvement or nerve compression
- Complications of the illness, e.g. pressure sores, constipation or post-herpetic neuralgia
- Treatment of the illness, e.g. neuropathy caused by chemotherapy or ART
- Co-morbidities, e.g. sickle cell disease.

### 2.2.2 Physiology of Pain

- Pain pathways involve the peripheral nervous system and central nervous system.
- The sensation of pain is made up of an initial fast, sharp pain and a later slow, dull, long-lasting pain and this is due to the difference in the speed of the nerve impulses in the different nerve-fibre types.
- When cellular damage occurs, a number of chemical substances are produced or released which influence the degree of nerve activity and therefore the intensity of the pain sensation.
- Pain from internal organs is perceived at a location that is not the source of the pain i.e. referred pain.
- Chronic pain can result in an altered perception to pain, leading to increased sensitivity or abnormal sensations such as burning or numbness.

### Types of Pain

- Pain can be classified according to:
  1. Duration
  2. Underlying mechanism
  3. Situation.
- Different types of pain respond differently to different types of analgesia; hence the importance for clinicians to determine the type of pain that a patient is experiencing in order to prescribe the most appropriate analgesia.
- Patients with life-threatening illnesses will often have both nociceptive and neuropathic pain, and many will also have more than one cause of pain
- A definition of pain terms can be found in Table 1.

**Table 1: Definition of pain terms**

<b>Acute pain</b>	Usually due to a definable acute injury or illness
<b>Allodynia</b>	Pain caused by a stimulus which does not normally provoke pain
<b>Analgesia</b>	Absence of pain in response to stimulation which would normally be painful
<b>Breakthrough pain</b>	A transitory exacerbation of pain that occurs on a background of otherwise stable and controlled pain
<b>Causalgia</b>	A syndrome of sustained burning pain, allodynia and hyperpathia after a traumatic nerve lesion, often combined with vasomotor dysfunction and later trophic changes
<b>Central pain</b>	Pain associated with a lesion in the central nervous system (brain and spinal cord)
<b>Chronic pain</b>	Results from a chronic pathological process
<b>Dysaesthesia</b>	An unpleasant abnormal sensation which can be either spontaneous or provoked
<b>Hyperaesthesia</b>	An increased sensitivity to stimulation
<b>Hyperalgesia</b>	An increased response to a stimulus that is normally painful
<b>Hyperpathia</b>	A painful syndrome characterized by an increased reaction to a stimulus, especially a repetitive stimulus, and an increased threshold
<b>Incident pain</b>	Occurs only in certain circumstances, such as after a particular movement or on standing: it should be regarded as chronic pain but, as it is intermittent, it is better managed with local measures where possible
<b>Neuralgia</b>	Pain in the distribution of a nerve
<b>Neuropathy</b>	A disturbance of function or pathological change in a nerve
<b>Neuropathic pain</b>	Pain which is transmitted by a damaged nervous system, and which is usually only partially opioid-sensitive
<b>Nociceptor</b>	A receptor preferentially sensitive to a noxious stimulus or to a stimulus which would become noxious if prolonged
<b>Nociceptive pain</b>	Pain which is transmitted by an undamaged nervous system and is usually opioid-responsive
<b>Pain</b>	An unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage
<b>Pain threshold</b>	The least experience of pain which a subject can recognize
<b>Pain tolerance level</b>	The greatest level of pain which a subject is prepared to tolerate

<b>Procedural pain</b>	Pain related to procedures /interventions: this is especially important in children with chronic illnesses (HIV and malignancies) and is an important cause of anxiety in children that can be prevented
<b>Sympathetic pain</b>	Caused by damage to sympathetic nerves

## 1. Duration

### Acute pain

- Is usually due to a definable acute injury or illness
- Has a definite onset and its duration is limited and predictable
- Is accompanied by anxiety and clinical signs of sympathetic over-activity.

Treatment is directed at the acute illness or injury causing pain, with the short-term use of analgesics.

### Chronic pain

- Results from a chronic pathological process;
- Has a gradual or ill-defined onset, continues unabated and may become progressively more severe; persists longer than the expected healing time for the injury or illness in question;
- Often leads to the patient appearing depressed or withdrawn and possibly being labelled as 'not looking like somebody in pain';
- Offers no protective benefits, serves no purpose and has detrimental effects causing changes at the level of the nervous system as well as psychological burden.

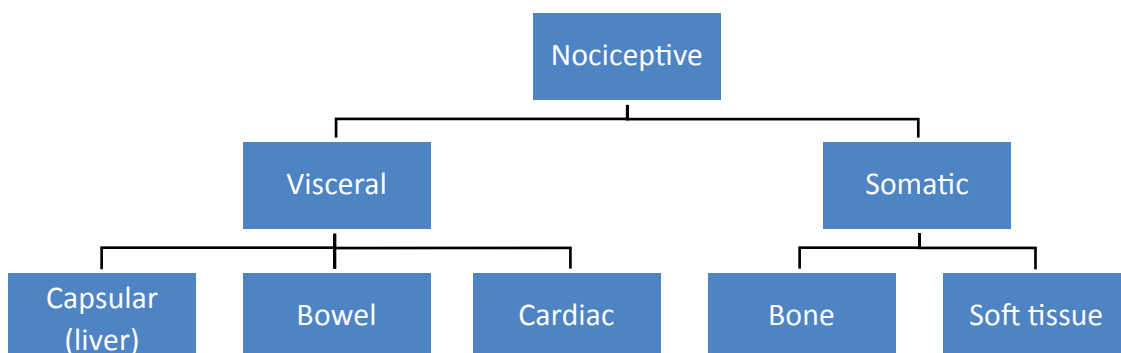
Treatment is directed at the underlying disease where possible, along with regular use of analgesics to relieve pain and prevent recurrence as well as psychological supportive care.

## 2. Underlying mechanism

### Nociceptive

Nociceptive pain is produced by stimulation of specific sensory receptors in the viscera and somatic structures (although the nerves are intact). Its characteristics are:

- **Somatic pain:** superficial (cutaneous) in skin, subcutaneous tissue or mucous membranes: sharp and well localised pain, deep muscles, tendons, joints: more diffuse and dull;
- **Visceral pain from organs:** dull and poorly localised - the sensation of pain may be referred to a cutaneous site, often associated with autonomic responses (e.g. sweating, nausea)



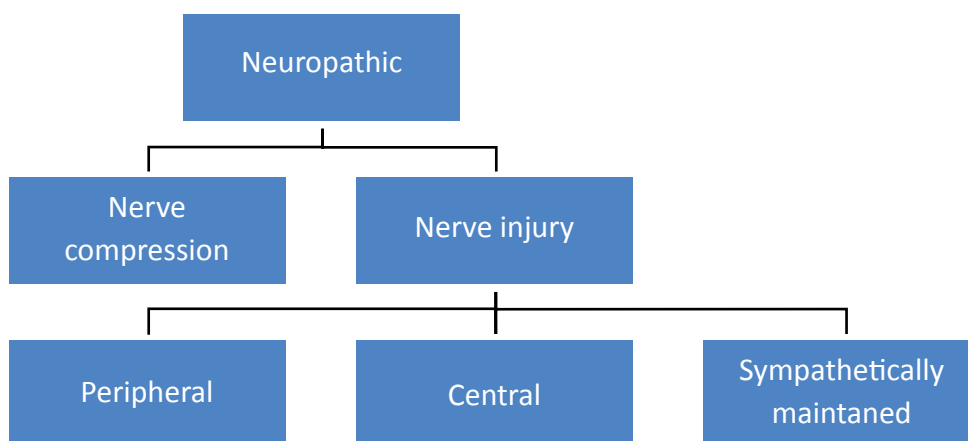
Source: Watson et al,2009, p226.

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### Neuropathic

Produced by damage to the central or peripheral nervous system (the nerves are abnormal). Characteristics:

- Burning pain (dysaesthesia)
- Shooting pain (lancinating);
- Aching sensation relieved by pressure applied to the affected area
- Increased sensitivity to a pain stimulus (hyperalgesia) or to a stimulus that is not normally painful (allodynia).



Source: Watson et al,2009, p227.

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### 3. Situation

- **Breakthrough**—a transitory exacerbation of pain that occurs on a background of otherwise controlled pain.
- **Incident pain** – occurs only in certain circumstances (e.g. after a particular movement).
- **Procedural pain** – related to procedures or interventions.

## Other Factors That Contribute to Pain Perception

- Psychological factors as well as spiritual issues and social circumstance influence pain; these factors can increase or decrease pain sensation and perception.
- The concept of total pain reminds us we need to holistically assess and manage chronic pain.
- The IASP definition of pain draws attention to the emotional component of the pain experience.
- Pain is often expressed in emotional terms such as ‘agonising’, ‘cruel’, ‘terrible’ etc.
- Integrated multi-disciplinary teams need to be involved in the management of chronic pain.
- Holistic support for a patient with chronic pain can have a profound effect on the patient’s quality of life and may focus on addressing feelings of helplessness and on building resilience.
- Women experience pain differently from men as a result of biological, psychological and social factors; men and women also respond differently to pharmacological and non-pharmacological pain management.
- Women in Africa are more likely to suffer pain than men and this may be because:
  - o They are more likely to be under-treated for their pain.
  - o They have higher levels of anxiety than men and this exacerbates pain.
  - o If they have HIV, they have unique pain syndromes of a gynaecological nature that are specifically related to opportunistic infections.
  - o Moreover, HIV-positive women are often young with babies and young children and the children may also have HIV, and this adds emotional, social and spiritual suffering to their pain.

### 1. Psychological Factors

- Pain is influenced by psychological factors as it affects the human consciousness.
- Psychological factors are just as important in managing pain as the physical cause of the pain.
- Psychological pain related to chronic pain often shows itself as depression or anxiety.
- Distress associated with chronic pain may present as anger, frustration, hopelessness, denial, grief, sadness or withdrawal.
- Avoiding activities and social contact affects the patient themselves and



leads to less activity, more social isolation and a focus on the pain – leading to a vicious circle of pain – lack of activity – fear – depression – more pain.

- o It has been shown that negative feelings, such as rejection or loss, create neuronal stimulation patterns similar to those created by noxious stimuli.

## 2. Spiritual Factors

- Spiritual and existential distress may manifest themselves in physical problems and are an important source of clinical suffering that can aggravate and even cause pain.
- Spiritual pain may or may not have a religious component and often reflects the patient questioning of the meaning of life generally, and that of his or her own life in particular.
- Hopelessness and despair make pain difficult to bear, and a sense of peace and strength from faith will help to make pain easier to live with.
- Spiritual pain may:
  - o prompt in the patient a re-evaluation of their life
  - o lead to the recovery of values and beliefs
  - o Be a transition point along their journey towards greater self-understanding.
- Recognition and support for spiritual issues is an integral part of pain assessment and management.

## 3. Cultural Factors

- Cultural factors play a major role in how we view health and illness and therefore pain.
- A sensitive approach to culture, ethnicity and language will prevent the aggravation of pain and help reduce emotional distress.
- Many cultures believe in 'supernatural' powers that can cause pain.
- Different cultures respond differently to pain and it is important to recognise the different behaviours such as shouting and crying, or being stoical.
- How we see the family and community respond to pain will affect how we as individuals respond to pain.
- Language may also be a challenge, with the patient being unable to communicate effectively with the health professional and visa versa.

## 4. Social Factors

- Unresolved social factors can aggravate pain, and management of such issues can facilitate pain control.
- Factors influencing pain may include the lack of aids for daily living, the lack of accessibility to community and local resources and services, along with financial and legal issues.

## Principles of Management of pain

- The management of pain is based on the type and cause of pain and needs to be holistic.
- It is important to treat the underlying cause of the pain if it is treatable (e.g. an opportunistic infection).
- The aims of pain management are:
  - o Prompt relief of pain
  - o Prevention of recurrence.
- In the management of pain, the goals are for the patient to be pain free at night, then at rest during the day, and then pain free on movement.
- It is important to discourage the acceptance of pain by health care workers as well as the patient and their family.
- Both pharmacological and non-pharmacological methods should be used to manage pain.
- Pain can be managed across a range of settings, including the home. It is only in severe cases where an individual may need to be hospitalized in order to get their pain under control.

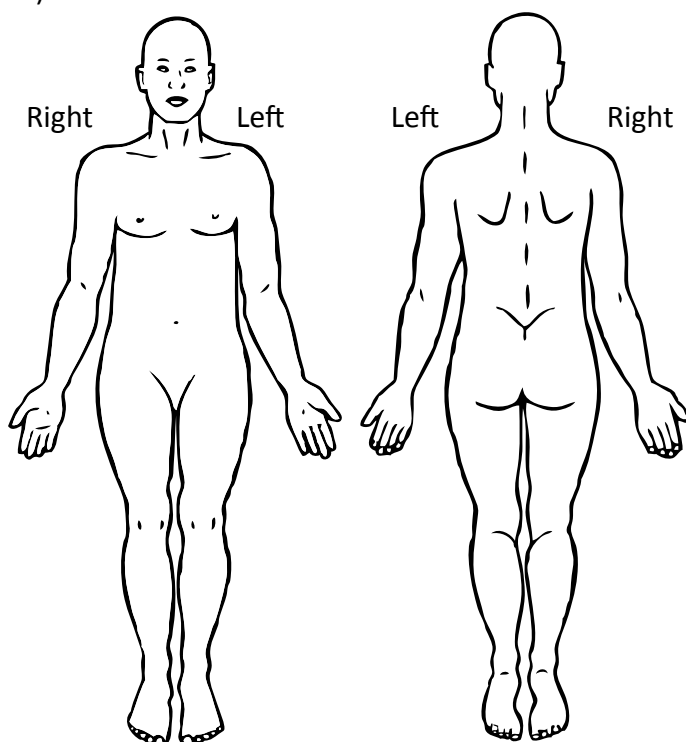
### Important Note

- Each person is different and will experience pain in a different way.
- The concept of 'total' pain is important but is often neglected, with emphasis only being put on physical pain.
- The experience of pain is a complex one and it is important to believe the patient – just because you may not find a physical cause for the pain does not mean that the patient is not experiencing pain.
- Pain not reported does not mean pain not experienced – you need to ask the patient.
- Psychological interventions are an integral component of the management of pain

## 2.2.3 Assessment of Pain

### Goals of Assessing and Measuring Pain

- **Goals of pain assessment**
  - To understand the experience of the patient and the underlying holistic factors and pathophysiology contributing to the pain
  - To prevent the onset of detrimental effects (both psychological and physical) as a result of untreated pain.
- **Goals of measuring pain**
  - To determine the presence, intensity and duration of pain
  - To determine the location of pain
  - To determine treatment efficacy.
- Assessment should not be confused with measurement, where a score is indicative of pain intensity and treatment efficacy.
- All findings or relevant information should be clearly documented. Of particular interest would be information obtained during initial assessment, pain scores, intervention and intervention efficacy.
- Clear and precise notes should be kept in a place easily accessible to other health professionals involved in caring for the patient.
- Several pain assessment and measurement tools are available, e.g. body diagrams to document the site of pain; and pain rating scales to follow the patient's pain and the effect of treatment (useful in managing difficult pain).



## Barriers to Pain Assessment and Measurement

- A number of barriers exist, not only for pain management but also for pain assessment and measurement.
- An awareness of existing barriers in a setting could eliminate the impact on the assessment and measurement process.
- The most important barriers are:
  - Lack of age-appropriate and validated pain-measurement tools
  - Lack of training on the use and implementation of pain measurement tools
  - Lack of knowledge on how to interpret a pain score once obtained
  - Lack of knowledge on how to differentiate between pain, anxiety, and emotional issues such as fear, depression and discomfort
  - Lack of skill in applying information obtained during assessment to the process of measurement and management
  - Lack of an open attitude where the patient is listened to and their experience is validated.

## Pain Measurement

- Pain measurement is complicated and requires:
  - Knowledge on the correct use of the measurement tool
  - Understanding of the scoring process
  - The ability to correctly interpret a score.
- Obtaining an initial score is vitally important:
  - For comparison with other scores after intervention
  - To determine treatment efficacy.
- Ideally, carry out pain measurements at regular intervals – either six or four measurements per week.
- Remember that most measurement instruments *do not acknowledge the presence of anxiety* and can therefore produce false high or false low scores. The behavioural indicators of anxiety are more or less the same as for pain, and it is possible to measure anxiety instead of pain.
- There are a number of different measurement tools available both for adults and children.

## Guidelines for Selecting a Measurement Tool

- Should be age appropriate
- Should have tested psychometric properties of validity and reliability
- Should be able to measure different pain levels
- Should be easy to use – many measurement tools are complicated and time consuming and not recommended in all situations
- Should be able to produce an easily understandable score
- Should have clear instruction on application and interpretation.

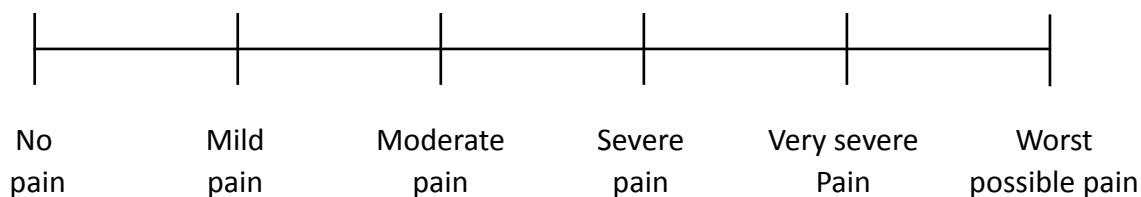
**Note:** Many pain measurement tools are available but few are tested and validated for use in Africa.

## Suggested Tools for Pain Measurement in Adults

### Numerical Rating Scale

- The health worker asks the patient to rate their pain intensity on a numerical scale that usually ranges from 0 (indicating 'No pain') to 10 (indicating the 'Worst pain imaginable'). *(it is easier from 0-5)*
- A variation of this scale is a verbal-descriptor scale, which includes descriptors of pain such as 'Mild pain', 'Mild-to-Moderate pain'. 'Moderate pain' etc.
- The numerical rating scale can be used by children, but ensure that the child is numerate when using a Visual Analogue Scale (VAS) that includes the use of numerical values.

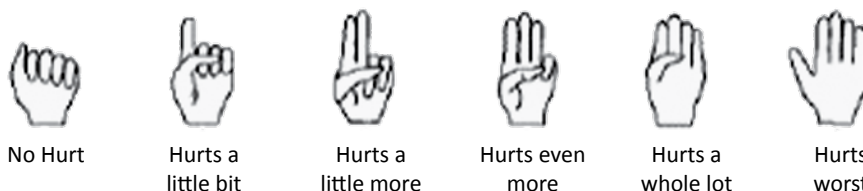
### Simple Descriptive Pain Intensity Scale<sup>1</sup>



### The hand scale

- The hand scale ranges from a clenched hand (which represents 'No hurt') to five extended digits (which represents 'Hurts worst'), with each extended digit indicating increasing levels of pain.

**Note:** it is important to explain this to the patient as a closed fist could be interpreted as worst possible pain in some cultures.



### The APCA African Palliative Outcome Scale (POS)

- The APCA African POS is a simple and brief multi-dimensional outcome measure, designed specifically for palliative care that uses a range of patient-level indicators including pain.
- The question on pain asks the patient to rate their pain (from 0 = no pain to 5 = worst/overwhelming pain) during the last three days.
- It is a useful scale when used as the complete tool to measure the outcomes of palliative care in general.

### How To Use A Pain Measurement Instrument

- Select the right instrument.
- Learn the basics of the instrument: how to use it, how to score and how to translate the score.
- Decide on the interval of measurement.
- Document all relevant information obtained during the process of assessment.
- Do the first measurement as soon as possible after admission or after referral.
- Based on the numerical score, decide on the severity of pain. A lower score normally indicates less pain or the presence of anxiety. This needs to be documented. It is sometimes useful to do more than one baseline score. It is, for example, difficult to score pain in a severely ill patient, a patient who is unconscious or one who is not responding. Here, scoring needs to be done more than once. If a patient is restrained and cannot move, and movement is a parameter, exclude movement from the scale and, if necessary, subtract the score total involved with movement from the end score.
- Use the WHO analgesic ladder to introduce treatment
- Wait the recommended time for administered medicine to produce analgesia: 30–60 minutes is standard.
- Score the patient again.
- Compare the second score against the initial score.
- If the numerical value is equal to or more than the first, the approach to treatment was unsuccessful. Either go the next step of the WHO analgesic ladder, or decrease the medicine interval, or increase the dose. Ensure that anxiety is ruled out and treated.
- Introduce the chosen second approach to pain management.
- Score the patient again. If there is no improvement in the score when compared with the initial score, pain is not being adequately treated so go up one step on the WHO analgesic ladder. If the pain score is less than the initial score, pain is being adequately treated and pain tolerance has been achieved.
- Document all relevant information.

## Important Note

Each patient is an individual and will react to pain differently. An individual or personal pain plan for each patient is therefore essential.

- Differentiate between pain and anxiety by eliminating aspects that could have contributed to the onset of pain:
  - Aspects of dosing – for instance, the time of last dose of analgesics given, a particular dose of analgesics, combinations of analgesics, the interval of drug administration (six-, four- or two-hourly)
  - The possible recent subjection to painful procedures – such as venipunctures, physiotherapy or wound dressings – that could have contributed to a lessened pain tolerance
  - Drug tolerance, withdrawal, over-sedation or side effects.
- Pain is an individual experience. Patients might react differently to the same pain stimulus.
- Remember the golden rule with children: don't wait for the child to indicate pain – they might not be able to do so (being either too sick or too sore, or not having the energy).
- Avoid downloading measurement tools from the internet or journals if they do not have clear instructions on how to implement them. These methods could be methodologically and/or conceptually flawed. Most, if not all of the available instruments were designed in mono-/dual-cultural or language settings and might therefore not be applicable for use in Kenya.
- The pharmacological management of pain cannot be determined by the numerical value obtained in the pain score. The numerical value serves only to indicate the presence and severity of pain, and to act as an indicator to use when evaluating drug efficacy.
- Any management plan must be discussed and explained to the patient and their family.

## Clinical Assessment

A comprehensive clinical assessment is fundamental to successful pain management. How questions are asked is important:

- Ask the patient to describe the pain in his or her own words.
- Assess each pain separately. Many patients have two to three different pains.
- Assess the impact of the pain on sleep, mobility, and function.
- Supplement this information by specific questions to define the exact nature of the pain.
- Ask what the pain means to the patient.
- Pain is always subjective, so believe the patient!
- Pain is what the patient says hurts.

The PQRST of Pain is a good tool for organizing an assessment (Table 2 below).

**Table 2, The P Q R S T of Pain**

<b>P</b>	Precipitating and palliating (relieving) factors
<b>Q</b>	Quality of pain (e.g. ‘burning, stabbing, throbbing, aching, stinging’)
<b>R</b>	Radiation of pain
<b>S</b>	Site (document on body diagram) Severity (document on pain assessment scale)
<b>T</b>	Timing (periodicity) Treatment (the effect of current and previous medications)

Failure to assess pain can lead to less than optimal pain control for the patient. Assessments should occur at regular intervals after initiation of the treatment, at each new report of pain or change in quality/intensity of pain, and at suitable intervals after pharmacological or non-pharmacological interventions.

The goal of the initial assessment is to characterize the pain by location, intensity and aetiology. Essential to the initial assessments are detailed history, physical examination, a psychosocial assessment and diagnostic evaluation.

**Assessment of Pain Requires Four Steps:**

<b>Step 1</b>	Assess whether the pain is being produced by direct or indirect tumour involvement, cancer treatment or whether it is unrelated to the tumour and treatment.
<b>Step 2</b>	Measure the intensity of pain and other symptoms.
<b>Step 3</b>	Assess the multiple dimensions of the expression of pain.
<b>Step 4</b>	Identify poor prognostic factors for pain control.

**Step 1: Determine the Nature and Possible Causes of Pain**

Identifying the aetiology of pain is essential to its management. Prompt diagnosis and treatment of these syndromes can reduce morbidity associated with unrelieved pain. In the great majority of patients, the history, physical examination and, occasionally, an x-ray, are adequate to appropriately assess the pain. In most cases, the pain is caused by direct tumour involvement. Psychological, cultural, and chemical addiction factors can further influence a patient’s pain experience.

**Step 2: Measuring Pain Intensity**

This assists in understanding the underlying pathology. Certain types of pain such as neuropathic pain and incidental pain can be difficult to control and may require higher doses of opioids, trials of different opioids or the addition of appropriate adjuvant analgesics.



**Step 3: Perform a Multidimensional Assessment**

Terminally ill patients need to be assessed regularly since symptoms can change rapidly.

Keep in mind that there are three steps in the pain experience:

**Production of pain** This occurs at the site of the cancer. This cannot be measured directly and can be **(nociception)** different from cancer to cancer, site to site, etc.

**Perception** This occurs at the level of the central nervous system/brain. This component too, cannot be measured and is also subject to the influence of modulation.

**Expression** The expression of pain is the main target of all our assessments and treatment. Two patients with the same level of perception may express dramatically different pain intensity. Therefore, we should not equate the intensity of pain expression directly with nociception. Doing this would be a one-dimensional approach that ignores the complexity of the pain experience.

Appropriate pain assessment requires us to consider the multiple dimensions of certain patient's expression of pain. Fortunately, in most cases, nociception remains the main component of pain. Therefore, most patients are likely to experience excellent pain control if regular analgesics are administered. It is approximately 25% of patients who show limited or no response to regular analgesics that influences of different dimensions on the pain experience are more likely to be operant; in this setting the patient should be reassessed for the presence of poor prognostic factors for pain control.

Some of the components of a multidimensional pain assessment include;

**a) Pain syndrome**

Type of pain

- Location, radiation, intensity (use scale), triggers
- Bone pain
- Visceral pain
- Neuropathic pain
- Incidental
- Are there other symptoms that need controlling?

**b) Drug**

Dosage

- Are there indications of tolerance?
- Are there signs of toxicity?
- What has been the response to individual opioids?
- What other treatments have been/are being used for pain relief?
- Effectiveness?

**c) Patient**

Underlying metabolic abnormalities (e.g. renal impairment, hypercalcemia, hepatic encephalopathy, etc.)

- Is there significant psychological distress?
- How has the patient coped previously with life stressors?
- Is there a history of drug/alcohol addiction?
- Is the patient cognitively impaired / delirious? (Use screening tools such as Folstein MMSQ to assess cognition)
- Are there spiritual issues that need to be addressed (e.g. what is the meaning of pain to the patient?)

**d) Social**

Influence of pain on the patient's daily living

- What are the family and social support systems?
- Is there severe family dysfunction?
- Are there financial concerns?
- Are there cultural issues influencing the illness experience?

**Step 4: Identify Poor Prognostic Factors**

The following are 'red flags' to alert to the possibility that difficulties may be encountered in trying to control pain;

1. Neuropathic pain.
2. Incidental pain (pain severely exacerbated by an incident such as movement, coughing, etc.).
3. Impaired cognitive functioning.
4. Major psychological distress.
5. Positive history of alcohol abuse or drug addiction (indicates poor coping strategies).
6. Somatization factor - Pain that has a large psychosocial or spiritual component is often referred to as "total pain" or "total suffering." You should suspect somatization if
  - Significant psychosocial or spiritual issues are identified;
  - The patient describes pain as "all over" (in absence of physical cause for "all over" pain such as widespread skeletal metastases or accumulation of opioid metabolites);
  - Pain appears to improve with socialization, physical activity or other distraction, and increases when alone;
  - Escalating doses of opioids produce toxicity with little or no pain relief; or there is a history of somatization under stress.

## Concept of Total Pain

Dame Cecily Saunders, who described the overlapping components of pain as physical, emotional, social, and spiritual, introduced the concept of total pain. Pain is always subjective, and the perception of pain may be modified by problems or influences related to any or all of the potential causes of suffering. The relationship of pain and suffering is complicated by the inter-dependence and inter-relationships between the different causes of suffering.

Physical pain must be controlled before other problems can be addressed and treated. Pain can be caused by or aggravated by psychosocial concerns, which must also be addressed before optimal pain control can be achieved.

Good pain control requires accurate and detailed assessment of every different pain experienced. Many patients with terminal illness have more than one pain, and each pain requires accurate assessment. Pain control requires knowledge of the different types of pain. In palliative care, where a lot of pain is chronic in nature, a different therapeutic approach is followed compared to the control of acute pain

Determining the type of pain is important as different types of pain respond to different treatments. Pain can be classified according to whether intact nerves are stimulated, nerve cells have been damaged, or the basis is purely psychological.

## UNIT 2.3: MANAGEMENT OF PAIN



**Time: 1 hour**

### **OBJECTIVES:**

At the end of this unit the health care worker will be able to:

1. Define pain management principles
2. Describe the WHO pain management ladder
3. Describe treatment of pain with opioid and non-opioid analgesics
4. Describe use of non pharmacological methods of pain management
5. Describe tolerance, physical dependence and addiction
6. Describe the use of adjuvants or co-analgesics

## COURSE NOTES

### 2.3.1 Pain Management Principles

- Relieve pain as fast as possible and prevent its return.
- Use pharmacologic and/or non-pharmacologic methods.
- Control pain while treating the underlying cause (e.g. infection).
- Reassess pain regularly using assessment tools.

#### Non-pharmacological pain management

- This can be:
  - Physical: e.g. massage, exercise, physiotherapy, surgery
  - Psychological: strengthen the patient's coping mechanisms through counselling, relaxation therapies etc.
  - Social: help the patient resolve social or cultural problems through community resources, financial and legal support, etc.
  - Spiritual: e.g. religious counselling and prayer.

## 2.3.2 The WHO Analgesic Ladder

The WHO guidelines for pain management include principles guiding route, timing, and dose: by the mouth, by the clock, and by the ladder.

### By the Mouth

The oral route is best for the management of chronic pain. Oral medications should only be abandoned if the patient is unable to take or retain them.

The intramuscular and intravenous routes are seldom used for long-term pain control. There are many other less invasive alternatives when a patient is no longer able to take oral medication such as the subcutaneous, buccal, sublingual, transdermal, and rectal routes.

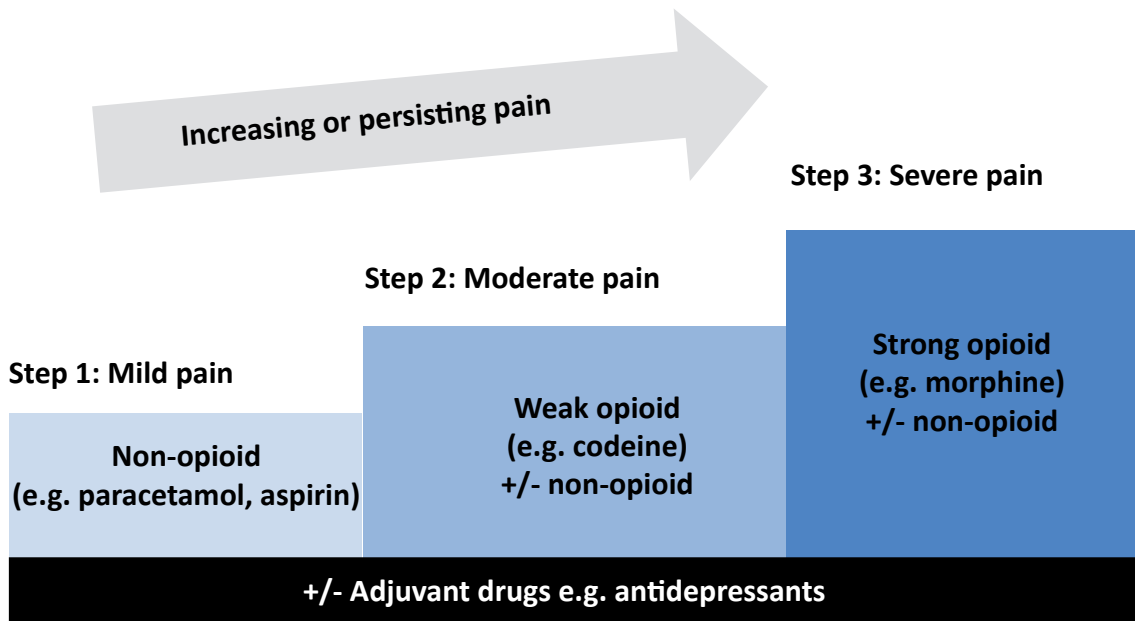
### By the Clock

- Analgesics should be given according to the clock (i.e., at regular intervals).
- Analgesics are given according to a strict schedule determined by the duration of action, in order to prevent recurrence of pain.
- Analgesics for chronic pain should never be given 'PRN' (as required).
- It is important to give the next dose before recurrence of pain.
- If pain is allowed to resurface, higher doses of analgesics will be needed to suppress the pain and it will subsequently be more difficult to control.
- A patient on a strict regular schedule of analgesia will also need to have available a breakthrough dose for any episodes of breakthrough pain.

### By the Ladder

The WHO three-step analgesic ladder representing mild, moderate, and severe pain should guide the choice of analgesic. Patients are usually commenced on step 1 analgesics. If the step 1 drugs do not produce adequate analgesia, treatment is escalated in an orderly manner to step 2 and then to step 3. If a weak opioid ceases to be effective it is important not to switch to another weak opioid on step 2 but to step 3 instead. A combination of a non-opioid and an opioid drug is effective in that the different drugs have different mechanisms of action and they potentiate each other's actions. It is often necessary and beneficial to continue with step 1 analgesics even when a patient is on step 3. Do not use step 2 and 3 analgesics together. Weak opioids should not be combined with strong opioids. These drugs bind to the same receptors and step 2 opioids will interfere with the efficacy of step 3 opioids.

## The WHO Analgesic Ladder



### 2.3.3 Management of Pain with Analgesics

#### 2.3.3.1 Starting a Patient on an Analgesic

This depends on the severity of the pain. The following steps may be useful.

For mild pain, start with a non-opioid (e.g. paracetamol) or a weak opioid (e.g. codeine): Common non-opioid analgesics include paracetamol, ibuprofen and diclofenac, piroxicam and mefenamic acid.

Oral codeine (codeine can also be given subcutaneously for patients unable to take oral medications).

If the pain persists or worsens, optimize the above dose of the analgesic and if this does not improve the pain, switch to a stronger opioid (e.g. morphine). If this is unsuccessful or if toxicity occurs, switch to a different opioid. Adjuvants may be used but first optimize the opioids. Where possible, avoid polypharmacy. Always consider non-drug modalities e.g. radiotherapy for bone pain, surgical repair of a pathological fracture.

The choice of analgesic depends on the severity, site and type of pain. Start patients on Step 1 analgesics for mild pain; if ineffective, change to a Step 2 analgesic, then to Step 3 as required.

If Step 1 or 2 analgesics don't work, don't switch to another analgesic at the same level: move up a step.

A combination of a non-opioid and an opioid drug is effective (they have different modes of action). Don't combine weak with strong opioids.

Other medications for managing pain (adjuvants) can be combined with Step 1, 2 or 3 drugs.

**If the oral route isn't possible, use alternative methods. These can include rectal, intravenous, nasogastric tube, transdermal and subcutaneous routes.**

**The majority of patients can have their pain controlled in the home care/outpatient settings using the WHO analgesic ladder as a guide. Only in very severe cases may they need to be managed as in-patients.**

#### Mild pain – Step 1

##### Paracetamol

###### Adult dose

500mg–1g po 6hrly; max daily dose 4g.

###### Children: under 1 year

10–15mg/kg po 6–8hrly; 1–5 years 10–15mg/kg po 6–8hrly; 5–12 years 250–500mg po 6–8hrly. Maximum dose 75mg/kg/day.

**Note:** hepatotoxicity can occur if more than maximum dose is given per day. Can be combined with a non-steroidal anti-inflammatory drug (NSAID).

##### Ibuprofen (NSAID)

###### Adult dose

400mg po 6–8hrly. Maximum dose 1.2g per day

###### In children

5mg/kg po 6–8hrly. Max 30mg/kg/day in three or four divided doses.

Caution: can cause serious side effects, e.g. gastro-intestinal (GI) bleeding or renal toxicity. If GI symptoms occur, stop and give H2 reception antagonist (e.g. Ranitidine).

##### Diclofenac (NSAID)

###### Adult dose

50mg po 8hrly. Maximum dose 150mg per day.

###### In children of 6 months to 12 years

2–3mg/kg per 24hrs po in two or three doses.

#### Moderate pain – Step 2 (weak opioids)

##### Codeine (Codeine is the commonest weak opioid:)

###### Adult dose

30–60mg po 4 hrly (max dose 180–240mg per day)

###### Children over 6 months

: 0.5–1mg/kg po 6hrly.

	<p>Codeine is often combined with Step 1 analgesics. Give laxatives to avoid constipation unless patient has diarrhoea.</p> <p>If pain relief is not achieved on the ceiling dose (max dose 240mg per day), move to a strong opioid (see Step 3 below).</p>
<p><b>Tramadol</b></p> <p><b>Adult dose</b></p> <p><b>Children over 12 years</b></p>	<p>50–100mg po 4–6hrly.</p> <p>50–100mg po 4–6hrly.</p> <p><b>Note:</b> Start with a regular small dose and increase if no response observed. Dose limit is 400mg/day.</p>
<p><b>Severe pain – Step 3 (strong opioids)</b></p>	
<p><b>Morphine</b></p> <p><b>Adult dose</b></p> <p><b>Children: opioid-naive infants &lt;6 months,</b></p>	<p>Morphine is the ‘gold standard’ against which other analgesics are measured.</p> <p>The correct morphine dose is the one that gives pain relief; there is no ‘ceiling’ or maximum dose, but any increase should be gradual. Starting dose is 2.5–20mg po 4hrly, the level depending on age, previous use of opiates, etc.</p> <p>Patients changing from regular administration of a Step 2 opioid should start on morphine 10 mg po 4hrly.</p> <p>If patient is cachexic, or not on Step 2 analgesics, start morphine at 5mg po 4hrly.</p> <p>Start frail/elderly patients on morphine at 2.5mg po 6–8hrly, due to the likelihood of impaired renal function.</p> <p>Starting dose 0.02mg/kg po 4hrly; opioid-naive infants &gt;6 months, starting dose 0.04 mg/kg po 4hrly.</p> <p>‘Breakthrough’ or ‘rescue’ doses of morphine can be given as often as required (ideally the same as the 4hrly dose). Keep a record of each rescue dose.</p> <p>Titrate the regular dose of morphine over several days until the patient is pain free. Either add the total daily dose and the total breakthrough dose given in 24 hours and divide by six to get a new 4hrly dose, or give 30–50% increments (e.g. 5–10–15mg etc.) As 4hrly doses. Increments of less than 30% are ineffective.</p> <p>If needed, give a double dose of morphine at night to allow pain-free sleep.</p>



If the patient can't swallow, use other routes, e.g. rectal, subcutaneous, buccal, intravenous or gastrostomy tube.  
Ratio of morphine PO:SC is 2:1, e.g. 10mg of oral morphine equates to 5mg of SC morphine.

Ratio of morphine PO:IV is 2–3:1, e.g. 30mg of oral morphine equates to 10mg of IV morphine.

#### **Explain common morphine side-effects to patients and prevent where possible:**

**Constipation** – therefore always give with a laxative, e.g. bisacodyl 5mg at night increasing to 15 mg if needed. (Do not give laxative if the patient has diarrhoea.)  
Nausea and vomiting – if this occurs, give metoclopramide 10mg 8hrly, or haloperidol 1.5 mg once a day.

**Drowsiness** – may occur in the first few days; if it does not improve after about three days, cut down on morphine dose.

**Itching** – less common. Can be managed with chlorpheniramine.

Patients on a stable morphine dose should not be sedated. If sedated, reduce the dose and consider adjuvants.

Morphine is available in immediate-release and slow-release oral formulations. Use slow-release morphine once pain is controlled. Divide the total 24-hour dose into two to get the twice-daily dosage.

Fentanyl patches can be started once pain is under control on morphine and you know the amount of analgesia the patient needs in 24 hours. Don't use Fentanyl for acute pain.

The smallest Fentanyl patch for use in children is 12mcgm (which corresponds to a total daily dose 45mg of oral morphine).

Urinary retention and pruritis are side effects that are more common in children than in adults.

### **2.3.3.2 Starting a Patient on Opioid**

#### **Step 1: Initiate Opioid**

##### **What are the Preferred Opioids?**

The following opioids are preferred in our setting: codeine, DF118, morphine, pethidine, fentanyl, and methadone. Their effectiveness is not limited by a 'ceiling' with increasing doses. Full agonists, unlike the partial agonists or mixed agonists-antagonists, will also not reverse or antagonize the effects of other full agonists.

**Starting Doses are:**

- Morphine 5 mg q4h po regularly and 2.5 or 5 mg po q1h prn for breakthrough pain (breakthrough administration- BTA).

To determine the new dose while titrating, add the number of breakthroughs being used in a 24- hour period and add that to the total daily dose. Divide by 6 to get the q4h doses. Alternately, increase the total daily opioid dose by 25-75% depending on the severity of the pain. Be sure to inquire about the effectiveness of these doses and titrate them between the 5%-20% daily dose range.

**NB:** If the patient requires more than three BTAs per day, s/he should contact the home care nurse or the attending physician and a further reassessment is necessary.

**Route of Administration**

Oral administration is preferred, as it is convenient and usually effective. When patients cannot take oral medications, other routes should be considered (eg: subcutaneous, rectal, transdermal).

**Step 2: Potential Side-effects**

What are common toxicities of the opioids?

- Nausea
- Constipation
- Somnolence
- dry mouth (xerostomia)
- pruritus, neurotoxic
- myoclonus (jerking of limbs or facial muscles)
- hyperalgesia/allodynia
- delirium
- hallucinations
- cognitive impairment

**Provide Relief**

All patients who develop side effects should be started on the following:

- **Antiemetic:** Metoclopramide for nausea. If nausea is a problem, regular metoclopramide can be given for the first three to four days.
- **Laxatives:** Use both a stimulant and a stool softener, e.g., senna and docusate. These can then be further increased to ensure a bowel movement at least every 2nd to 3rd day. Avoid bulk laxatives. These patients frequently have anorexia, early satiety and chronic nausea, and are not able to ingest the necessary amounts of liquids for these laxatives to be effective.

Explain that the opioid needs to be taken every four hours if immediate release formulations are used.

- The cancer pain is constantly present.
- After four hours, the effect of the opioid diminishes significantly.

**NB:** If the patient wishes an uninterrupted night's sleep, he or she may try doubling the regular bedtime dose and taking either the regular or breakthrough dose whenever he or she wakes up during the night. The regular regimen would be started again in the early morning on awakening.

- Encourage normal activity and good fluid intake
- Avoid activities that can be affected by increased somnolence.
- Reassure the patient and family.

### 2.3.3.3 Maintaining a Patient on an Opioid

Patients on opioids will require regular assessment. Assessments must include monitoring for opioid adverse effects and signs of disease progression. Opioid titrations will be required to manage increased pain resulting from disease progression or opioid tolerance. The appropriate dose is the amount of opioid that controls pain with the fewest adverse effects.

### Titrating Opioids

In most cases, titration involves an increase in opioid dose. Dose increases can either be:

- 30-50% increases of the previous dose – e.g., if the previous dose was morphine 120 mg po/day, the new dose, if a 50% increase is decided upon, will be 180 mg/day; or
- The new dose may be determined by the average amount of opioid used as breakthrough doses per 24 hours – e.g. a patient is taking morphine 20 mg po regularly every four hours and has used, on average, five breakthrough doses per day in the previous couple of days. Each breakthrough dose consists of morphine 12 mg po. The total amount of breakthrough opioid is, therefore, 60 mg of po morphine per day. This is then added to the regular dose of 120 mg per day, giving a total daily dose of 180 mg (morphine 30 mg po 4hourly ).
- If the pain is severe, a further 20-30% in the total daily dose may be required.

Occasionally, opioid doses may need to be reduced:

- If pain improves dramatically as a result of other interventions (e.g., palliative radiotherapy, surgical fixation of a pathological fracture); severe

- sedation due to opioids is accompanied by good pain control; or
- Renal impairment is present.

One to three regular opioid doses can be withheld in patients with very severe side effects – i.e. severe sedation, miosis, and respiratory depression. If an acute overdose occurs, naloxone may need to be administered if respiratory rate is less than eight per minute.

## What is the Maximum Dose of an Opioid Agonist?

Contrary to other drugs, such as anticoagulants or anticonvulsants, that have an established safety dose range, the adequate dose of opioid agonist is extremely variable and it should be titrated according to analgesic effects and toxicity, e.g., while one patient may achieve excellent pain control on 5 mg of morphine orally every four hours, another may require 50 mg of morphine every four hours and another 500 mg every four hours. The maximum dose is limited by toxicity and this varies widely from patient to patient.

## Opioid Toxicity

These occur in patients taking opioids in high doses or for prolonged periods of time or in patients who develop renal impairment. It is postulated that active opioid metabolite accumulation is responsible for some or most of this toxicity.

## Management of Opioid Toxicity

Several strategies have been recommended to manage opioid-related toxicity. These include switching from one opioid to another opioid agonist, hydration, and reducing the opioid dose. Reducing the opioid dose is an option if pain is well controlled and the toxicity is minimal. A combination of rotating to an alternative opioid and hydration is often effective.

<b>Step 1</b>	Hydrate
<b>Step 2</b>	Rotate opioids (see “Opioid Rotations”)
<b>Step 3</b>	Exclude underlying aggravating metabolic factors
<b>Step 4</b>	Treat symptoms e.g. hallucinations / agitation: Haloperidol is the drug of choice.

**NB:** Benzodiazepines or other drugs (such as baclofen or clonazepam) are almost never required to treat opioid metabolite induced myoclonus or toxicity. Increased benzodiazepines are only required if the myoclonus is so severe that a generalized seizure appears to be imminent or if the myoclonic jerks are painful.

### 2.3.3.4 Opioid Rotations

#### Reasons for Switching Opioids

- Poor analgesic response to a particular opioid
- Opioid toxicity
- Use of very high doses of a particular opioid making administration via oral or parenteral route of that opioid impractical. (Maximum concentrations of parenteral formulations are: morphine sulphate:  $\pm 50$  mg/ml, hydromorphone:  $\pm 30$  mg/ml).

<b>Step 1</b>	<p><b>Calculate the total daily dose of the opioid</b></p> <p>Add the breakthrough doses used in 24 hours to the total of the regular doses used in 24 hours.</p>
<b>Step 2</b>	<p>Use equianalgesic dose ratio tables to calculate the dose of the new opioid</p>
<p><b>NB:</b> Remember that these tables are only guidelines and that close clinical monitoring is required during the switching process.</p>	
<b>Step 3</b>	<p>Take into account the lack of complete cross-tolerance between opioids</p> <p>When switching from one opioid to another, decrease the dose of the new opioid by 20-30% because cross tolerance between opioids is not always complete, e.g. a patient may have become tolerant to one of the side effects, such as somnolence, of a particular opioid, but when switched to the equianalgesic dose of another opioid the patient may once again experience initial somnolence.</p> <p>If a patient has used many breakthroughs in the last 24 hours (four or more) then assess for delirium or profound psychological distress. If these are present, then the dose of the new opioid may need to be reduced by up to 50%.</p>
<b>Step 4</b>	<p><b>Establish the regular dose</b></p> <p>Divide the total daily dose of the new opioid by the number of doses to be given in a day. In the case of immediate-release formulations of opioids that need to be given regularly every 4 hours, the number of daily doses will be 6. Methadone can be given less frequently (often every 8 hours but occasionally every 12 hours or even every 24 hours.)</p>
<b>Step 5</b>	<p><b>Administer breakthrough doses</b></p> <p>Administer breakthrough doses at 10% of the total daily dose every hour when necessary. Monitor the effect of these doses. If ineffective, the dose may need to be increased to 20% of the total daily dose. On the other hand, if it is effective but causes significant somnolence, then it may need to be decreased to 5% of the total daily dose.</p>

NB: Patients and family should be warned that if more than three breakthroughs are required per day, they should contact their physician/nurse and be reassessed.

**Step 6**      **Assess regularly**  
Patients should be followed up on a daily basis during the rotation period and until stable (pain is well controlled; 3 or less breakthroughs are being used per day; and no severe side effects) for at least 48 hours.

### 2.3.4 Adjuvant Analgesics

Adjuvant analgesics are drugs that have a primary indication other than pain but are analgesic in some painful conditions or are capable of decreasing the side effects of analgesics. They are commonly administered in combination with one of the primary analgesics (e.g. opioids).

Although their primary purpose is not analgesic, these medications relieve pain through other mechanisms. Adjuvants are particularly useful in pain that is only partially sensitive to opioids, e.g. neuropathic and bone pain, smooth or skeletal muscle spasms, or pain related to anxiety.

Use adjuvants alone or in conjunction with Step 1, 2 and 3 analgesics.

The types of adjuvants that are relevant to palliative care are described further below and are:

- Antidepressants
- Anticonvulsants
- Antispasmodics
- Muscle relaxants / Anxiolytics
- Corticosteroids.

#### Antidepressants

- Use for neuropathic pain, presenting primarily as burning or dysaesthesia. Eg:
- - Amitriptyline. Adult dose 10–75mg at night, where you should start with a low dose and slowly increase it as needed. Can also be given in a dose of 0.5–2mg/kg at night.  
Children's dose: 2–12 years 0.2–0.5 mg/kg po at night; 12–18 years 10–25mg po at night.
- Side effects include dry mouth and drowsiness.
- Use with caution in the elderly and those with cardiac disease.

#### Anticonvulsants

- Use for neuropathic pain. Eg:
  - o Carbamazepine. Adult dose should start at 100mg twice a day, and can be increased to 800mg twice a day. Children's dose: 2.5–10mg/kg po 12hrly; Increase gradually to avoid side effects.

- o Sodium valporate 200mg – 1.2g per day.  
Children: 7.5–20mg/kg po 12hrly.
- o Gabapentin 100mg three times a day; increase up to 3.6g daily.  
Children 2–12 years 10mg/kg on day 1, twice/day on day 2, three times/day on day 3; maintenance dose 10–20mg/kg 3–8hrly Children 12-18 years 300mg on day 1, 300mg twice a day on day 2, 300mg three times/day on day 3; maintenance dose 300mg two to three times a day
- **Note:** Use Phenytoin in the absence of these drugs, at the rate of 100mg 2–3 times/day (2.5–10mg/kg po 12hrly in children). But use Phenytoin and Carbamazepine **with caution** because of the rapid metabolism of other drugs metabolised in the liver.

#### Antispasmodics

- Use for muscle spasm, e.g. colicky abdominal pain or renal colic. Eg:
  - o Hyoscine Butylbromide (Buscopan) Dose: Adult: start at 10mg three times /day; Can be increased to 40mg three times/day  
Children: 1month – 2 years: 0.5mg/kg po 8hrly 2-5 years: 5mg po 8 hrly 6-12 years: 10mg po 8 hrly.
- **NB.** Can cause nausea, dry mouth and constipation

#### Muscle Relaxants / Anxiolytics

- Use for skeletal muscle spasm and anxiety-related pain. Eg:
  - o Diazepam. Adult dose 5mg orally 2–3 times/day.  
Children 1–6 years 1mg/day in 2–3 divided doses; children 6–14 years 2–10mg/day in 2–3 divided doses.

#### Corticosteroids

- Use for bone pain, neuropathic pain, headache due to raised intracranial pressure, or pain associated with oedema and inflammation. Eg:
  - o Dexamethasone. Adult dose 2–4mg per day for most situations, apart from raised intracranial pressure, nerve compression and spinal cord compression. For raised Intracranial pressure start at 24mg per day and reduce by 2mg daily to the lowest effective maintenance dose. For nerve-compression types of pain 8mg is often used, and for spinal cord compression 16mg is usually the starting dose. Children: Prednisolone 1–2mg/kg po daily.
  - o If dexamethasone is Not available, then adults can also be given prednisolone where a conversion rate of 4mg dexamethasone to 30mg prednisolone can be used.
- **Note:** In advanced disease, corticosteroids may improve appetite, decrease nausea and malaise, and improve quality of life. Adverse effects include neuropsychiatric syndromes, gastrointestinal disturbances and immunosuppression.

## 2.3.5. Tolerance, Physical Dependence and Addiction

### Definitions, Clinical Relevance and Misconceptions

Health care professionals, patients and families have exaggerated concerns about opioids and their potential side effects, in particular tolerance, physical dependence and addiction. Therefore it is critically important to understand the meaning of these terms and their clinical relevance to the management of cancer pain.

#### 2.3.4.1. Tolerance

##### Definition

Tolerance is a physiological state characterized by a decrease in the effects of a drug (e.g., analgesia, nausea or sedation) with chronic administration.

##### Clinical Relevance:

It is important to distinguish between tolerance to analgesia and tolerance to side effects.

##### 1. Tolerance to Analgesia.

Patients with unchanging pain can have a consistent level of pain relief from the same dose of opioids over time. The need for higher doses of opioids is typically due to worsening pain and disease progression, rather than tolerance. If analgesic tolerance does develop, increase the dose until side effects are not tolerated.

##### 2. Tolerance to Opioid Side Effects.

Tolerance usually develops to many of the side effects of opioids (sedation, nausea, itch) in a few days. Tolerance almost never develops to constipation. Constipation should always be anticipated and treated. If a patient does not tolerate the side effects of one opioid, another opioid should be tried.

##### Misconceptions:

- To some, the need to increase the dose in response to the patient's report of pain is misinterpreted as a sign that tolerance may be developing. Unfortunately, this sometimes leads the physician to reduce the dose in a mistaken attempt to avoid or delay the development of tolerance. The appropriate response is to reassess the pain and increase the dose as indicated to relieve pain.



- Sometimes, to prevent the development of analgesic tolerance, opioids are administered at intervals which are too far apart to maintain continuous pain relief. This practice is inappropriate because it subjects patients to needless cycles of pain and pain relief.
- Often, health care professionals and patients are concerned about using opioids from the 3rd step of the WHO ladder, such as morphine, because of the mistaken belief that the medication will lose its analgesic effect; they want to save it until the pain is really severe. This concern about analgesic tolerance is unfounded and can lead to inadequate pain management.
- Some health care workers and patients believe that using morphine for pain relief will suppress respiration and possibly cause death. In fact, clinically significant respiratory depression and sedation are very rare in cancer patients. This is because tolerance to the sedative effects of morphine develops rapidly, and because pain reverses morphine's depressant effects.

### 2.3.4.2. Physical Dependence

#### Definition:

Physical dependence is the physiological adaptation of the body to the presence of an opioid. It is defined by the development of withdrawal symptoms when opioids are discontinued, when the dose is reduced abruptly or when an antagonist (e.g., naloxone) or an agonist-antagonist (e.g., pentazocine) is administered.

#### Clinical relevance

Physical dependence is a normal and expected response to continuous opioid therapy. Physical dependence may occur within a few days of dosing with opioids, although it varies among patients. Physical dependence (indicated by withdrawal symptoms) does not mean that the patient is addicted.

Health care workers should advise patients to take their pain medication as directed, and that withdrawal symptoms may occur if they reduce their dose or stop taking the medication. Symptoms of withdrawal may include agitation, insomnia, diarrhea, sweating, and rapid heartbeat. If the source of pain is successfully treated or removed, physical dependence is easily treated by gradually decreasing the opioid dose, e.g., reducing the daily dose by 10 to 25 percent every 2 days. When a daily dose of 10-15 mg of parenteral morphine (or its equivalent) is reached, maintain that dose for 2 days, then discontinue.

The development of physical dependence should not limit analgesic therapy. Antagonists and agonist-antagonists in the patient who is physically dependent should

be strictly avoided because their use will neutralize the analgesic effect and cause a withdrawal syndrome.

### **Misconceptions:**

- Physical dependence is frequently equated mistakenly with addiction. It is incorrect to use the term 'physical dependence' (a physiological state) to describe addiction (a dysfunctional psychological and behavioral syndrome).
- Patients who express concern about physical dependence should be given correct information and reassured. Example: "Do not to stop taking your medication abruptly or you will have symptoms of withdrawal. If you no longer need opioids for pain relief (for example after a course of radiotherapy), your physician can gradually decrease your dose over several days."

### **2.3.4.3. Addiction**

#### **Definition:**

While tolerance and physical dependence are physical changes in the body, addiction is defined by aberrant changes in behavior. Addiction is compulsive use of drugs for nonmedical reasons; it is characterized by a craving for mood altering drug effects, not pain relief. Addiction means dysfunctional behavior, in sharp contrast to the improved function and quality of life that result from pain relief. Aberrant behaviors which indicate addiction may include: denial of drug use; lying; forgery of prescriptions; theft of drugs from other patients or family members; selling and buying drugs on the street; using prescribed drugs to get "high.

#### **Clinical relevance:**

Addiction is extremely rare in cancer patients who use opioids for pain. Biochemical, social and psychological factors are more important in the development of addiction. Opioids should not be withheld for fear that a patient will become addicted. If a pain patient requests a strong analgesic, it is likely that the patient has inadequate pain control.

#### **Misconceptions:**

- People who fear addiction, yet desire pain relief sometimes think "So what if I get addicted, I am going to die anyway." Such thinking creates an unnecessary

trade-off between addiction and pain relief; in fact, addiction is rare and should not be a worry when opioids are used appropriately to relieve pain.

- Patients and family members who express concern about addiction should be given correct information and reassured. Example: “Sometimes patients taking opioids for pain relief are concerned about addiction. However, you are taking opioids for pain relief whereas addicts take drugs to get high. You are not an addict if you take pain medications to relieve your pain.”

#### **2.3.4.4. Pseudo-Addiction**

##### **Definition**

Pseudo-addiction describes what happens when healthcare workers perceive as addictive behavior a pain patient’s requests for more or stronger pain medications. In fact, the patient’s behavior may be a response to inadequate pain management. Pseudo-addictive behavior is pain-relief seeking behavior. Pseudo-addiction is an iatrogenic phenomenon, e.g. it is when problems result from the treatment efforts of health professionals.

##### **Clinical Relevance**

Pseudo-addictive behavior may occur when analgesics are prescribed in inadequate doses or at dosing intervals that are longer than the duration of action of the drug. Pseudo-addictive behaviors are more likely to occur in patient care settings where health care professionals are inadequately trained in pain management and the rational use of opioids. The appropriate clinical response to pseudo-addictive behaviors is to reassess the patient’s pain and to treat the pain adequately.

#### **2.3.6 Special Considerations in HIV&AIDS**

- Pain in HIV&AIDS (see Table 3 below) is highly prevalent, has various syndromal presentations, can result from two or three sources at a time and has the potential of being poorly managed.
- Such pain may be directly related to HIV infection, immunosuppression or HIV therapy.
- In South Africa the prevalence of neuropathic pain in AIDS patients was 62% prior to antiretroviral therapy, with men more likely to experience pain than women.

**Table 3: Common Sources of Pain in HIV&AIDS**

Cutaneous/ Oral	Visceral	Somatic	Neurological/Headache
<ul style="list-style-type: none"> <li>• Kaposi’s Sarcoma</li> <li>• Oral cavity pain</li> <li>• Herpes zoster</li> <li>• Oral or oesophageal candidiasis</li> </ul>	<ul style="list-style-type: none"> <li>• Tumours</li> <li>• Gastritis</li> <li>• Pancreatitis</li> <li>• Infection</li> <li>• Biliary tract disorders</li> </ul>	<ul style="list-style-type: none"> <li>• Rheumatological disease</li> <li>• Back pain</li> <li>• Myopathies</li> </ul>	<ul style="list-style-type: none"> <li>• HIV-related headaches from encephalitis, meningitis etc</li> <li>• HIV-unrelated headaches from tension, migraine etc.</li> <li>• Iatrogenic (AZT)</li> <li>• Peripheral neuropathy</li> <li>• Herpes neuritis</li> <li>• Neuropathies associated with DDI, D4T toxicities</li> <li>• Alcohol, nutritional deficiencies</li> </ul>

*Modified from Carr*

- Pharmacological pain management should be as per the WHO analgesic ladder (see earlier in the chapter).
- NSAIDs, tricyclic antidepressants, anticonvulsants and non-pharmacological interventions are important – although NSAIDs could exacerbate bone marrow disease and worsen the gastro-intestinal effects of HIV and ARVs so should be used **with caution**.
- Many of the ARVs, especially the protease inhibitors, cause abdominal discomfort, nausea and vomiting.
- Headache and peripheral neuropathies are also common side effects of ART.
- Some antiretroviral medicines interact with analgesics and so **caution** needs to be used when giving analgesics to patients on ART. The main interactions occur with the adjuvant analgesics such as phenytoin, carbamazepine, dexamethasone and amitriptyline.
- Women with HIV have unique pain syndromes of a gynaecologic nature specifically related to OIs and cancer of the pelvis and genito-urinary tract.
- African women with HIV are often young with babies and young children, and if they also have HIV this adds emotional, social and spiritual suffering to their physical pain.

## Important Note

- Pain is often inadequately treated.
- Failure to assess pain levels and type causes poor pain control.
- A person with long-standing pain may not show the usual signs of pain.
- Never use slow-release opioids as rescue medication.
- Significant percentages of adults and children cannot metabolise codeine, so it may be ineffective.
- Patients will often have more than one pain.
- Children younger than six months are more sensitive to possible opioid-induced respiratory depression, so they need a lower starting dose.

## UNIT 2.4: MANAGEMENT OF COMMON SYMPTOMS IN PALLIATIVE CARE



**Time: 2 hours**

### **OBJECTIVES:**

At the end of this unit the participant will be able to:

1. Describe the common symptoms in patients with HIV, cancer life threatening illnesses
2. Assessment common symptoms in patients with HIV, cancer life threatening illnesses
3. Manage the common symptoms in patients with life threatening illnesses

## COURSE NOTES

### 2.4.1 Palliative Care Principles

- Managing symptoms is a crucial part of palliative care.
- Good pain and symptom control is an essential component of all palliative care.
- Listen to what the patient and family are saying; both verbal and non-verbal communication is necessary.
- Holistic assessment underpins good symptom control, so excellent history and careful examinations are both very important.
- Evaluate the symptom by thinking through the likely aetiology and underlying pathophysiology.
- Avoid unnecessary interventions.
- Formulate a management and treatment plan.
- 'Treat the treatable':
  - o Consider radiotherapy and chemotherapy if available.
  - o Consider antibiotics for reversible infections.
  - o Drain a pleural effusion.
  - o Tap ascitic fluid.
  - o Clean and dress painful wounds.

- Prescribe essential medications:
  - o Keep numbers of medications to a minimum.
  - o Balance benefits of medications with possible side effects.
  - o Remember affordability and accessibility.
  - o Make sure you explain the reasons for prescribing the medications and how they should be taken.
- Remember to offer support and explanation to the family and empower their input.
- Review, re-evaluate, re-formulate plans

### **The impact of symptoms**

- Consider the following impacts of symptoms on a patient's overall situation:
  - o When a patient is vomiting and confused, how can they talk about their fears and anxieties?
  - o When a patient is frightened and lonely, how can they cope with their fungating wound when the smell makes everyone avoid them?
  - o When a family listens to their loved one cough and fight for breath with no relief, how can they feel at peace?
  - o When no one talks openly about what is happening, how do the patient and family decide what treatment to have and what they can afford?
- These are some of the key issues for palliative care providers, and the assessment of symptoms is the key to trying to overcome some of them so that proper symptom management plans can be put in place.

## **2.4.2 Assessment and Management of Symptoms**

- Assessment must always precede treatment.
- There are a number of tools that can be used for assessment, and information about these can be found in the core texts used for this pocketbook.
- Regular assessment is important for setting treatment goals, for monitoring the response to specific treatment, for communicating between members of the healthcare team, and for quality control.
- A general principle of symptom management is to assess, plan, implement, evaluate and include the patient and family throughout the process.

### **Common symptoms and clinical problems**

- Most patients with advanced disease will have potentially devastating symptoms or clinical problems.
- Some common symptoms or clinical problems, described further below,

include:

- o Anorexia and cachexia
- o Breathlessness
- o Confusion
- o Constipation
- o Dehydration
- o Diarrhoea
- o Distress
- o Fatigueo Insomnia
- o Malnutrition
- o Nausea and vomiting
- o Sore mouth
- o Wounds.

## 1. Anorexia and Cachexia

- Weakness, profound weight loss and poor appetite are common problems in advanced cancer, HIV and AIDS, and end-stage organ failure.
- Cachexia is not associated with hunger or thirst, nor will it improve by forced feeding or hydration.
- Cachexia is often debilitating and frustrating, particularly for families who may try to pressurise patients to eat so they can stay strong.

### Cause

- The underlying mechanisms are not fully understood and differ with different diseases.
- There is release of inflammatory mediators including cytokines. These, along with alterations in metabolism, cause a catabolic state to be induced, with resultant profound weight-loss that involves both fat and skeletal muscle.

### General Measures

It is important to ensure that there is not anorexia or malnutrition due to a reversible cause such as;

- Lack of available or digestible food
- Dysphagia
- Sore mouth or altered taste
- Dyspepsia, or nausea and vomiting, or constipation
- Pain
- Metabolic disturbance – e.g. hypercalcaemia or uraemia
- Onethatissecondarytotreatmentsuchaschemotherapy,radiotherapyordrugs.
  - o Support should be given to the family and patient to understand the underlying process and to see food as something to enjoy rather than endure.



- o Presentation can be helpful with small, appetising meals and an emphasis on fluid intake.
- o Remember that as the terminal phase is reached, a reduction in food and fluid intake is very normal.

### Assessment and Management

- Added nutritional supplements are expensive and seldom make a significant difference in advanced disease.
- Enteral nutritional support is occasionally useful in specific situations:
  - o Where tumours of the head, neck and oesophagus exist and where swallowing is difficult despite good appetite and the disease is not far advanced.
  - o Surgical placement of a feeding gastrostomy tube can be straightforward and helpful (refer to core texts for details).
  - o May be associated with complications such as aspiration pneumonia and diarrhoea.
  - o Parenteral nutrition is seldom indicated and in any case is costly and burdensome.
  - o Corticosteroids (e.g. dexamethasone 2–4mg 5days po) may be of short-term benefit.
  - o Corticosteroids should not be used in children if anorexia/cachexia is the only symptom that might benefit.
  - o There may be benefit from a short trial of corticosteroids in children with associated nausea, pain, asthenia or depressed mood.
  - o Dexamethasone dose in children is:
    - o <10kg: 0.15mg/kg/dose BD
    - o 10–20kg: 2mg po BD
    - o 21–40kg: 4mg BD
    - o >40kg: 8mg BD
  - o As an alternative, use Prednisone 0.05-2mg/kg divided 1–4 times a day.

## 2. Breathlessness

- Difficulty in breathing is a frightening experience.
- Think of the words that patients use to describe their experience, such as ‘suffocating’, ‘choking’, ‘could not get enough air’, ‘it felt like I was about to die’.
- **Causes**
  - o **Respiratory:** primary or secondary lung cancers, pleural effusion, pulmonary embolus, tracheal tumours, airway collapse, infection, lymphangitis carcinomatosa, chronic obstructive pulmonary disease (COPD), weak respiratory muscles;
  - o **Cardiac:** superior vena cava obstruction, anaemia, cardiac failure,

- o cardiomyopathy, pericardial effusion;
- o **Other:** ascites, secondary to treatment such as radiotherapy, chemotherapy or pneumonectomy.

### General Care

- o Adjust position – usually best to be sitting up, although in patients with a pleural effusion it is best that they lie on the affected side with the good lung upwards so as to maximise ventilation.
- o Ensure good ventilation by opening windows, using a fan or even fanning with a newspaper.
- o Adjust activity and help with slow, deep breathing.
- o Gently suction any excessive secretions and **in young babies ensure that their noses are unblocked using normal saline nose drops.**

### Assessment and Management

- Take a careful history, asking about severity, duration, and associated features such as breathing being worse when lying down or on exertion, pleuritic chest pain or haemoptysis.
- Treat reversible conditions if possible, such as anaemia, heart failure, infection, pulmonary embolus or pleural effusion.
- Address any underlying anxiety and panic.
- Use medications to relieve symptoms:
  - o Morphine 2.5–5mg orally every four hours (but if already taking oral morphine for pain, titrate dose and advise on taking extra doses as required);
  - o Diazepam 2–5mg at night, especially for anxiety and panic;
  - o Dexamethasone 8–12mg daily for specific causes, e.g. superior vena caval obstruction, lymphangitis carcinomatosa;
  - o Consider other medications, such as broncodilators, diuretics or oxygen, depending on their availability and the cause of the breathlessness.
  - o **In children, give morphine at 25–50% of the normal starting dose for pain (see Chapter 4 for more details). If the child is already on morphine, increase the dose by one-third.**
  - o **Add a benzodiazepine in children if breathlessness is severe. (Note: oral/rectal diazepam works as fast as parenteral, and you can use injectable diazepam rectally.) These might be:**
    - o **Lorazepam 25–50mcg/kg as a single dose or 4–8hrly po/SL**
    - o **Midazolam 200–500mcg/kg (max 10mg) SL, or intra-nasally as a single dose, or 100mcg/kg sc as a single dose, or 300–700mcg/kg over 24 hours as a subcutaneous infusion**

- o Salbutamol nebuliser solution: 6months – 5 years 2.5mg prn, or 5–12 years 5mg prn but via nebuliser if bronchospasm is present.

### 3. Cough

- Cough is the physiological reflex employed to clear irritant, or foreign material from the respiratory tract.

#### Treatment

- The specific causes and take general symptomatic measures e.g. avoid smoke, fumes or any atmospheric humidification.
- Patient should be placed in a position of least discomfort and expectoration aided in cases of productive cough; this may be contraindicated for patients who are weak or debilitated.
- Use bronchodilators for bronchospasm and antibiotics for infection.
- Consider cough suppressants for persistent dry cough such as opioids and opioid analogues.
- Nebulizer and local anesthetics may also be used where necessary. Corticosteroids may be used for lymphangitis carcinomatosa.
- Sedation may be useful, especially at night.

### 4. Confusion

- This is one of the most distressing and difficult-to-manage symptoms.

#### Causes

- Uncontrolled pain
- Urinary retention or severe constipation
- Changes in environment, leaving home, transfer from one ward to another
- Metabolic disturbance: uraemia, hypercalcaemia, hyponatraemia
- Infection: urinary tract infection, cryptococcal meningitis, other opportunistic infections
- Hypoxia
- Raised intracranial pressure, strokes
- Medication-induced through opioids, antimuscarinics, corticosteroids
- Withdrawal state such as alcohol, benzodiazepines, opioids
- Dementia, delirium, HIV encephalopathy
- Sudden sensory deprivation (blindness, deafness).

#### General care

- Keep surroundings calm, reassuring and as familiar as possible.
- Seek to remind the patient where they are and orientate them in time.
- Remember that the patient may be very deaf and so only seem confused.
- Avoid physical restraint unless for reasons of patients safety.

- Support the family to be able to stay with the patient and express their worries and fears.

**Assessment and Management: Consider the Following Questions;**

- Have new medications been started? – consider stopping these.
- Are there any signs of infection? – treat appropriately.
- Is the patient dehydrated? – give oral fluids and consider parenteral infusion.
- Is there urinary retention or constipation? – relieve with urinary catheter or laxatives.
- Is there any reversible organ failure? – assess and manage appropriately.
- Use medications to relieve symptoms but take care not to sedate more than is necessary.
- For mild agitation, give:
  - Diazepam 5–10mg daily
  - Or Lorazepam 1–2mg po/SL (give oral tablets via this route if available).

**For severe Delirium, Give:**

- Haloperidol 1.5–5mg up to 8hrly until settled
- Or Chlorpromazine 25–50mg po/pr if available
- Add diazepam as above but do not use alone for severe delirium because it might worsen the confusion.
- For children, start an antipsychotic – e.g. haloperidol 0.05–0.15mg/kg per 24hrs as a continuous infusion, or in divided doses twice or three times a day po/sc/IV.
- Give midazolam 500mcg/kg SL as a single dose, or 100mcg/kg sc as a single dose or 300–700mcg/kg over 24 hours by sc infusion
- Or Lorazepam 25–50mcg/kg (max 1mg) as a single dose or 4–8hrly po/SL.
- Don't use benzodiazepines alone, because they carry the risk of paradoxical agitation; however, they can be used in conjunction with antipsychotics to sedate children.

## 5. Bowel Obstruction

### Causes

- Mechanical obstruction or paralytic (functional) obstruction due to autonomic neuropathy
- Retroperitoneal infiltration
- Spinal cord disease
- Postoperative peritonitis
- Metabolic disorders
- Radiation fibrosis
- Drugs e.g. opioid and anticholinergics.

**Treatment:**

Bowel obstruction is traditionally surgically managed but for patients in palliative care, particularly those with advanced cancer, conservative therapy for sub acute and incomplete bowel obstruction will produce equivalent results.

**6. Constipation**

- Constipation is defined as 'unduly infrequent and difficult evacuation of the bowels'.
- This is very common in palliative care and often can be predicted and prevented.

**Causes**

- Direct effects of disease:
- Intestinal obstruction from tumours in the bowel wall or external compression from abdominal masses
- Damage to lumbosacral spinal cord
- Secondary effects of disease:
- Decreased food intake and low-fibre diet
- Dehydration
- General body weakness
- Metabolic abnormalities – hypokalaemia, hypercalcaemia
- Medications:
- Opioids such as codeine or morphine
- Anticholinergic drugs such as tricyclic antidepressants
- Diuretics
- Concurrent disease:
- Diabetes mellitus, hypothyroidism
- Haemorrhoids, anal fissures.
- The two most common causes are related to the side effects of opioids and the effects of progressive disease.

**General Care**

- Encourage fluid intake and fruit, vegetables and fibre in the diet.
- Remember that even if a patient is not eating much, they still need to move their bowels regularly.
- Remember to anticipate constipation as a side effect of medications such as morphine and amitriptyline.
- Prescribe prophylactic laxatives together with morphine, especially in adults.
- 

**Assessment and Management**

- Remember to assess whether there is obstruction.
- Rectal examination may be essential to determine whether there are hard

- faeces, impaction or high obstruction (rectum is empty and ballooned).
- Oral treatments:
    - o Bisacodyl 5mg at night (up to 20mg)  
Senna 1 to 2 tablets at night
    - o Paw paw seeds dried and crushed: 1 teaspoon at night with water  
Vegetable oil or margarine: 1 tablespoon at breakfast
    - o For children an osmotically active laxative (eg Lactulose) is preferable to a stimulant laxative (Bisacodyl) as the stimulants may cause severe abdominal pain in children.
  - Rectal treatments:
    - o Glycerol or bisacodyl suppositories if available
    - o May need to consider digital removal of faeces.
    - o Non-pharmacological management:
      - o Patient education and dietary advice, e.g. encouragement of a high-fibre diet.
      - o For children, try to prevent constipation when starting opioids by adding laxatives, e.g.:
        - o Bisacodyl: 6–12 years 5–10mg once daily po
        - o Or Sennakot.
        - o Suggested constipation management in children:
          - o Step 1: try lactulose, building the dose up over one week:
            - o <1year 2,5ml BD
            - o 1–5 years: 5mls BD
            - o 6–12 years 10mls BD
          - o Step 2: if no improvement, add Senna
            - o 2–6years ½–1 tablet BD po
            - o 6–12 years 1–2 tablets BD po
          - o Step 3: If already on opioids, use step-2 drugs straight away.
        - o If on rectal examination the stool is found to be hard, try a glycerine suppository. If soft but not moving, try a bisacodyl or senna suppository. If the rectum is empty, try a bisacodyl suppository to bring the stool down or a high-phosphate enema.
        - o For severe constipation, try a phosphate enema or a bowel prep product (e.g. Movicol) if available.

## 7. Dehydration

- Dehydration is a common symptom.
- There is a need and desire for relatives and the medical or nursing team to want to keep patients well hydrated.

- **Diagnosis and prognosis**
  - o Dehydration may occur when a patient has an illness from which you expect them to recover, e.g. an episode of diarrhoea in a patient with lung cancer who has a prognosis of several months, or severe diarrhoea in an HIV and AIDS patient.
  - o Presence of other symptoms:
    - o Dehydration may significantly impair drug excretion and so increase side effects. This is particularly true for morphine.
    - o Try to stop unnecessary medication or reduce the dose while maintaining symptom control.
    - o Supplementary fluids may be given for a short period of time to reduce distressing symptoms such as hallucinations or myoclonic jerks.
  - o Presence of a dry mouth rather than thirst:
    - o See also the section below on mouth care.
    - o The patient may report feeling thirsty but they appear well hydrated and their symptom may actually be a dry mouth.
    - o If the patient is very thirsty and measures to keep their mouth moist are ineffective and they are unable to swallow, supplementary fluids should be considered.
    - o Are they close to death?
  - o A patient who is nearing death will often struggle to manage oral fluids. They may even cough when they swallow.

### Assessment and Management

- A dilemma occurs when the patient is very ill and entering the terminal phase. In most patients nearing death, a reduction in fluid intake is natural and appropriate. They no longer have a requirement for fluid and full explanation is likely to reassure the family and reduce the request for supplementary fluids.
- Remember to keep the mouth and lips clean and moist, because dry oral mucosa may be a worse symptom than thirst.
- There are, however, some situations in which it may be appropriate to consider artificial hydration. If so, aim to hydrate via the oral route but consider IV or SC infusions if needed. SC may be the least invasive and can even be given in a home situation. 1
- Excessive hydration may result in fluid overload and necessitate venous cannulation, which can become painful and difficult. In deciding to give supplementary fluids, several factors should be considered:
  - o Giving more than sips of oral fluids in this situation risks the complication of aspiration and pneumonia.
  - o Often, families worry that the patient will be uncomfortable and will need hydration.

- o It is important to ensure the family and patient are aware that comfort can be maintained by keeping the mouth moist, that fluids are not needed and that they can cause harm in this situation.

## 8. Diarrhoea

- Diarrhoea is defined as the passage of more than three unformed stools within a 24-hour period.
- In a child, diarrhoea refers to abnormal frequency as well as consistency.
- Breastfed babies may pass a stool after each feed; in this case, loose consistency is more important than frequency as a sign of disease.
- In bottle-fed infants more than seven stools per day indicates diarrhoea, while the indicator for toddlers is more than three.

### Causes

- Imbalance of laxative therapy
- Drugs such as antibiotics, NSAIDs, ARVs
- Faecal impaction – fluid stool leaks past a faecal plug or tumour mass
- Radiotherapy involving the abdomen or the pelvis
- Malabsorption
- Colonic or rectal tumours
- Concurrent disease
- Odd dietary habits
- HIV
- Urinary tract or any other systemic infections in children.

### General Care

- Increase fluid intake where possible.
- Provide reassurance that most diarrhoea is self-limiting.
- In children, temporary lactose intolerance may be a problem necessitating the use of lactose-free milks such as soya or the use of yoghurt with live cultures.

### Assessment and Management

- Treat or exclude any specific causes.
- Discontinue laxatives if prescribed and review.
- If due to antibiotics, give metronidazole 400mg tds for 7–14 days.
- Review other medications as appropriate.
- If necessary, opioids such as loperamide, codeine and morphine can be used.
- If blood is present in a child's stool, give ciprofloxacin and add metronidazole in areas where amoebic dysentery is prevalent.
- Dosage: ciprofloxacin 15mg/Kg for three days *NB. Exclude Neonates*



## 9. Distress

- Distress encompasses the psychological response to the challenge of a life-threatening illness.
- Screening tools for distress may be used; however, the key to dealing with distress is sensitive listening and supportive communication.
- Symptoms may include anxiety and low mood.
- Many people experience temporary symptoms as they adjust to the psychological challenges of their illness (adjustment disorder).

### General Care

- Offer skilled counselling and support.
- Recognise that when symptomatic, medication or psychiatric referral may be needed.
- Unrelieved physical pain and symptoms will contribute to distress.
- Depression may sometimes be interpreted as being due to supernatural forces – therefore careful explanations for behaviour will help the patient and their family to understand what is happening.

## 10. Depression

Depression is often misunderstood, under-diagnosed and under-treated.

- Assessment and management:
  - o The key factors which distinguish depression that may require anti-depressant medication and psychiatric referral include:
- Low mood more than 50% of each day
- Loss of any enjoyment or interest
- Excessive or inappropriate guilt
- Thoughts of suicide.
  - o Ongoing support and counselling may be needed.
  - o Antidepressants take several weeks to be effective, so should be tried for at least 2–4 weeks.
  - o If depression does not respond to counselling, give anti-depressants:
- Amitriptyline – start with 25mg at night and increase gradually to 75–150mg. (The anti-depressant effect is unlikely to be seen at less than 75mg.) The main side effects are drowsiness, dry mouth and constipation.
- Imipramine, if available, is an alternative that might be less sedating.

### Anxiety

- This may be a symptom of depression.
- Assessment and management:

- o Symptoms included feelings of panic, irritability, tremor, sweating, lack of sleep and a lack of concentration.
- o Ensure the patient is given an opportunity to talk about their fears and anxieties.
- o Non-pharmacological interventions may help, such as massage and relaxation.
- o If persistent symptoms are hindering quality of life, consider medication with benzodiazepams, e.g. diazepam 5–10mg at night.

## 12. Fatigue

- Chronic fatigue is very common in people with advanced disease.

### Causes

- Multiple causes, often obscured by coexisting disease processes
- Anaemia
- Pain
- Emotional distress
- Sleep disturbances
- Poor nutrition.

### General Care

- Try to manage lifestyle around the periods of greater energy or fatigue.

### Assessment and Management

- Treat the underlying cause of the fatigue where possible – e.g. if anaemic, give a blood transfusion as appropriate.
- Can give low doses of psychostimulants, e.g. methylphenidate (Ritalin) or antidepressants.
- Non-pharmacological interventions include energy conservation and physical exercise, and stress reduction by relaxation and meditation.

## 13. Insomnia

- Insomnia is a subjective complaint of inadequate nocturnal sleep – manifested as difficulty initiating or maintaining sleep, early-morning awakening, non-restful sleep or a combination of all of these.
- It is common in those with advanced disease.

### Causes

- It may be transient or chronic:
  - o Transient: secondary to life crisis, bereavement, illness

- o Chronic: associated with medical or psychiatric disorders, drug intake or maladaptive behavioural patterns.
- In advanced disease it emerges as a psychological or physiological side effect of diagnosis and/or treatment.

### General Care

- Try to reduce the intake of nicotine, caffeine and other stimulants and avoid alcohol near bedtime.
- Exercise regularly in the earlier part of the day.

### Assessment and Management

- Benzodiazepines are the most commonly used hypnotic medications for sleep – they offer prompt symptom relief by decreasing time to sleep onset, improving sleep efficiency, and imparting a sense of restful sleep for most patients.
- Intermediate-acting:
  - o Temazepam 7.5–30mg; half-life 8–12 hours
  - o Oxazepam 10–30mg; half-life 5–15 hours.
- Long-acting:
  - o Alprazolam 0.25–1mg; half-life 12–20 hours
  - o Lorazepam 0.5–2mg; half-life 10–22 hours
  - o Clonazepam 0.5–2mg; half-life 22–38 hours
  - o Diazepam 2.5–10mg; half-life 20–50 hours.
- However, these are not indicated for long-term treatment of chronic insomnia because of the risk of tolerance, dependency and other side effects. Note: despite being longer acting, Lorazepam has the least active metabolites of the benzodiazepines and this can therefore be used over a longer period, especially in older patients, without a cumulative drowsy effect.
- If insomnia in a child is not improved by addressing sleep hygiene, then the following medications may be considered:
- Sedating antihistamines (e.g. Promethazine):
  - o Under 1 year: 5–10mg at night
  - o 1–5 years: 10–20mg at night
  - o 5–12 years: 20–25mg at night
- Tricyclic antidepressants:
  - o Imipramine
  - o 5–8 years: 10–25mg po at night
  - o 9–12years: 25–50 mg po at night
  - o >12 years: 25–75mg po at night
- Amytriptaline:
  - o 2–12 years: 200–500mcg/kg (max 25mg) once daily at night
  - o 12–18 years: 10–25mg po at night

- Benzodiazepam (for short-term use only)
- Diazepam (Valium):
  - 6 weeks – 1 year: 0.25–1mg at night
  - 1–6 years: 0.5–3mg at night
  - 6–14 years: 1–5mg at night
- Melatonin is a useful drug within children’s palliative care, particularly for children with neurological disorders who struggle to sleep (including blind children). Dose: 0.5–10mg at night

## 14. Malnutrition

- Malnutrition is very common in many settings in Africa and in particular in children’s palliative care.

### Causes

- Poverty
- Incorrect feeding practices, early weaning (birth of second child)
- Anorexia associated with illness, mouth ulcers or oral thrush
- Nutrient loss from malabsorption, diarrhoea or HIV enteropathy
- Increased metabolic rate due to disease or infection (especially TB).

### General Care

- Malnutrition is effectively a social not a medical disorder, although it causes medical problems.

### Assessment and Management

- Stage 1 – initial treatment: life-threatening problems are identified and treated.
- Stage 2 – rehabilitation: intensive feeding is given to recover weight loss, emotional and physical stimulation is increased, and the carer is trained to look after the child.
- Stage 3 – follow up.
- Follow your national guidelines for the management of malnutrition, as appropriate.
- Where available, refer to food and nutritional support programs.
- Malnutrition in children often leads to other distressing symptoms that add to the suffering – e.g. oral sores, angular stomatitis, dermatitis, corneal ulceration, gastric distension, irritability, hunger, headaches. These should be managed as outlined in the other sections of this pocketbook.

## 15. Nausea and Vomiting

- Nausea is the unpleasant sensation of being about to vomit and can occur alone or can accompany vomiting.
- Vomiting is the forceful expulsion of gastric contents.
- This is a very common symptom with many different causes and may be very distressing.
- Patients have been known to say that nausea is worse than pain.

### Causes

- Pharmaceutical: opioids, digoxin, anticonvulsants, antibiotics
- Toxic: infection, radiotherapy, chemotherapy
- Metabolic: hypercalcaemia, ketoacidosis, renal failure
- Intracranial: cerebral tumours, cerebral infections, meningeal metastases, raised ICP
- Gastrointestinal: gastric stasis, intestinal obstruction, constipation, candidiasis.

### General Care

- Ensure the patient is in well ventilated areas, to avoid smells permeating which can trigger nausea and vomiting.
- Avoid the eating of big meals and encourage small appetising meals.
- Avoid spicy or fatty meals.
- Ensure adequate fluids by mouth if possible.
- Ginger may be useful, e.g. ginger tea.

### Assessment and Management (see also Table 2 below)

- Treat reversible conditions such as oesophageal candidiasis, raised intracranial pressure, constipation and gastro-oesophageal reflux and heartburn.
- Review the medication to see whether any causal link exists, such as use of opioids, digoxin toxicity, chemotherapy, antiretrovirals or antibiotics.
- Consider giving medication via a non-oral route if severe nausea or intractable vomiting occurs. Try the rectal or parenteral routes, then transfer back to oral administration when the symptoms are under control.
- Use a step-wise approach to prescribing anti-emetic medication, depending on your assessment and the pattern of symptoms. You may only have limited access to medications, but still try to prescribe carefully and review.
- Consider non-pharmacological approaches as appropriate – e.g. surgery, acupuncture, cognitive therapy:
  - o The acupuncture point for nausea and vomiting is situated 2–3 fingers down from the top crease of the wrist in the groove between the two tendons.

- o Take your thumb and index or middle finger and press firmly on points on both sides of the wrist when nauseous feelings persist.
- o Remember, patients may have more than one cause of nausea and may need more than one anti-emetic.

**Table 4: Characteristics and Treatment of Nausea and Vomiting**

Pattern	Visceral	Somatic	Neurological/Headache
<p>Gastric stasis or poor stomach emptying</p> <ul style="list-style-type: none"> <li>• Vomiting is main symptom</li> <li>• Vomiting often relieves nausea</li> <li>• Patient feels full quickly when eating</li> <li>• May have gastro-oesophageal reflux</li> </ul>	<ul style="list-style-type: none"> <li>• Medications such as morphine</li> <li>• Constipation</li> <li>• Squashed-stomach syndrome due to liver enlargement or large-volume ascites</li> </ul>	<ul style="list-style-type: none"> <li>• Metoclopramide 10–20mg 8hrly before meals</li> <li>• Domperidone 20–30mg 8hrly</li> <li>• Consider dexamethasone 8mg daily if squashed-stomach syndrome</li> </ul>	<p>Metoclopramide:</p> <ul style="list-style-type: none"> <li>• 1–12 years: 300mcg/kg po in three divided doses</li> <li>• &gt;12 years: &lt; 60kg: 5 mg po tds</li> <li>• &gt;12 years &gt;60kg: 10 mg po tds</li> </ul> <p>Manage GORD by thickening feeds, maintaining upright position after feeds and using an antacid</p>
<p>Blood chemistry disturbance or toxins:</p> <ul style="list-style-type: none"> <li>• Intractable nausea is the main symptom</li> <li>• Vomiting often does not relieve nausea</li> </ul>	<ul style="list-style-type: none"> <li>• Medications such as morphine</li> <li>• Renal failure</li> <li>• Hypercalcaemia</li> <li>• Liver failure</li> </ul>	<ul style="list-style-type: none"> <li>• Haloperidol 1.5 – 5mg at night</li> <li>• Prochlorperazine 5–10mg 8hrly</li> </ul>	<p>Haloperidol :</p> <ul style="list-style-type: none"> <li>• Oral: &lt; 12 years: 0.025–0.05mg/kg per day in two or three divided doses. &gt; 12 years: 1–4mg at night</li> <li>• SC infusion: Child 1 month to 12 years: 25–85mcg/kg over 24hrs. Child 12–18 years: 1.5–5mg over 24hrs</li> <li>• Ondansetron or Granisetron for chemotherapy-related nausea and vomiting</li> </ul>

Pattern	Visceral	Somatic	Neurological/Headache
<p>Raised intracranial pressure:</p> <ul style="list-style-type: none"> <li>• May be worse in the morning</li> <li>• May be worse on movement</li> <li>• Vomiting does not relieve nausea</li> </ul>	<ul style="list-style-type: none"> <li>• Intracranial tumours or infections such as toxoplasmosis</li> <li>• Meningitis such as TB or cryptococcus</li> <li>• Malaria</li> </ul>	<p>Dexamethasone</p> <ul style="list-style-type: none"> <li>• 8–16mg daily (give in the morning to avoid disrupting sleep, and take care in prescribing</li> <li>• if untreated infections)</li> <li>• Promethazine 25mg 8hrly</li> <li>• Cyclizine 25–50mg 8hrly</li> </ul>	<ul style="list-style-type: none"> <li>• Dexamethasone: 0.03–0.2mg/kg per day in 2–4 divided doses</li> <li>• Haloperidol (as above)</li> </ul>
<p>Bowel obstruction:</p> <ul style="list-style-type: none"> <li>• Large-volume vomiting</li> <li>• May be partial when some flatus or faeces are passed</li> <li>• May be complete</li> <li>• Remember to consider surgery if patient is strong enough and single site of obstruction</li> </ul>	<p>Abdominal or pelvic tumours</p> <ul style="list-style-type: none"> <li>• May be a single site of obstruction, such as the sigmoid colon, or many levels such as ovarian carcinoma with peritoneal spread</li> </ul>	<ul style="list-style-type: none"> <li>• Metoclopramide 10–20mg 8hrly (Avoid if complete obstruction or if it worsens abdominal colicky pain)</li> <li>• Hyoscine butylbromide 20–40mg 6hrly</li> <li>• Promethazine 25mg 8hrly</li> <li>• Cyclizine 25–50mg 8hrly</li> <li>• Best given by subcutaneous infusion</li> <li>• Octreotide if available</li> </ul>	<ul style="list-style-type: none"> <li>• Metoclopramide 0.1–0.2 mg/kg/dose 6hrly PO, SC or IV</li> <li>• Haloperidol sc infusion: Child 1 month to 12 years: 25–85mcg/kg over 24hrs. Child 12–18 years: 1.5–5mg over 24hrs</li> <li>• Hyoscine butylbromide: 1 month to 2 years: 1.5mg/kg in three divided doses. 2–5 years: 5mg po tds. 6–12 years: 10mg po tds</li> <li>• Steroids may help to decrease oedema</li> </ul>

## 16. Weight Loss & Cachexia

This is a common patient with advanced cancer.

### Causes:

- Due to alterations in protein, carbohydrate and lipid metabolism caused by inflammatory cytokines released by the tumour.
- In patients with AIDS, it usually relates to systemic infections and chronic gastrointestinal dysfunction.

**Treatment** options for weight loss include;

- Correct or palliate cause of malnutrition, anorexia,
- Treat tumour where feasible,
- Dietary measures and counselling.

## 17. Terminal Restlessness

Terminal restlessness is an agitated delirium that occurs in some patients during the last few days of life. Clinical features include agitation, restlessness, impaired conscious state, muscle twitching, multifocal myoclonus, seizures and distressed vocalizing.

### Treatment:

- Exclude restlessness due to; anxiety, fear, unrelieved pain, urinary retention, faecal impaction, drug, alcohol or nicotine withdrawal.
- Review opioid and use benzodiazepines to manage the patient

## 18. Terminal Respiratory Congestion ('Death Rattle')

Terminal respiratory congestion is the rattling, noisy or gurgling respiration of some patients who are dying.

### Causes

- Accumulation of pharyngeal and pulmonary secretions in patients who are unconscious or semi-conscious and too weak to expectorate.

### Treatment:

- Position the patient on their side
- Oropharyngeal suction should be reserved for unconscious patients
- Anticholinergic drugs to suppress the production of secretions
- Hyoscine hydrobromide 0.4mg SC, ± repeat at 30min, then q2-4h or 0.6-1.2mg/24h CSCI
- Antiemetic; sedative; occasional agitated delirium



- Atropine
- Reassure relatives that the noisy breathing is not causing any added suffering for the patient

### 2.4.3 Special Considerations in HIV and AIDS

- As the immune system becomes exhausted, an individual becomes susceptible to a wide range of infections, which in turn cause different symptoms. Thus prevention and treatment of OIs is an important part of good symptom control.
- Enabling access to medicines for symptom control is a challenge, particularly when the medicines are expensive.
- Recurrent or persistent diarrhoea can be a challenge in patients with advanced AIDS.
- Many of the patients with diarrhoea will have an identifiable infection, which should be treated.
- Chronic diarrhoea needs to be taken as seriously as pain – particularly in areas where there is a lack of proper sanitation and/or easily accessible sanitation.
- Sweating and fever are frequent throughout the course of AIDS – it is important to undertake careful assessment and treat any underlying conditions where possible.
- Almost all patients with AIDS will have some form of skin problem – e.g., dry skin and itching. In such cases:
  - Avoid excessive bathing.
  - Underlying infections (e.g. seborrhoeic dermatitis or scabies) should be treated.
  - Multiple purple-brown nodules scattered all over the body are characteristic of Kaposi's sarcoma.
  - Topical creams can help:
    - Aqueous cream (can be used as a substitute for soap)
    - Hydrocortisone 1% may help in the treatment of inflammation
    - Chlorhexidine 0.5% solution can be used after bathing.
  - Antihistamines can help reduce itching:
    - Chlorphen-iramine 4mg tds.
    - Promethazine 10–25mg at night
  - Treat herpes zoster with Acyclovir 200mg at five a day for five days if available – it needs to be started within 72 hours of the rash first appearing.
- Good nutrition is essential for maintaining an adequate immune system.

## Side Effects of Treatment (e.g. ART)

- ARVs are the best available form of palliative treatment for AIDS at present, and the decision as to when to start or stop ARVs and which combination to use is complex.
- ART is meant to reduce plasma viral load significantly and to increase CD4 levels, allowing for immune recovery and reducing the frequency of OIs. Quality of life is thus improved.
- Each country will have its own guidelines with regard to the use of ARVs and these should be followed as appropriate. (Please refer to NASCOP guidelines)
- Those on ART may well experience a range of symptoms, including:
  - o Pain, including neuropathic pain
  - o Diarrhoea
  - o Fever
  - o Neurological symptoms
  - o Skin problems
  - o Nutritional problems
  - o Emotion and psychological symptoms
  - o Social and spiritual issues.
- Palliative care therefore has a key role to play in the care of people on ART.

## Important Note

- All symptoms and management options will not be covered here, so please use the References list towards the end of this manual to access further information as needed.
- Priority has been given to affordable and available medications in a Kenyan setting.
- All symptoms must be managed on an individual basis.
- Many symptoms are subjective and the impact they have on the individual will vary from person to person.
- Symptom management can be complicated by factors such as malnutrition and decreased renal function.
- Care without adequate pain and symptom control is supportive care and not palliative care.
- Treatment using ARVs is a complex issue – it is beyond the remit of this Manual to describe how to start and manage someone on ARVs (*Please Refer ; ART Guidelines, Guidelines for Antiretroviral drug therapy in Kenya or AIDS in Kenya; Trends, Interventions and Impact*)

## UNIT 2.5: PRINCIPLES OF SKIN, WOUND AND ORAL CARE



**Time: 1 hour**

### **OBJECTIVES:**

At the end of this unit the participant will be able to:

1. To discuss the general approach to oral care
2. To describe management of common oral problems in patients with HIV&AIDS, cancer and other life limiting illnesses.
3. To describe general principles of skin care
4. To describe general principles of management of decubitus ulcers

## COURSE NOTES

### 2.5.1 General Approach to Oral Care

The consequences of an unhealthy or painful oral cavity are significant. Not only are there physical implications of reduced oral intake and weight loss but, in addition, there may be psychological effects due to impaired communication and feelings of exclusion and social isolation.

The aim of oral care is to preserve a clean and healthy mouth and prevent complications such as candidiasis or other infections e.g. xerostomia (subjective feeling of mouth dryness), sialorrhoea (excessive salivation), stomatitis, halitosis (unpleasant or bad breath) and haemorrhage.

### 2.5.2 Management of Common Oral Conditions

If able, patients should be encouraged to perform their own oral care but most palliative care patients are likely to require some assistance. It is a duty of carers to carry out oral hygiene in dependent patients.

Treatment can be considered as follows

- General oral hygiene: tooth brushing and use of mouth washes
- Treatment of specific problems e.g. bacterial infections, candidal infection, viral infections and xerostomia, stomatitis (or mucositis).
- Dental care for dental caries and gingivitis

## Sore Mouth

- Perhaps more than any other symptom, a sore mouth affects communication as well as comfort.
- A sore mouth is very common in palliative care and may be severe in patients with HIV and AIDS or who are receiving chemotherapy or radiotherapy.

### Causes

- Infection such as candidiasis or herpes
- Mucositis due to radiotherapy or chemotherapy
- Ulceration
- General debility
- Poor dental hygiene
- Dry mouth due to medications, damage to salivary gland due to radiotherapy or tumour, or mouth breathing
- Erosion of buccal mucosa by tumours, with possible fistula formation
- Iron deficiency
- Vitamin C deficiency.

### General Care

- Most problems can be prevented by keeping the mouth clean and moist and treating any infections promptly.
- Check the mouth, teeth, tongue, palate and gums regularly for dryness, inflammation, ulcers, infection or inflammation.
- Ensure the patient and family know how to care for the patient's mouth using what is available.
- Avoid harsh brushing; use a soft brush or a soft cotton cloth instead.
- A simple mouthwash with sodium bicarbonate or saline (a pinch in a glass of water is sufficient) can be very effective.
- Sucking ice or pieces of fruit such can help a dry mouth – [use lollies for children](#).
- Use petroleum jelly on the lips after cleaning.
- [For children, give paracetamol prior to feeding](#).
- 

### Assessment and Management

- Treat pain in accordance with the WHO analgesic ladder (see Chapter 4).
- Remember that mucositis can cause severe pain and require oral morphine.
- [Commercially available teething gels \(Teejel, Bonjela\) may be useful for children with sore mouths](#).
- Treat oral candidiasis and remember you may not see white patches but only inflammation:
  - Nystatin oral drops 1–2mls 6hrly after food and at night; hold dose in mouth to allow it to act topically. [Nystatin 1ml qds for children](#).

- Fluconazole 50mg daily for five days; use higher doses (200mg daily for two weeks) if patient has difficulty swallowing and you suspect oesophageal candidiasis. [Fluconazole in children: 6mg/kg po stat and then maintenance of 3mg/kg per day for up to 21 days in severe cases.](#)
- Ketoconazole 200mg daily is an alternative, but watch for drug interactions.

**Treat Other Infections:**

- Apply Gentian Violet three times daily; useful for many sores.
- Metronidazole mouthwash, made by mixing crushed oral tablets or intravenous injection with fruit juice, helps with smelly sore mouths, especially with oral cancer.
- Consider acyclovir 200mg po for five days for herpes infection.
- Oral or parenteral medications may be needed to treat severe infections.

**Treat Inflammation:**

- Consider the use of steroids, such as oral dexamethasone 4–8mg or prednisolone powder or solution, for ulceration and inflammation – but ensure that any infection is well treated as steroids may exacerbate them.
- [Steroid erosol preparations \(eg Betamethasone\) sprayed on an ulcer BD may be useful.](#)

### 2.5.3 General Principles of Skin Care

Careful clinical assessment can lead to early diagnosis and therefore better treatment. Accurate diagnosis of skin disorders largely depends on taking a careful history and a thorough examination in good light. Simple laboratory examinations such as skin scraping for fungus and staining with 20% potassium hydroxide (KOH) can confirm the diagnosis. In doubtful diagnostic situations, it is best, if possible, to do a skin biopsy for culture or histology. Blood tests for HIV and syphilis should form the basis of an early assessment of selected patients in primary care.

The following are features of skin conditions in HIV&AIDS.

- Common conditions may present with unusual or florid lesions (e.g., eczema, acne, and skin infections).
- Certain specific presentations have diagnostic value in HIV&AIDS (e.g. Kaposi's sarcoma).
- Conditions may be seen in an unusual setting (e.g., herpes zoster in young adults).
- Multiple infections are frequently seen in the same patient.
- Severe drug reactions are more frequent

- Skin pain is typically caused by wounds, pressure sores, and post-herpetic neuralgia.

### Wounds Management Principles

- Treat reversible causes by treating underlying pathological processes (e.g., scabies, folliculitis, fungal infections). See specific sections below.
- Non-pharmacologic
- Symptom Management  
People with skin disease tend to feel self-conscious and family members and friends may avoid touching them. Encourage carers to provide both physical and emotional support, to reduce this sense of isolation. In some cases,
  - listening to the patient and touching and hugging them may be of more value than an ointment.
  - In general, certain measures such as over-bathing, the use of antiseptics and strong soaps, and the rubbing of skin with abrasive material should be avoided.

### Causes

- Fungating skin cancers (primary or secondary) such as breast, sarcoma, squamous tumours or melanoma
- Poor wound healing due to debility, poor nutrition and illness
- Pressure sores due to debility and immobility.

### General care

- Cleaning wounds:
  - Use a simple saline solution made by boiling water and adding salt (a pinch for a glass or one teaspoon for 500mls).
  - Use salt-water baths for perineal wounds.
  - Avoid caustic cleaning agents such as hydrogen peroxide.
  - Consider leaving a wound exposed to air (though watch for maggots).
  - If needed, apply clean dressings daily, or more often if there is discharge.
  - Consider making simple dressings from local materials such as old cotton cloths washed and cut to size.
  - Help the patient's family to learn the skills to do the dressings daily.
  - Prevent pressure sores by changing the patient's position regularly
- Keep skin dry and clean.
- Consider a water-filled surgical glove for pressure relief of critical areas.
- For child patients, disguise smells in the room using vanilla, incense, candles etc.

### Assessment and Management

- Is there pain?
  - Use non-adherent dressings, and soak them off prior to changing.
  - Give analgesia 30 minutes before dressing changes.
- Is there an unpleasant smell?
  - Sprinkle crushed metronidazole tablets directly onto the wound (avoid enteric-coated tablets) or use metronidazole gel if affordable.
  - Consider using locally available remedies such as natural yoghurt, paw-paw and tried-and-tested local herbs.
  - Honey or sugar can be used temporarily on a dressing, for de-sloughing necrotic wounds. Dressings should be changed twice a day (as they become moist), but within a few days you can revert to dry dressings or metronidazole.
- Is there discharge?
  - Use absorbent dressings and change them frequently.
- Is there bleeding?
  - If the bleeding is severe, consider radiotherapy or surgery and use dark cloths to soak up the blood.
  - Clean the wound carefully to avoid trauma during dressing changes.
  - Consider crushed topical sucralfate g tablets, or tranexamic acid 500mg tablets.
- Are there maggots?
  - If suspected, use a pad soaked with turpentine oil held close to the wound but not touching.
  - Gently remove any maggots with forceps when they appear, and repeat every day till clear.

### Pharmacological Symptom Management

Simple pharmacological agents can often bring considerable relief and improve quality of life.

Address skin pain both topically and systemically as necessary (see sections on herpes zoster and decubitus ulcers). For topical analgesia, soak dressings in lignocaine or mix 1 ampoule lignocaine into a carrier medium such as aqueous cream.

Avoid prescribing topical treatments, especially steroids, without a proper clinical diagnosis

## 2.5.4 General Principles of Management of Decubitus Ulcers

Being bedridden may lead to a breakdown of skin and the development of bedsores (decubitus ulcers), particularly if the patient is paraplegic or hemiplegic or has reduced sensation or mobility from Parkinson's disease or a fracture. The condition is compounded by incontinence and moisture on the dependent skin.

Health care workers, especially nurses, should assess skin integrity carefully and frequently to identify early symptoms and offer preventive treatment. Teach family carers preventive measures as well as signs of decubitus ulcers.

### Management

- Treating Reversible Causes
- To prevent ulcers, teach family to:
- Relieve pressure by turning patient frequently (2 hourly) and positioning with pillows.
- Massage pressure points to increase circulation.
- Maintain hygienic skin care.

### Pharmacological Symptom Management

Wound treatment depends on the severity of the pressure sore

- Infection: Need to be treated with topical and/or systemic antibiotics.
- Odor: For treatment of offensive odour often associated with such wounds (often due to contamination by anaerobic bacteria): see section on fungating tumours and odours below.
- Bleeding: If bleeding is a problem in a bedsore: Apply calcium alginate dressing, a dressing containing fibres of mixed sodium and calcium alginate, to the bleeding area. The dressing of calcium alginate provides a moist healing environment as well as being a haemostat. Alternatively, apply adrenalin topically to stop bleeding. Dilute 1 ml adrenaline ampoule (1 in 1000) with 10 ml normal saline and use topically.
  - Systemic pain management: Administer systemic analgesia using the WHO ladder. Shallow pressure sores are most painful and respond to Step 1 analgesics.
  - Topical pain management: Treat with dressings containing lignocaine in addition:
  - For each 150 m of aqueous cream with 800 mg metronidazole (tablets crushed finely) that is applied to the wound add 2 ml 2% lignocaine to the mixture (which may also be strengthened



## UNIT 2.6: PALLIATIVE CARE EMERGENCIES AND MANAGEMENT



**Time: 1 hour**

### **OBJECTIVES:**

At the end of this unit the health care worker will be able to:

1. Describe the general principles of palliative care emergencies
2. Identify the types of palliative care emergencies
3. Assess palliative care emergencies
4. Describe the management of acute confusional states
5. Outline the management of bowel obstruction
6. Describe the management of spinal cord compression
7. Describe the management of seizures
8. Outline the management of massive haemorrhage
9. Outline the management of acute respiratory failure
10. Outline the management of hypercalcemia
11. Describe the management of shock
12. Outline the management of severe headache due to cryptococcal meningitis
13. Outline the management of severe drug reactions

## **COURSE NOTES**

### **2.6.1 Palliative Care Principles**

- A palliative care emergency is any change in a patient's condition that requires urgent and immediate intervention.
- Assessment must be prompt and complete if good results are to be achieved.

- The following should be considered during the management of a palliative care emergency:
  - o The nature of the emergency
  - o The general condition of the patient
  - o The stage of the disease and prognosis
  - o The availability of possible treatments
  - o The affordability of possible treatments
  - o The likely effectiveness and toxicity of available treatments
  - o The patient's wishes
  - o The carer's wishes.

## 2.6.2 Types of Palliative Care Emergencies and Principles of Assessment

Major emergencies occurring in palliative care include:

- Bone fractures
- Choking
- Haemorrhage
- Hypercalcaemia
- Seizures
- Severe pain
- Spinal cord compression (SCC)
- Stridor
- Superior vena cava obstruction (SVCO).

### Assessment of the Emergency

- What is the problem? It is important to make a proper diagnosis.
- Can the problem be reversed?
- What effect will the reversal of the problem have on the patient's overall condition?
- Can active intervention maintain or improve the patient quality of life?
- Is the treatment option in mind available and affordable?
- What is the patient's wish?
- What is the carer's wish?

## 2.6.3. Assessment and Management of Palliative Care Emergencies

### 1. Severe Pain

This should be assessed and managed as per the WHO analgesic ladder and is covered in Unit 2.2

## 2. Bone Fractures

- Bone fractures can occur with no or minimal trauma, especially to weight-bearing bones such as the femur or vertebrae.

### Causes

- Fractures are common when there are widespread bone metastases in cancers such as lung cancer, breast cancer, renal cancer and myeloma.
- Bone fracture may also be due to osteoporosis or trauma.

### Signs and Symptoms

- Severe pain around the site
- Deformed limb
- Pain on movement
- Bone grating
- Inability to use the limb
- Patient may go into acute confused state.

### Assessment and Management

- Analgesia and efforts to immobilise the site of fracture comprise the first remedial steps.
- Immobilise the limb where possible. This may mean applying a splint or a plaster-of-paris cast – though if the patient is fit enough it may be possible to surgically stabilise the fracture.
- Internal or external fixation may be required.
- Radiotherapy can be given, and even a single fractional dose may be of benefit as it prevents further progression of bone metastasis
- 

## 3. Spinal Cord Compression (SCC)

Spinal cord compression occurs in approximately 5% of patients with cancer. Early diagnosis and treatment is imperative, as the most important determinant of neurological outcome is the degree of neurological impairment at the time of starting therapy. Delay in treatment may leave the patient paralyzed and without bowel and bladder control. About 80% of ambulatory patients will remain so if treatment is prompt, but less than 30% of non-ambulatory patients will be able to walk after treatment again if treatment is not prompt. The majority of SCC occurs in the thoracic spine and the majority are caused by extramural tumour.

### When to Suspect SCC

Pain is the initial symptom in approximately 90% of patients with SCC and this can precede the development of neurological deficit by many days to weeks. Central back pain, aggravated by movement, coughing or straining is a prominent symptom. Occasionally, the pain can worsen when the patient is supine. Nerve root irritation

at the site of the vertebral involvement may be the presenting symptom, producing unilateral or bilateral radicular pain. Neurological signs can be overt or discrete, and can consist of progressive weakness and sensory loss, as well as urinary retention and loss of bowel control. Examination may reveal signs of motor weakness, reduced muscle tone, sensory loss or reduced reflexes. Reduced rectal tone can also be present.

### Assessment

MRI scanning, when available, is probably the investigation of choice for spinal cord disease.

Myelography has been for a long time the standard investigation used to confirm the diagnosis and plan the treatment but is contraindicated where raised intracranial pressure is present or suspected. CT scanning may provide much of the required information. Plain x-rays as the sole investigation are not recommended since the uncommon situation of extradural metastases not secondary to vertebral involvement may have normal x-rays.

### Management of a Suspected SCC

- Refer the patient as soon as possible to a centre that will be able to confirm the diagnosis and initiate therapy (radiotherapy, occasionally surgery).
- Initiate dexamethasone as soon as the diagnosis is made or strongly suspected. Various doses are recommended. A conventional starting dose is 8-10 mg three to four times a day.

## 4. Seizures

- Seizures can be frightening and their occurrence is often unpredictable.
- People may attach significance to these events, such as being bewitched.
- Seizures can be generalised, with jerking of the whole body, or limited to a specific area such as an upper limb or face. The period of jerking is often followed by a period of unconsciousness.
- Most seizures are self-limiting and efforts can be made to prevent or limit future seizures.
- A prolonged seizure lasting more than 10 minutes or one that does not terminate needs more urgent treatment.

### Cause

- Pre-existing epilepsy
- Stroke
- Trauma, including subdural haematoma
- Primary or secondary brain tumour
- Intracranial bleed

- Biochemical disturbance, eg. hyponatraemia, hypoglycaemia, uraemia or hypercalcaemia
- Infections such as cerebral toxoplasmosis, meningitis, malaria or encephalitis
- Alcohol withdrawal.

### General Care

- Keep the patient safe and free of hazards until the seizure is complete.
- Protect the airway of the patient so they can breathe – but do not place anything in their mouth (eg spoons, spatulas).
- Loosen any tight clothing if possible.
- After the seizure is over, place the patient in the recovery position and ensure someone stays with them. Observe and record the length and frequency of the seizures.
- Support the family and patient, and address their fears and concerns.
- 

### Assessment and Management

- No treatment is needed for self-limiting seizures that last less than five minutes.
- To stop more prolonged seizures:
  - Diazepam 10mg given per rectum or IM; repeat after 10 minutes
  - Midazolam 5mg sc is available; may also be given buccally
  - Paraldehyde 5–10mls diluted in saline as a rectal enema
  - Phenobarbitol 200mg IM if patient not responding to diazepam.
- To prevent seizures or reduce their intensity and frequency:
  - Phenyton 150–300mg daily and titrate gradually, watching for toxicity and drug interactions
  - Sodium valproate 600mg daily in divided doses and titrate to maximum 1500mg; this is the medication of choice when there is concern about drug interactions, including those in patients on ARVs.
- In children, a suitable rectal valium dose would be:
  - If weight is unknown: <3years 5mg; >3years up to 10mg
  - If weight known: 0.5–1mg/kg up to a maximum of 10kg.
- Clonazepam (Rivotril) 0.02mg/kg per dose slow IV (max = adult dose of 1mg).
- Phenobarbital 20mg/kg IV or PO in neonates and 10mg/kg in infants and older children, then 4–6mg/kg/day IV, SC or PO.
- Midazolam 100mcg/kg SC over one minute, then if necessary 200–700mcg/kg over 24 hours by sc infusion.
- If available, paraldehyde 0.1–0.5ml/kg mixed with an equal amount of mineral oil in a glass syringe and administered rectally is an effective and safe drug for managing seizures in children who have not responded to

the above measures, especially where are concerns around respiratory suppression.

## 5. Superior Vena Cava Obstruction (SVCO)

Superior vena cava obstruction (SVCO) is due to compression or invasion of the superior vena cava by mediastinal lymph nodes or tumor in the region of the right main bronchus. It is caused most commonly by carcinoma of the bronchus (75%) and lymphomas (15%).

Cancer of the breast, colon, oesophagus and testis, account of the remaining 10%.

- SVCO is the partial or complete obstruction of blood flow through the superior vena cava into the right atrium.
- SVCO usually results in impairment of the venous return.

### Causes

- External compression by tumour or lymph nodes, or thrombosis as a result of compression.

### Signs and symptoms

Symptoms are those of venous hypertension and include

- Breathlessness (laryngeal oedema),
- Headache (cerebral oedema),
- Visual changes,
- Dizziness and
- Swelling of the face, neck and arms.
- Engorged conjunctivae,
- Peri-orbital oedema,
- non-pulsatile dilated neck veins and
- dilated collateral veins (chest and arms).
- Visual changes
- Unclear mind (muzziness)
- Cough
- Dysphagia.
- Some patients may complain of a sensation of drowning. This condition is common in patients with tumours within the mediastinum, i.e. bronchial carcinoma, cancer of the breast and lymphoma.

Without treatment, SVCO can progress over several days leading to death. Prognosis is poor in a patient presenting with advanced SVCO unless the primary cancer is responsive to radiotherapy or chemotherapy.

**Assessment**

- Examination may reveal engorged conjunctivae, peri-orbital oedema, dilated neck veins and the collateral veins on the arms and chest wall.
- Late signs include; pleural effusions, pericardial effusion and stridor.
- 

**Management**

- In advanced disease the patient needs relief of their acute symptoms.
- Give high-dose corticosteroids (e.g. dexamethasone 16mg PO/IV) and, if available, urgent radiotherapy.
- At the same time, treat dyspnoea symptomatically with morphine (5mgs 4hrly) and/or a benzodiazepine.
- Practical management of dyspnoea is also important – e.g., teach the patient how to breathe slowly, and encourage a calm environment.
- Without treatment, SVCO carries a very poor prognosis.
- Emergency treatment needed for advanced, acute SVCO.
- Consider prophylactic anti-convulsant
- **Contact specialist oncology centre as a priority**

## 6. Choking

- Choking is the inability to breathe as a result of acute obstruction of the pharynx, larynx or trachea.
- This can be due to local tumour or neurological swallowing difficulties, as well as a more general obstruction.
- **In children, especially with a sudden onset of choking, think about foreign bodies!**

**Assessment and Management of Choking from Local Tumours**

- Acknowledge the patient's and family's fears.
- Discuss interventions truthfully with the patient and family.
- High-dose steroids may be useful to reduce the swelling around the obstructing tumour.
- Palliative radiation, if available, may also help.
- Midazolam 5mg sc can help to sedate the patient and reduce anxiety.
- Rectal diazepam can be used, especially in the community.

## 7. Stridor

- A stridor is a high-pitched sound of breathing in partial laryngeal or major-way obstruction.
- It is common in head and neck tumours or mediastinum.
- It causes exhaustion from laboured breathing and anoxia.

**Causes**

- Pressure on the upper airways by extrinsic compression caused by such things as enlarged lymph nodes or primary tumour in the lungs, head or neck.

**Management**

- If impending obstruction is diagnosed, consider whether pre-emptive treatment with radiotherapy or tracheostomy is indicated.
- Discuss the possible events with the patient and their family.
- Offer sedation with morphine and benzodiazepines; 5–10mg morphine and 5–10mg diazepam given PO/SC/IV/PR depending on the patient's condition.
- In hospital, and if facilities are available and the condition of the patient allows, consider:
  - o Bronchoscopy
  - o Chemotherapy
  - o In children, consider dexamethasone high dose 0.5mg/kg 1V over 2 minutes
  - o Nebulise children with adrenaline: 1ml of 1: 1000 added to 4mls of saline, with a minimum of 30 minutes between sessions.
  - o Give parenteral morphine and/or benzodiazepine if the breathlessness is severe (Note: oral/rectal diazepam works as fast as parenteral and so you can use injectable diazepam rectally.)

## 8. Haemorrhage

Haemorrhage may be from the underlying tumour or caused by medication i.e. causing gastric erosion. Generalized clotting deficiencies, seen in thrombocytopenia, hepatic insufficiency or ant-coagulation with warfarin, are also contributory factors particularly in patients with cancer.

- Haemorrhage is profuse bleeding from one of the major blood vessels, e.g. the carotid artery.
- While uncommon, haemorrhage can be a frightening event for patient and carers.
- Haemorrhage is, however, often predictable and needs to be proactively managed – e.g., make medicines available in the home care setting in case the possible emergency occurs.
- Epistaxis (severe nose bleed) is particularly prevalent in children with haematological malignancies.



**Causes**

- Catastrophic bleeding from a large blood vessel due to tumour erosion from areas such as the head and neck, stomach, pelvis, bladder or lungs.
- Patients with cirrhosis may also have torrential bleeding from oesophageal varices.
- Many patients also have disorders of their blood-clotting systems.
- Low platelets associated with malignancies (bone marrow infiltration) and HIV.

**Assessment and Management**

- Communicate gently and truthfully and stay with the patient.
- Use dark cloths to soak up the blood.
- Pack a bleeding nose with gauze and BIPP or use nasal tampons. Adrenalin-soaked ribbon gauze may also help as it causes local vasoconstriction.
- For small oral bleeds, crushed cyclocapron may help.
- Sedation (such as diazepam 10mg PO/PR) is indicated if the patient is distressed.
- Remember that if the bleeding is torrential, the blood pressure will drop quickly and so medications will not be effective.
- The family or staff of a patient having the likelihood of a haemorrhage should be counselled about that possibility and advised what they should do in such a situation – as well as being offered support after the event if it occurs.
- In children, aim for rapid and complete sedation with benzodiazepines, and/or opioids if available; use parenteral routes.
- If able to swallow, give children double the usual dose of morphine with or without diazepam.
- If unable to swallow, give large doses of morphine and diazepam rectally.  
Rectal valium dose:
  - If weight is not known: <3years 5mg; >3years up to 10mg
  - If weight known: 0.5–1mg/kg up to a maximum of 10kg.

Non-acute haemorrhage may be treated by oncological, systemic and local measure. Palliative radiotherapy is very useful for superficial tumours and those of the bronchus and genito-urinary tract. If radiotherapy is not appropriate, coagulation should be enhanced with oral tranexamic acid 1g t.d.s. But caution is necessary with haematuria since clots may form in the tranexamic acid or adrenaline (1:1000) soaks may be useful. Sucralfate may act as a local astringent to stop stomach mucosal bleeding but inhibits absorption of other medication such as proton pump inhibitors.

Acute haemorrhage, which may be caused by erosion of a major artery, may be a rapidly terminal event. It may be possible to anticipate such an occurrence and

appropriate medication and a red/green blanket to reduce the visual impact should be readily available. Relatives or others who witness such an event will need a great deal of support. If the haemorrhage is not immediately fatal such as with a haematemesis or bleeding from the rectum, vagina or superficially ulcerated wound, **the aim of treatment is local control if possible and sedation of a shocked, frightened patient.** Rectal or sublingual diazepam (Stesolid 10mg) or midazolam 10 mg SC or buccally act quickly.

## 9. Hypercalcaemia

Hypercalcaemia occurs as a result of increased osteoclastic activity (which releases calcium from bone) and decreased excretion of urinary calcium. This is attributed to locally active substance produced by bone metastases or by factors such as ectopic parathyroid hormone related protein (PTHrP) or cytokines, and occurs in 10% of the cancer population. The tumours most commonly associated with hypercalcaemia include squamous cell carcinoma of the bronchus, carcinomas of the breast and prostate, multiple myeloma and other squamous cell tumours. Hypercalcaemia is a threatening metabolic disorder associated with cancer.

### Causes

- Lytic bone lesions, thus causing calcium to be released from the bone, along with a decrease in the excretion of urinary calcium.

### Signs and Symptoms

- General malaise
- Nausea and vomiting
- Anorexia
- Constipation
- Bone pain
- Thirst and polyuria
- Polydypsia
- Severe dehydration
- Drowsiness
- Confusion and coma
- Cardiac arrhythmias.

### Assessment and Management

- A corrected plasma calcium concentration above 2.6 mmol/l defines hypercalcaemia.
- It is often mild and asymptomatic and significant symptoms usually only develop with levels above 3.0 mmol/l although some patients may have significant symptoms at lower levels. Levels of 4.0 mmol/l and above will

cause death in few days if left untreated.

- 80% of hypercalcaemic patients with cancer survive less than one year.
- Treatment of hypercalcaemia can markedly improve symptoms even in patients with advanced disease.
- Proper management of hypercalcaemia makes end-of-life care and management less traumatic for the patient and the carer.
- The patient may be admitted for hydration and bisphosphonate therapy (e.g. disodium pamidronate 60–90mg in sodium chloride 0.9%, 500ml over 2–4hr). However, this treatment might not be available due to cost.

#### 2.6.4 Special Considerations in HIV and AIDS

- In HIV and AIDS the most common palliative-care emergencies are SCC (often due to TB), seizures due to infections, and overwhelming sepsis.
- Treatment for such emergencies is as above, with special consideration of anti-infection agents.
- Overwhelming sepsis in a patient with HIV and AIDS may not display the typical signs of fever.
- Intracranial or meningeal infection should be considered when there is a rapid decrease in the level of consciousness.
- Opportunistic infections may present with sudden deterioration or collapse.

#### Important Note

- While the required facilities to manage some palliative care emergencies may be limited in some Kenyan settings, health workers should always endeavour to undertake impeccable assessment, communicate with the patient and the family, and do whatever they can for the patient.
- Clear thinking is crucial in handling emergency situations, and calmness and patient comfort are paramount

## UNIT 2.7: END OF LIFE CARE



**Time: 1 hour**

### **OBJECTIVES:**

At the end of this unit the health care worker will be able to:

1. Define end of life care
2. To describe the management of patients at end of life
3. To discuss the recognition of death
4. To describe immediate care after death

## COURSE NOTES

### 2.7.1 End of Life Care

- Death is a part of life, and people need to be allowed to die in peace and with dignity.
- During the dying phase, patients should continue to receive adequate pain and symptom control.
- Palliative care neither hastens nor postpones death and views dying as a normal process.
- It is important that palliative care is delivered in a culturally sensitive manner.
- Palliative care patients have had a diagnosis of a life-threatening illness such as HIV&AIDS and cancer; therefore there is usually a preparatory period for death.
- *It is hard to watch and care for a dying child. It is important to support the parents and to encourage them to give the child special attention and demonstrate affection during his or her dying stages.*

### Preparing to Care for the Dying

#### Prepare Yourself

- Contemplate your own death and preferences for dying – this can help you empathise with a patient who is losing everything known to them and the

family who are losing a precious loved one. However, it is important not to apply your own preferences to the patient.

- Some principles for preparing yourself to care for the dying are as follows:
  - Where possible, get to know the patient and family for some time before death. If referred late, spend time with patient and family to gain their confidence.
  - Ensure the patient and family are aware that you will care for them.
  - Prepare the patient and family well in advance for death.
  - Be knowledgeable about the medical management of all possible events.
  - Be aware of spiritual aspects and needs, and provide for them.
  - Encourage the family to talk to the patient, reassure them and pray with them (as appropriate).
  - Find out whether the patient has any special requests for the family after death.
  - Be familiar with, and respect, religious and cultural rituals surrounding death and dying,
  - Facilitate bereavement support for the family.
  - Be aware of your own affection for the patient. You too have bereavement needs. Know how to address them with a trusted team member.
- Remember that autonomy will be a priority for adults with the cognitive capacity to understand decisions.
- [Children have partial autonomy that increases in proportion to their increasing abilities to comprehend situations and accept responsibility for their decisions.](#)

### **Prepare the Patient and their Family**

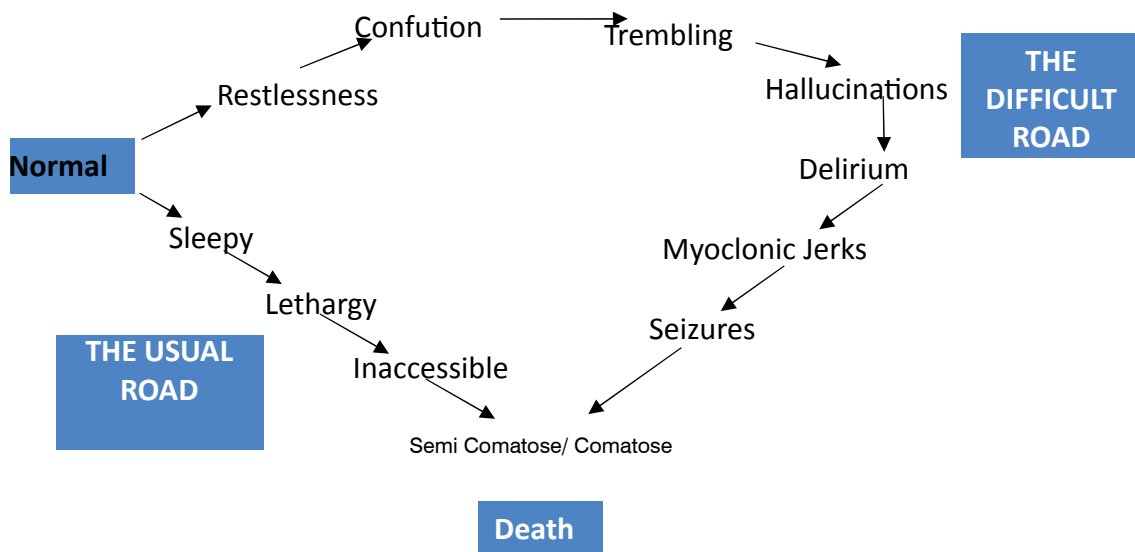
- Gently ensure that the patient and their family understand that death is near and explain some of the signs of dying – e.g.:
  - Gradual increase in drowsiness and/or weakness
  - Changes in breathing pattern
  - Death rattle
  - Cheyne–Stokes respiration
  - Skin colour changing as circulation changes
  - Possible terminal restlessness.
- The presence of a loved one, holding hands, touching, praying etc. can bring comfort to the patient.
- The importance of having friends and family needs to be recognised and respected.
- Reassure the patient and the family that dying is not usually uncomfortable – e.g. grunting is not a sign of pain.

- Be prepared to discuss cultural issues and support cultural needs as long as they do not cause suffering to the patient.
- [Hold family conferences to facilitate future placement of any children.](#)
- Explore and discuss the issue of a patient writing a will and/or other inheritance issues to protect the bereaved.
- Facilitate the resolution of unfinished business.

## 2.7.2. Management of the dying

- The holistic approach continues to the end of life and beyond.
- Help from other team members or organisations should be sought when indicated.
- There are different ‘roads to dying’ – Fig. 4 below. The majority of patients take the ‘usual’ road; however, when the patient is treading the ‘difficult’ road, it is important to be there to support them and their family.

**Fig. 4; Road to Dying**



- It is not possible to accurately estimate the time of death; you can only say that death is getting closer.
- The dying person may remain aware of their surrounding until the moment of death. However, this awareness may be limited (e.g. confused about time, mumbling, staring into space, odd movements of the hands, seeming to see things).
- Hearing often remains intact so take care in conversation and include the patient if talking at the bedside even if they appear asleep or unconscious.

- Encourage the family to continue talking to the patient even when he/she is too weak to respond.
- Reduce unnecessary medications but continue with pain and symptom control.
- As the patient is dying, the body organs begin to decline.

### 2.7.3 Management of Symptom at End of Life

As death nears, symptom management continues to be essential (see other chapters for specific interventions), but the focus may shift and practices may differ from what was appropriate earlier in the disease process. Generally, it is important to:

- Revisit all prescribed treatments and review them with new goals appropriate for end-of-life-care.
- Discontinue treatment that does not contribute to the patient's comfort.
- Continue medication that, if stopped, may cause distress to the family, if not the patient.
- Adjust dosages of pain medication and adjuvants as needed due to reduced circulation and organ function and increasing side effects.
- Use alternative routes to administer medication once the patient can no longer swallow.
- Continue nutritional support, but respect the patient's wishes. Because families are often disturbed when attempts to provide nutrition are discontinued, it is wise to offer sips of water, chips of ice, or even just to moisten the mouth and lips with a damp cloth.
- For dyspnoea, fan the face; give morphine
- For respiratory panic attacks, provide reassurance and encourage breathing exercises; give diazepam 2.5 to 5 mg.
- For 'death rattle', reposition the person in bed and reassure the family. To dry secretions, give hyoscine butylbromide 20 mg 4 hourly.
- For nausea and vomiting, give antiemetics SC
- For delirium, review drugs (Neuro-Psychiatric Problems). Consider haloperidol. For agitated delirium, consider haloperidol, with diazepam 5 mg 4 to 6 hourly for sedation.
- For 'terminal restlessness', treat the physical cause (e.g., full bladder, pain). Encourage the presence of family member. Consider sedation.
- For convulsions, give diazepam 5–10 mg (repeat if required to max of 30 mg).
- For haemorrhage (e.g. haematemesis),
- For urinary retention or incontinence, if possible, catheterize the patient.

- Near death, hepatic and renal functions are reduced, so medications may linger in the body. Therefore the patient who had their pain controlled by regular doses of morphine may now manifest some of the side effects as the active ingredients accumulate in the bloodstream.
  - **Action:** stop the morphine for a day (with instructions for breakthrough pain) and then commence again at a lower dose or with longer hours between (e.g. extend intervals from 4-hourly to 6-hourly).

## Special Considerations for Pain and Symptom Management at the End of Life

- As the disease advances towards the end of life there may be an escalation in pain and other symptoms, requiring ongoing increases and adjustments to be made in drug therapies.
- If the patient has received good palliative care, their pain should be controlled before they enter the terminal stage of the illness. However, this will often not be the case.
- The pain and symptom assessment and management measures addressed in earlier chapters of this pocketbook are still appropriate for the terminal phase of illness, although several alternative methods of administering analgesics may be required as a result of decreased oral intake and consciousness.
- Such alternative methods of providing analgesia include:
  - Rectally
  - Sublingually or buccally
  - Transdermally via pain patches such as fentanyl
  - Subcutaneously – can be done at home
  - Via a nasogastric tube
  - Intravenously (in hospital).

### Rectal Analgesia

- Morphine suppositories are sometimes available.
- The rectal route can be used for long-acting morphine, such as morphine sulphate tablets (MST) 12-hourly.

### Sublingual or Buccal Analgesia

- Morphine solution is absorbed from the buccal mucosa – however, because absorption is variable, a larger dose may be needed.
- Morphine solution can therefore be given in this way to moribund patients.



### Subcutaneous Analgesia

- The subcutaneous route is useful if the patient is unable to ingest medication.
- Intermittent dosing via a subcutaneous needle (butterfly) can be given, such as 4-hourly morphine.
- Syringe drivers, when available, can be used to administer analgesics and other symptom control drugs subcutaneously. This is a safe and relatively painless way. It is often used in a hospice or home care setting.
- There are different types of syringe drivers available. The most frequently used is the Graseby MS26 infusion pump that delivers a constant amount of analgesia through a butterfly needle inserted into the subcutaneous space over a 24-hour period.
- To deliver analgesia via a syringe driver, you need to:
  - Convert the dose of morphine from the oral dose to a subcutaneous dose – do this by adding up the total oral dose over 24 hours and dividing it by two. For instance, 10mg 4hrly orally = 60mg per 24hrs orally = 30mg per 24hrs parentally.
  - Dilute the amount of parenteral morphine in a luer-lock syringe with normal saline/ sterile water and fill up the syringe to a fluid length of 48mm (around 8–9mls). (Note: normal saline should not be used with cyclizine as it causes crystallisation.)
  - If a Graseby MS26 syringe driver is used, then set it at a rate of 2mm/hr in order to provide 24 hours of continuous morphine.
  - Insert a butterfly needle under the skin over the abdomen, upper arm or thigh.
- Other drugs can also be given via the syringe driver, such as anti-emetics (e.g. Cyclizine), metoclopramide, haloperidol, hyoscine or midazolam.
- Care needs to be taken to ensure that if more than one drug is given via the syringe driver, they can be mixed safely. For instance, dexamethasone should not be mixed with other drugs as it will precipitate out.

### Challenges to the Subcutaneous Route are as Follows:

- In some places across the Kenyan region, the subcutaneous route has not been an acceptable method of pain control, while for others it has been. So the culture and environment needs to be considered when considering using this route.
- Involving the patient and their family – there is often fear about using the syringe drivers.
- Which machine to use – simplicity, convenience, availability and cost all need to be taken into account. The 'Springfusor' may be used instead of the Graseby pump, because it uses a spring so does not need batteries, and it is simpler and cheaper.

- Some drugs are irritating to be given subcutaneously, e.g. diazepam, chlorpromazine and prochlorperazine.
- Drugs need to be changed every 24 hours and the needle site checked, so the patient needs to be seen by a health professional every 24 hours – which may not be possible in some settings.

## Decreasing Intake of Food and Fluids

- The patient may not experience hunger and may feel very little thirst. There is no problem with this so long as their mouth is kept clean and moist.
- Usually patients do not need parenteral fluids or enteral feeding; however, on occasion this may be provided to help control symptoms of dehydration.
- Teach the family to clean the patient's mouth with a moist cloth and apply petroleum jelly to the lips in order to prevent drying and cracking.

## Respiratory Symptoms

- Death rattle – i.e. noisy, rattling breathing when a patient is deeply unconscious and close to death – can be a distressing problem for relatives. But it is rarely a problem for the patient.
- Death rattle is usually due to pooling of saliva, though there may also be respiratory tract infection, pulmonary oedema or gastric reflux.
- Explanation and reassurance for the family and staff are essential.
- Positioning to maximise postural drainage may help, depending on the cause.
- Suction is seldom needed and may be traumatic unless the patient is deeply unconscious.
- Antimuscarinic medications are effective when given early for salivary pooling.
- Hyoscine hydrobromide 20mg SC is usually the most available.
- Hyoscine hydrobromide SC 400mcg and glycopyrronium 200mcg SC are alternatives.
- Hyoscine hydrobromide can be given to children aged 1–12 years: 10mcg/kg SC/IV as single dose, or 20–60mcg/kg over 24 hours in SC or IV infusion.
- Glycopyrronium 4–10mcg/kg 6hrly IV or SC (max 200mcg/dose) can be given.
- Cheyne–Stokes breathing may alarm family members in the periods of apnoea. They need to be reassured that this can persist for some time before death.

## Travelling the 'Difficult' Road

- Restlessness, confusion, hallucinations and delirium can be treated with haloperidol 1.5–2.5mg. First, though, exclude remediable causes such as a full bladder or rectum.
- Seizures should be treated with diazepam 5–10mgs IV (or, if not possible, IM). If available, midazolam 2.5–5mgs SC (which lasts up to three hours).
- Manage patient and family calmly, touching and holding the patient and family member as appropriate.

## Children

- A child dying is painful to watch and care for in any culture.
- Depending on the age of the child, death may be acknowledged, even feared; but many children are more trusting, more spiritual and accept death although fearing separation.
- It is important to support the parents and to encourage them to give special attention and demonstrate affection during the dying stages.

### 2.7.4 Recognizing Death

If the patient is dying at home, the health care service provider should describe to the family what to expect. Once death occurs the clinical signs will include:

- No heartbeat nor pulse
- No breathing
- Fixed pupils, eyelids may be open or closed
- Waxy skin colour and darkened extremities
- Drop in body temperature
- Relaxed muscles and sphincters (incontinence may occur)

When the patient dies, one is expected to encourage the family to take their time at the bedside to say goodbye. Some might want a minister, rabbi, or imam to attend to them and the body; others may wish to quietly take their leave. It is important to remember that a body remains infectious for about a week after death, and universal precautions should be applied to all bodies regardless of diagnosis.

Death certificates and insurance reports are the next trauma that the family must face. Because the right of confidentiality remains intact even after death, the health service provider is often trapped in the conflict between truth-telling and respecting confidentiality. As far as death notifications are concerned, patients with AIDS die from a variety of immediate causes, such as pneumonia, tuberculosis, or Kaposi's sarcoma, and these may be cited as the cause of death rather than AIDS.

If the patient had insurance, completing insurance certificates is trickier since the forms ask direct questions about HIV tests and AIDS. It is a good idea not to send forms directly to an insurance company, but to alert the family to the facts written on the form, and allow them to decide whether or not to submit it.

### 2.7.5 After Death

- Immediately after death there will be rituals to be carried out according to custom or religion. Allow the family to take this over.
- Remember that burials in Kenya will often take place within 2-14 days;
- The body may need to be preserved and transported – this may be done in a mortuary or traditionally in the village. Such action can preserve the body so that the funeral can take place up to 10 days later.
- There are many different customs and rituals that will be upheld in different parts of Kenya– e.g.:
  - Many cultures believe that the spirit is around for several days after death.
  - Friends and relatives may accompany the body for the first 24 hours. The body is never left alone but prayers, hymns and comfort are there for the body and the family.
  - In some cultures, food and precious belongings are put into the coffin.
  - The body may be buried in the ancestral home, in the garden.
- In Kenya, cremation is rare.
- The extent and the depth of bereavement differ in every culture.

### 2.7.6 Special Considerations in HIV&AIDS

- A similar approach is needed for patients who are dying, regardless of their disease.
- The medication regimen needs to be simplified to only those medicines needed for good symptom control. This may therefore include stopping ARVs or anti-TB treatment.
- The provision of care through home-based care services and HIV support services is important.
- It is important that everyone caring for the patient is aware of universal precautions, particularly if handling bodily fluids.
- It can be hard to know when the end is really the end, because patients may be seriously ill with an OI, which is treated and then they recover.
- Signs and symptoms associated with decreased survival include:
  - Poor performance status, with more than half the daytime spent in bed

- End-stage organ failure and anorexia      Decreased response to ART, or the development of resistance
- Wasting and loss of >30% lean body mass
- Very low CD4 count.
- However, actual survival time may vary from days to weeks, months or even years.

## Important Note

- Whether we have met with death before or not, we all need to take time away to think about our death and what we would like if all things were equal.
- As we attend to our patient in this situation, we need to ask ourselves constantly, 'What would I want if I was dying like this?'
- Not everyone will have a peaceful death.
- Many of patients die at a young age. The commonest age range in Kenya is 30–40, a time when there is unfinished business, anxiety about the children, etc.
- Bringing someone to peace with their family and their God before death can be one of the most rewarding events in the life of a carer, professional or volunteer.

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# Aspects of Palliative Care

## Module 3



**Time: 3 Hours**

### **OBJECTIVES:**

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

1. Define human nutrition
2. Explain the role of nutrition in palliative care
3. Describe the key aspects of nutrition care
4. Discuss the goal of nutritional therapy in palliative care
5. Outline clinical assessment of nutritional status of patients with life threatening illnesses
6. Describe the relationship between nutrition and HIV & AIDS, cancer and other life threatening illnesses
7. Describe the nutrient requirements of people living with HIV & AIDS, cancer and other life threatening illnesses
8. Discuss the nutritional counselling for specific dietary problems
9. Describe food and drug interaction in palliative care

### **Course Outline:**

- Introduction to human nutrition
- Explain the role of nutrition in palliative care
- Outline clinical assessment of nutritional status of patients with life threatening illnesses



- Describe the relationship between nutrition and life threatening illnesses
- Describe the nutrient requirements of people living with life threatening illnesses
- Discuss the nutritional counselling for specific dietary problems
- Describe food and drug interaction in palliative care

## UNIT 3.1: RELATIONSHIP BETWEEN NUTRITION AND PALLIATIVE CARE



**Time: 1 hour**

### **OBJECTIVES:**

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

1. Define nutrition
2. Describe the key aspects of nutrition care
3. Role of nutrition in palliative care
4. Discuss the goal of nutritional therapy in palliative care
5. Outline the relationship between nutrition, HIV & AIDS and cancer
6. Discuss the types of HIV & AIDS and cancer related malnutrition
7. Discuss the effects of HIV & AIDS and cancer and Life threatening illnesses on nutrition

## **COURSE NOTES**

### **3.1.1 Definition of Human Nutrition**

#### **Definition**

**Nutrition** is the sum of all processes involved in taking in of food and nutrients and their assimilation and use for proper body functioning and maintenance of health. The successive stages include ingestion, digestion, absorption, assimilation and excretion.

**Nutrients** are components of food. They are divided into 2 major groups' macro and micronutrients. Macronutrient includes; Carbohydrates, proteins, fats and oils, while micronutrient includes vitamins and minerals. Others are dietary fibre and water

#### **Overview of Nutrition**

Good nutrition is essential for achieving and preserving health while helping the body to protect itself from infections. In addition, a nutritious diet is essential to make up for the loss of energy and nutrients caused by infections. Providing quality care and support requires addressing the nutritional needs of people with HIV & AIDS and

Cancer at all stages of the disease. Because good nutrition can contribute a person's well being at all stages of the illness and prolongs life, it is an important part of holistic palliative care.

## Key Aspects of Nutrition

- Food availability and access: Right amount and quality (right mix of nutrients)
- Food intake: Ability to consume the right quantity and quality of food at the time the body needs it
- Digestion and absorption of food and nutrients
- Metabolism and utilization of food to meet needs for growth, reproduction and maintenance of health
- Excretion of extra components of food, toxins and wastes

### 3.1.2 Goals of Nutrition Therapy

The goals of nutrition therapy for patients in active treatment and recovery are designed to restore nutrient shortages, maintain nutritional health, and prevent complications. the following are the goals to nutrition therapy:

1. Prevent or correct malnutrition.
2. Prevent wasting of muscle, bone, blood organs and other lean body mass.
3. Help the patient tolerate treatment.
4. Reduce nutrition-related side effects and complications.
5. Maintain strength and energy.
6. Protect ability to fight infection
7. Help recovery and healing.
8. Maintain or improve quality of life.

### 3.1.3 The Role of the Nutritionist / Dietician

Nutritionist / dieticians work collaboratively to make nutrition, hydration, and feeding recommendations. When facing difficult decisions it is often reassuring for families to hear similar messages from multiple care team members. Often the Nutritionist/ dieticians familiarity with practical aspects food and fluid at the end of life including chewing and swallowing problems and cessation of thirst and hunger make them best able to address families concerns and answer questions. Nutritionist/dieticians may find that they need to answer the same question many times. The complexity of the issue demands that topics be approached and sorted through from multiple perspectives, always assuring that consistent answers are provided so that patients and their families feel secure in making sensitive end of life food and fluid decisions. The following are the roles of nutritionists in palliative care:

- Assessment of the patients nutritional needs
- Nutritional counselling
- Planning of the diets to manage complications and according to the drugs plan
- To encourage families to supply to patients the patients favourite meals or home prepared foods
- Educate patients and their families about end of life care choices
- The Nutritionist is part of the palliative care centre ethics committee

### **3.1.4 Relationship Between Nutrition and Cancer, HIV&AIDS and other Life Threatening Illnesses**

Cancer or HIV&AIDS increases energy requirements through increases in resting energy expenditure, reductions in food intake, nutrient malabsorption, and complex metabolic changes that result in weight loss and wasting. Repeated illnesses and/or nutritional deficiencies suppress the immune system and make the individual more susceptible to severe infections and/or malnutrition, accelerating the progression of the disease and reducing survival. HIV&AIDS further complicates and reinforces this downward spiral, this results to a vicious cycle as explained here below.

### **3.1.5 Types of HIV-related Malnutrition**

Two types of malnutrition result in wasting in HIV&AIDS:

- Starvation-related wasting results from voluntary or involuntary reduction in food intake and can be reversed by increasing food intake on recovering from an opportunistic infection.
- Cachexia-related wasting results from alterations in metabolism and responds poorly to increased food intake. What is known about cancer-related cachexia may assist in developing effective interventions.

### **3.1.6 Effect of Cancer on Nutrition**

Tumours may produce chemicals that change the way the body uses certain nutrients. Especially tumours of the stomach or intestines may affect the body's use of protein carbohydrates and fat. A patient may appear to be eating enough, but the body may not be able to absorb all the nutrients from the food. Diets higher in protein and calories can help correct this and prevent the onset of cachexia. Drugs may also be helpful. It is important to monitor nutrition early, as cachexia is difficult to completely reverse.

Nutrition therapy can help cancer patients get the nutrients needed to maintain body weight and strength, prevent body tissue from breaking down, rebuild tissue, and fight infection.

Eating guidelines for cancer patients can be very different from the usual suggestions for healthful eating. Nutrition recommendations for cancer patients are designed to help the patient cope with the effects of the cancer and its treatment. Some cancer treatments are more effective if the patient is well nourished and getting enough calories and protein in the diet. People who eat well during cancer treatment may even be able to handle higher doses of certain treatments. Being well-nourished has been linked to a better prognosis (chance of recovery).

## UNIT 3.2: CLINICAL ASSESSMENT AND NUTRITIONAL MANAGEMENT OF PATIENTS



**Time: 1 hour**

### **OBJECTIVES:**

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

1. Outline the goals of nutritional assessment
2. Describe nutritional assessment for special groups
3. Explain the role of nutrients in the management of HIV & AIDS, cancer and other life threatening illnesses
4. To discuss the management of specific dietary problems related to cancer, HIV&AIDS
5. To discuss the management of specific dietary problems in special groups (children and others) related to cancer, HIV&AIDS

## **COURSE NOTES**

### **3.2.1: Definition and Outline of the Goals of Nutritional Assessment**

A key nutritional care and support for PLWHA and Cancer patients is to prevent weight loss and to maintain normal nutritional status.

#### **Nutritional Assessment**

It involves judging a person's nutritional status, situation, and vulnerability to poor nutrition by taking measurements and/or asking questions. Based on results, PLWHA or cancer patient can be referred for specialized care if necessary.

Nutritional assessment is a process that determines a client's nutritional status and problems. The major purpose of a nutritional assessment is to determine the severity of nutritional impairment and probable causes

## Goals of Nutritional Assessment

- To confirm an adequate nutrient intake, improve eating habits, and help build and maintain stores of essential nutrients
- To confirm correct weight status, and maintain a healthy weight by preventing overall weight loss particularly of muscle mass (lean body mass or fat mass)
- To confirm absence of illness that aggravates nutritional wasting, and assist the patients in assessing treatment for illnesses that reduces food intake
- To adjust meals and meals plans for other chronic illnesses associated with HIV&AIDS or cancer.
- To facilitate provision of therapeutic nutritional care and support during advanced stages of disease

Early nutrition screening and assessment can identify problems that affect the success of HIV & AIDS treatment and anticancer therapy. Patients who are underweight or malnourished may not respond well to HIV & AIDS and cancer treatments.

Malnutrition may be caused by the HIV&AIDS or cancer or made worse as the disease progresses. Finding and treating nutrition problems early may help the patient gain or maintain weight, improve the patient's response to therapy, and reduce complications of treatment.

Screening and assessment are done before beginning HIV&AIDS or anticancer therapy, and assessment continues throughout treatment.

Because the ability to tolerate treatment is better for the well-nourished patient, screening and assessment are done before beginning HIV&AIDS or anticancer therapy. Appropriate nutrition management is begun early, and nutritional status is checked often during treatment.

Screening is used to identify patients who may be at nutritional risk. Assessment determines the complete nutritional status of the patient and identifies if nutrition therapy is needed.

## Steps in Nutritional Care

- Carry out a nutritional assessment.
- Prepare a nutrition care plan.
- Conduct a counselling/education session.
- Prepare a food drug-plan with the client (or caregivers).
- Agree on and carry out a follow-up plan.
- Refer PLWHA for specialized care if necessary.

## Nutritional Practices for PLWHA and Cancer Patients

- Have periodic nutritional status assessments, especially weight.
- Increase energy needs according to the disease stage. *Achieve additional energy by eating sufficient amounts of balanced foods, including one or more snacks between meals.* Severely malnourished (BMI<16) PLWHA and in-patients should be treated with appropriate therapeutic feeds.
- Maintain high levels of sanitation, food hygiene, and food/water safety at all times. Get de-wormed twice a year.
- Practice positive living behaviours, including safer sex, alcohol avoidance or moderation, moderate or no consumption of junk food, management of depression and stress, seeking support from family and friends.
- Do physical activity or exercises to strengthen or build muscles and increase appetite and improve health.
- Drink plenty of clean, safe water (filtered and boiled or treated) and use clean, safe water to swallow medicines and prepare juices.
- Seek prompt treatment for all opportunistic infections and other diseases, and manage symptoms with dietary practices, especially for illnesses that may interfere with food intake, absorption and utilization.
- If on medicine, including ARVs, manage drug-food interactions and diet-related side-effects. If taking traditional herbs or nutritional supplements, inform the clinician

### 3.2.2 Basic Nutritional Assessment

Anthropometric assessment includes weight (% change over time) and BMI (for adults) and weight-for-height (for children). Others include height, MUAC; skin fold thickness, waist/hip ratio and body surface area.

Bio-chemical assessment includes haemoglobin (Hb), haemogram, and blood sugar. Others include micronutrients (e.g. serum zinc, retinol), triglycerides and cholesterol (especially for those on ARVs), CD4 count, and WBC levels.

### Clinical Assessment

A clinical assessment consisting of the current and past medical history and related clinical examination is vital in gauging nutritional risk. The physical exam will check the body for general health and signs of disease, such as lumps or growths. The nutritionist will look for loss of weight, fat and muscle, and fluid build-up in the body.

Dietary assessment methods/tools include food recall, food frequency, appetite assessment, food diversity, total food consumption and food record diaries



Malnutrition among PLWA and cancer patients manifests itself most commonly as weight loss, wasting and faltered growth in children. It is a result of deficiency in specific macro or micro nutrients.

### 3.2.3 The Role of Nutrients in the Management of HIV&AIDS, Cancer and other Life Threatening Illnesses

Nutritional needs vary with sex, age and disease status. Some comparative average nutritional needs include:

- Adult men: 2,430 Kcal/day
- Adult women: 2,170 Kcal/day
- Pregnant women: 2,460 Kcal/day
- Lactating women: 2,570 kcal/day
- Protein intake: 1–2g of protein per kg of normal body weight.
- Asymptomatic people with HIV (those who do not have symptoms): 10% more energy than HIV-negative individuals of the same age, sex and physical activity level (i.e., 200–300 additional Kcal)
- Symptomatic people with HIV&AIDS: 20–30% more energy per day than HIV-negative individuals of the same age, sex and physical activity level
- Patients on ART: energy requirements remain the same

## Specific Nutrients Requirements

### Energy Requirements

The human body expends energy, even when at complete rest. Infections and diseases, increases the body energy needs depending on severity of the disease. Basically, a cancer and HIV&AIDS patient needs increases with the progression of the disease. The main energy giving foods in Kenya are;

**Carbohydrates and sugars:** maize, rice, beans, peas, potatoes, sorghum, cassava, wheat, sweet potatoes, arrow roots, millet and green bananas.

Sugary foods are table sugar, honey, jam, cakes and biscuits

Fats and oils provide more than twice the energy of an equivalent amount of carbohydrates. They add flavour and taste to food, which helps to stimulate appetite. They also maintain the function and integrity of the cell membranes structure. They also enhance the absorption of the fat-soluble vitamins (A, D, E, and K).

### Strategies to Meet energy Requirements of PLWHA and Cancer Patients

There is a need to try and meet the energy requirements in order to sustain the increased basal metabolic rates. The following are strategies to offer to the client or care givers.

- The patient need consume two or more snacks between meals to help meet the energy needs
- Make dietary adjustments and meals plans using locally available foods
- Promptly treat or manage any condition that may reduce food intake or nutrient absorption or utilization, such as diarrhoea, mouth sores etc.
- If the patient is losing weight (more than 10% of the usual weight) and cannot access enough food to meet his or her energy needs, efforts must be made to provide additional food support

## Micronutrients

It is not known whether cancer and/or its treatment increases micronutrient needs.

Factors affecting the ability to meet micronutrient needs include;

- Disease location and process,
- Treatment modality and
- Medications.

Tumours located in the digestive tract have the potential of causing obstruction resulting in poor intake and therefore micronutrient deficiency. Deficiency of B vitamins can arise from prolonged general malnutrition. Normal metabolism of micronutrients may also be altered by disease process. Hypercalcemia resulting from disease cannot be regulated through diet therefore restriction may not be required. Resection of the lower gastrointestinal tract may result in malabsorption and micronutrient deficiencies.

Radiation induced side effects can cause generalized poor intake, which may result in micronutrient deficiencies. Greater losses of electrolytes may occur with radiation-related nausea, vomiting and diarrhoea. Chemotherapy can have a direct effect on micronutrient levels. For instance, carboplatin can decrease serum electrolytes, specifically magnesium and potassium. Asparaginase can cause azotemia accompanied by an increase in calcium and phosphorous excretion due to increased protein degradation. Side effects of chemotherapeutic agents such as nausea, vomiting and diarrhoea, can lead to electrolyte imbalances. Other commonly used drugs can alter micronutrient levels (e.g. use of antibiotics can lead to electrolyte imbalance secondary to diarrhoea).

### Strategies to Meet Them

A daily multivitamin and mineral supplement may be recommended for individuals whose micronutrient intake is limited for a prolonged period. Due to potential interactions between specific chemotherapy medications and vitamins, patients receiving chemotherapy should consult their physician before taking supplements. Megadoses of vitamins and minerals are not advisable due to their potential toxicity or actual impairment of immune function (i.e. zinc).

## Food Supplements

A healthy, balanced diet usually provides all the required nutrients. Multiple vitamin and mineral supplements may not be easily available, they are expensive, and buying these supplements will leave less money for food. It is therefore better to advise families to provide a good mixed diet rather than buy supplements except when the person with HIV&AIDS is unable to eat or absorb a normal diet.

Where resources permit, when a patient's food intake is low, multivitamins and mineral supplements can help to meet the nutritional requirements. Also, HIV infection can lead to a loss of vitamins and minerals needed by the immune system to fight infections and maintain the immune system. Deficiencies of vitamins A, C, and E (antioxidants) and minerals can result in oxidative stress, a condition that may accelerate immune cell death and increase the rate of HIV replication.

Micronutrients are vitamins and minerals that are needed only in small amounts. Macronutrients, such as carbohydrates, sugars, fats, and proteins, are needed in larger amounts. Studies have highlighted the importance of micronutrients for people with HIV&AIDS. For instance, daily micronutrient supplementation was found to increase survival in adults with low CD4 cell count. There are also reports that excessive doses of vitamin A and zinc have a detrimental effect on survival.

## Water and Hydration

### Increase Fluids

Fluids keep your body working properly. That's why it is important to drink eight to 10 cups of fluid a day.

### Artificial Nutrition and Hydration

Artificial nutrition is defined as the provision of fluids through an intravenous access to a vein. The healthcare professional has the obligation to inform and support those making the decision about artificial nutrition and hydration. The ethical matters involved in these decisions include the person's right to refuse any unwanted medical interventions and the requirement that the healthcare professional tell the truth to the patient and do no harm.

### 3.2.4. Management of Specific Symptoms

#### Introduction

Nutritional practices can help PLWA or cancer manage symptoms either due to the disease or drugs. Service providers should counsel the patients experiencing these symptoms to find feasible nutritional practices they can follow.

The following recommendations offer practical guidelines in symptom management

#### 1. Diarrhea

##### Plenty of Fluids to Avoid Dehydration

- Soup, juice, water, black tea
- Between meals rather than with meals
- Avoid carbonated drinks
- Avoid strong citrus (orange/lemon) juices because they may irritate the stomach
- Use the recipe for replacement of water and salt

##### Eat More

- Starchy foods (oatmeal, potatoes, white rice, corn-soya blend, sweet potatoes)
- Food rich in fibre (millet, peas, lentils, banana) to help retain fluids
- Guava juice
- Salty foods
- Soft fruit and vegetables
- Small meals frequently rather than three large meals.
- Eggs, chicken, or fish for protein
- Boiled or steamed foods, avoiding fried foods

##### Avoid:

- Dairy products
- Greasy, high-fat food
- High-fibre food
- Sugar
- Food with a laxative effect (e.g., prune)
- Caffeine and alcohol
- Nicotine

## 2. Constipation

- Eat regular meals to ensure bulk in the gut.
- Include foods that are high in roughage (e.g., raw fruit and vegetables, whole-wheat bread, oats, dried fruit).
- Eat stewed/dried prunes.
- Drink lots of fluids.
- Get regular exercise.

### Avoid:

- Laxatives and enemas which cause loss of water and salts
- Delaying going to the toilet.

## 2 Poor Appetite

- Eat whenever and whatever you feel like eating.
- Eat smaller, more frequent meals.
- Take exercise.
- Drink high energy drinks such as milk, yoghurt and sour-milk drink.

**Avoid** strong-smelling foods

## 3 Weakness

- Let others help you by preparing and bringing food.
- Eat fruit and yoghurt.
- Leave food for a bed-fast person in a cooler bag by the bed.
- Use canned or frozen food.

## 4 Nausea

- Take smaller meals or snacks.
- Try cold or chilled foods.
- Eat dry toast, crackers and cereals, and soft fruit like bananas.
- Get someone else to prepare the food.
- Avoid lying down immediately after eating (wait at least 20 minutes).
- Replace lost fluid by taking soups, water, juice, and jelly.
- Drink lemon juice in hot water; drink ginger root (crush ginger in cold water, boil in water for 10 minutes; place in covered container; strain ginger and drink liquid).
- Avoid caffeine (coffee and tea) and alcohol.
- Avoid having an empty stomach — nausea is worse if the stomach is empty.

## 5 Loss of Taste

- Use flavour enhancers, salt, spices, herbs and lemon.
- Chew food well and move around in the mouth to stimulate receptors'

## 6 Heartburn

- Eat small frequent meals.
- Drink fluids but do not drink too much with food.
- Avoid foods such as cabbage, beans, onions that create gas in the stomach.
- Eat long enough before sleeping so food can digest.

## UNIT 3.3: HIV & AIDS AND CANCER DRUG FOOD INTERACTION IN PALLIATIVE CARE



**Time: 1 hour**

### **OBJECTIVES:**

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

1. To describe the food and drugs interactions in cancer patients
2. To describe the food and drugs interactions in HIV & AIDS patients

## **COURSE NOTES**

### **3.3.1. Guidelines for PLWHA on Medication**

- Refer PLWHA who lose 10% or more of weight in 2-3 months for assessment for ARVs.
- Inform PLWHA about the drugs they are taking.
- Tell PLWHA how HIV affects nutrition:
- Explain possible food-drug interactions, including drug side effects and their management through diet.
- Advise PLWHA to seek medical care for symptoms (and symptoms that are severe or persistent associated with increased nutrition requirements and affect food intake (e.g., oral thrush, loss of appetite, diarrhoea, and fever).
- Drugs like ARVs may have side effects that reduce food intake.
- Advise PLWHA on every contact to adhere to medications and complete the full course.
- Explain dietary recommendations for each drug.
- Advise PLWHA to drink 8 glasses or 4 large cups/day of clean, safe (boiled or treated) water, and more when one has diarrhoea or vomiting.
- Advise PLWHA taking drugs to avoid alcohol.
- Refer PLWHA on Zidovudine or Lamivudine for haemoglobin assessment at least every 6-8 months; if anaemic, initiate low levels of iron and folic acid.

## Guidelines for PLWHA on Herbal Remedies

- Herbs should not replace standard therapy, should not be toxic, and should not overburden the body's ability to metabolize them.
- Herbs should not interact negatively with, or reduce the effectiveness of, medications.
- PLWHA should keep health workers informed of herbs taken.
- PLWHA should be advised of harmful effects of herbal preparations and be advised to avoid self-prescription.

## Guidelines for PLWHA on Micronutrient Supplements

- Supplements are no substitute for balanced meals.
- Supplements do not treat HIV, though they may improve immunity to fight infection.
- A health worker should advise on necessary supplements and required amounts (overdose can be dangerous).
- A health worker may recommend supplementation in case of deficiency or infections that can cause deficiency (diarrhoea, specific intolerances, severe malnutrition).
- The diet supplements industry is not well regulated in many countries, and labels may not be accurate.

### 3.3.2 Potential Drug-food Interactions of Common Drugs in Kenya

- Most main first-line ARVs (Zidovudine, Nevirapine, Lamivudine, Efavirenz, Stavudine) can be taken with or without food.
- **Zidovudine:** Best on an empty stomach, e.g., 30-60 minutes before breakfast or evening meal. If stomach irritation, take with food but limit the amount of fat/oil in the meal.
- **Nevirapine:** No dietary restrictions. Can be taken with or without food. Clients taking it should avoid St. John's Wort, a yellow-flowered plant (*Hypericum perforatum*) sometimes used for depression.
- **Lamivudine:** Can be taken with or without food
- **Efavirenz:** Can be taken with or without food. If taken with food, client should limit the amount of fat/oil in the meal.
- **Stavudine:** Can be taken with or without food



### 3.3.3 Drugs Associated with Diet/nutrition-related Side-effects

1. Most ARVs have side effects (appetite loss, nausea/vomiting, diarrhoea, constipation, abdominal pain, changes in taste) that may affect food intake.
2. Drugs that have body composition side effects:
  - Zidovudine and Lamivudine increase risk of anaemia.
  - Efavirenz may increase fat level in blood.
  - Most protease ARVs increase risk of elevated lipid levels, lipodystrophy (fat mal-distribution) and sugar resistance.
  - Isoniazid inhibits metabolism of vitamin B6 and may cause vitamin B6 deficiency.

Some herbs/nutrient supplements may interact with some ARVs, e.g., St. John's Wort with Nevirapine, Efavirenz.

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# Psychosocial Aspects of Palliative Care

## Module 4



**Time: 15 Hours**

### **OBJECTIVES:**

By the end of this module the participants will be able to

- Describe psychosocial aspects of palliative Care
- Describe Communication in the context of palliative care
- Explain the concept of counselling in palliative care
- Discuss the importance of spirituality in palliative care
- Discuss Loss, Grief and Bereavement in Palliative
- Discuss the importance of support for care givers
- Discuss Human Sexuality in the Context of Palliative Care
- Discuss complimentary therapy in Palliative Care

### **Content Outline:**

- Psychosocial aspects of palliative Care
- Communication in the context of palliative care
- Concept of counselling in palliative care
- Spirituality in palliative care
- Loss, Grief and Bereavement in Palliative
- Support for care givers
- Human Sexuality in the Context of Palliative Care
- Complimentary therapy in Palliative Care

## UNIT 4.1: PSYCHOSOCIAL CONCEPTS IN PALLIATIVE CARE



**Time: 2 hours**

### **OBJECTIVES:**

By the end of this unit the participants will be able to

1. Define psychosocial care
2. Explain factors that lead to psychosocial problems
3. Describe effects of Psychosocial problems faced by patients with life threatening illnesses
4. Discuss signs and symptoms of psychosocial problems
5. Describe various interventions applied to psychosocial problems

## COURSE NOTES

### 4.1.1 Overview of Aspects of Psychosocial Problems

Palliative care patients have psychosocial needs, which need to be supported. It is important that these needs are identified and addressed in a holistic manner in order to minimize psychological problems.

#### **Definition of Psychosocial**

**Psych:** the mind (unique feelings, emotions, thoughts, understanding, attitudes, and beliefs an individual has)

**Social:** interpersonal relationships and what goes on in the natural environment.

**Psychosocial** can mean the dynamic relationship between social and psychological experiences where the effects of one continually influence the other.

## 4 .1.2 Factors Contributing to Psychosocial Problems

Social experiences may lead to psychological consequences and also some individuals with psychological problems will experience social consequences

Social experiences that can lead to Psychological problems e.g. Loss of loved ones, sickness (self and/or parent), physical disability (self and/or parent), Lack of basic needs: e.g. schooling, loss of social status, domestic violence (gender issues)

Psychological experiences that can lead to Social problems e.g. Anger, helplessness, suicidal thoughts, worries, frustration, mental illness, lack of peace of mind

Psychosocial problems in HIV affected children and adults need to be addressed from individual child, family and community levels.

### Individual Child Level

- Poor Parenting,
- Caring for both parents and other siblings,
- Separation from brothers and sisters
- Chronic Illness, Death or sickness of a parent, Loss of home,

### Family Level

- HIV Illness or cancer in family members
- Stigma & discrimination
- Multiple losses
- Dysfunctional relationships (abuse, substance abuse, domestic violence)
- Single parenting
- Child-headed households
- Elderly caregivers
- Chronic illness
- Death and bereavement

### Community Level

- Lack of knowledge of HIV or cancer
- Lack of knowledge of patients needs
- Worsening poverty
- Stigma and discrimination
- Over stretched communities due to increasing numbers of orphans and vulnerable children
- Peer influence

## Effects of the Psychosocial Problems Faced by Children, Adolescents and Adults

- Anti-social behaviour
- Failing to form relationships
- Failure to adhere to drugs
- Running to the streets
- Exposure to risk behaviours

## Stigma & Discrimination

The effects of stigma are stereotyping, bias, distrust, labelling, unfounded fear, avoidance and aggression amongst others.

Discrimination is stigma in action, stigmatizing thoughts and beliefs lead to discriminatory behaviour. Discrimination is an act or behaviour as a result of stigma and involves denial of rights and opportunities and/or social, psychological and physical abuse

### 4.1.3 Psychosocial Problems in Patients with HIV&AIDS and Cancer

Some patients may present with symptoms at various levels such as;

- Physical
- Behavioural
- Emotional
- Cognitive
- Social

## Physical Symptoms

- Multiple pains
- Abdominal pain
- Headache
- Chest pain
- General malaise
- Fatigue

## Behavioural Symptoms

- Restlessness
- Hyperactivity
- Withdrawal and self neglect
- Aggressiveness
- Sleep disturbance
- Acting out
- Stealing
- Drug abuse and sexual promiscuity
- 

## Emotional symptoms

- Emotional neglect in infants from sick depressed mother
- Irritability
- Lack of interest in surroundings
- Depression, sadness and mood changes
- Suicidal tendencies
- Anxiety, fear and anger
- Temper tantrums

## Cognitive Symptoms

- Inability to concentrate
- Regression of milestones
- Forgetfulness or poor memory
- Confusion
- Poor academic performance

## Social Symptoms

### Older children

- Avoidance and rejection by peers (due to effects of wasting, skin lesions etc)
- Social withdrawal and isolation
- Complications of treatment
- Antisocial behaviour

**Note: Recognize the psychiatric symptoms in children and refer as appropriate.**



## 4.1.4 Management of Psychosocial Problems

### Assessment

- In-depth investigation of the psychosocial dynamics affecting the client and his/her environment.
- Individual counselling and education of patient and family
- Medical treatment e.g. antidepressants, anxiolytics and antipsychotics where necessary
- Referral to counsellors/psychologists/psychiatrists

**Note: The provider must be fully aware of all aspects of the patient's treatment, stage of the illness and readiness for treatment or ARVs.**

### Management

Types and levels of Psychological and Social Intervention

- Play therapy
- Family therapy
- Group therapy
- Support Groups e.g. post-test clubs
- Psychotherapy

#### Family Therapy

This is where the counsellor works with the whole family for the benefit of the child taking into consideration the family systems, social and cultural values and the environment,

#### Support Groups

This is an informal group made of clients/patients with similar problems

Not necessarily structured and it can be open or closed

It is a common psychosocial intervention offered to willing participants (important to prepare the clients in advance).

#### Group Therapy

This is a therapeutic process between a counsellor and a group with common problems.

The group benefits from sharing experiences, learning from others, counsellor's professionalism and personal interaction.

#### Play Therapy

This is a therapy directed through play and games using toys and other tools or appropriate media

Art therapy is directed through drawings and paintings

### **Psychotherapy**

This is a process between a therapist and a child where the child and his family are assisted to acknowledge, comprehend, understand and adjust through their feelings, thoughts and behaviour to handle a problem

### **More intense, one-to-one intervention**

It's also known as talk therapy, counselling, psychosocial therapy or, simply, therapy.

Most forms of psychotherapy use only spoken conversation

Though some also use various other forms of communication such as the written word, art work, drama, narrative story, or therapeutic touch

## **Referral points**

- Support groups for psychosocial and economic empowerment
- Psychologists for psychological interventions
- Psychiatrists for treatment of mental disorders
- Social workers/ NGOs and CBOs for contact tracing and case management
- Community health workers for home based care
- Religious leaders for spiritual care
- Directory for referral and networking
- Referral and networking directory needed at each clinic
- Linkages with medico-legal team
- Children's department
- Social services
- Police
- Others as found appropriate

## UNIT 4.2: COMMUNICATION IN THE CONTEXT OF PALLIATIVE CARE



**Time: 1 hour**

### **OBJECTIVES:**

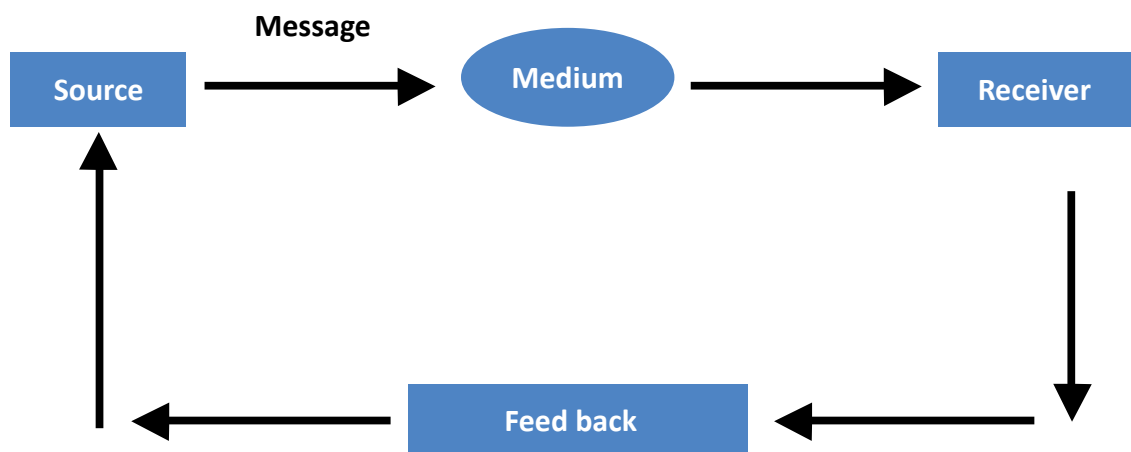
By the end of this unit the participants will be able to:

1. Explain the concepts of communication in relation to palliative care
2. Describe the process of breaking bad news
3. Discuss how to communicate with children

## COURSE NOTES

### 4.2.1 Concepts and Components of Communication

#### Communication Process



#### **The Source**

The source is the person, usually a member of the health care team, who initiates or sends a message, and then waits to receive a response from the receiver. Senders and receivers both send and receive messages.

### The Medium

This is the language used in communication, which can be complicated by:

- Body language, which must be interpreted within the individual's cultural context
- Sender and receiver meaning different things even though sharing a common language
- The use of interpreters/translators
- Jargon or medical language that is confusing and often scary to lay persons

### The Environment

This is the space in which communication occurs. Psychological, physiological, and physical barriers that hinder effective communication include:

- Interruptions, such as physical barriers (tables) between speakers, telephones ringing (and being answered by the HCW)
- Lack of privacy
- Interactions perceived by the person as menacing, such as the HCW crowding the patient or sitting between the patient and the door
- Lack of time to have a meaningful interaction
- Direct light from windows or other sources shining into people's eyes
- The state of the relationship among the communicators if there has been previous communication of 'bad news' or conflict
- The mental and emotional state of the patient and HCW—for example, a confused patient or a distracted HCW
- The patient's physical condition, as when the patient is in pain or uncomfortable

### Cultural Setting

- Do not make assumptions based on a person's race or language, but assess people as individuals.
- Respect the common taboo against talking about death if the patient's cultural view is that doing so invites death in.
- Respect the norm of some cultures not to openly express feelings of grief.
- Realize that the information you offer can be selectively offered—and may be selectively received—depending on the person's culture and whether or not it is acceptable to talk about a particular topic.
- Recognize that while a HCW has medical authority, he or she does not have cultural or spiritual authority. Once there is no more curative care and the patient is removed from the hospital setting, the traditional healer may be involved as the sole provider of health care and advice.

- Remember that in some areas the traditional healer might play a far more important role than any other HCW and that some persons with HIV&AIDS/ cancer in rural areas may never visit a health care centre or hospital.

## Power Dynamics

As an authority figure expected to play the lead role, the HCW must use more than usual sensitivity and patience to negotiate shared decision making with patients and families. An example is asking patient opinions on matters concerning them, or beginning with psychosocial/spiritual issues with which they are more comfortable

- Avoid jargon, which exaggerates the imbalance in knowledge between the HCW and patient.
- Ensure that there are always more family members than staff at family conferences or meetings.
- Ensure that you and the patient are at the same eye level. Both should be sitting down rather than one standing and one sitting. If the patient is lying in bed, prop him or her up as far as is comfortable and sit down, though preferably not on the bed, in order to maintain comfortable personal space.

## Expectations

- Realize that both parties have expectations, and they are not necessarily the same.
- Understand that the patient wishes to hear a certain message, and the HCW wish to convey one, but they are not always the same.

### 4.2.2 Barriers to Communication

- Language and culture
- Making judgments statements.
- Conflicting medium
- Recipient Problem
- Adults failure to come to the patients level
- Lack of self-awareness of the HCW expressing frustration, hopelessness, and disempowerment about the health care system.
- Fear of discussing their illness
- Change of HCWs due to staff shortages and less than perfect health care systems, making it difficult to develop a stable patient-HCW relationship.
- The receiver is the person receiving or hearing the communication, and responding by sending her/his own message.

- When the receiver is the person living with HIV&AIDS/cancer, barriers to correctly understanding the sender's communication include:
- The person not accepting the diagnosis of HIV&AIDS/cancer and not being ready to talk about end-of-life care.
- Different interest between the HCW and the patient and family.
- The person not having negotiated the losses associated with HIV&AIDS/cancer
- Families already having suffered multiple losses and complicated bereavement.

### 4.2.3 Principle of Communication

#### Effective Communication in Palliative Care

- Identifies and aims to address all the needs of the patient, family and care provider (i.e. psychological, spiritual, social, cultural and physical issues);
- Provides information according to the patient's preferences (whether good or bad news);
- Invites the patient to share their agenda in a conversation;
- Aims to communicate the truth by means of accurate essential information;
- Facilitates appropriate referrals, inter-disciplinary assessment, continuity of care, discharge planning, end-of-life care and bereavement support, as well as conflict resolution and stress management;
- Advises on the resources available to address holistic needs and concerns;
- Provides patients with a sense of security, consistency and comfort;
- Educates family members and care providers on how to manage pain, distress and other symptoms in the patient and how to communicate effectively;
- Aims to improve relationships at all levels, including those involving family members, care providers and the community;
- Documents as appropriate the main discussions with the patient, family and other care providers;
- Ensures a good flow of information within and between organisations involved in service delivery;

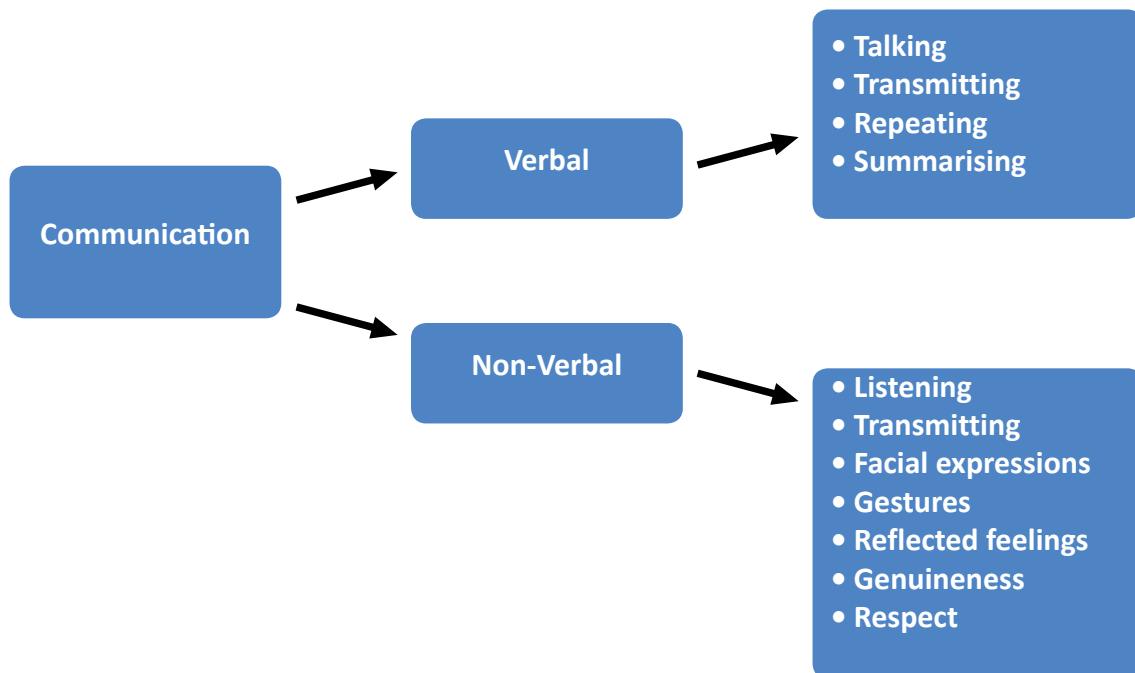
#### Principles of Communication to Help Care Providers Communicate Effectively

- Communicate with sensitivity, empathy, compassion and support to the patient and family.
- Listen attentively and allow tears and emotions to be expressed without rushing the patient.

- Check for understanding, because mis-communication is common as a result of language, culture, the environment and stress.
- Take into account the family and its ethnic, cultural and religious roots.
- Family meetings are useful for identifying and meeting the patient's and the family's informational and care needs, as well as for understanding the family's dynamics.
- Debriefing is available for caregivers who need support following the death of a patient whom they have been caring for.
- Pay attention to the patient, family members and fellow care providers.
- Be aware of the importance of non-verbal communication such as facial expressions.
- Use clear and suitable language (i.e. that which is understood by the patient), and use an interpreter where necessary.
- Ask appropriate questions and allow the patient and family to ask questions each time you see them.
- Ensure that the patient and family have understood what you are saying, and that you have understood what they are saying, by asking questions, paraphrasing, summarising etc.

#### 4.2.4 Types of Communication

- **Communication** (as a generic process) is a two-way process between two or more persons in which ideas, feelings and information are shared, with the ultimate aim of reducing uncertainties and clarifying issues. Communication only becomes complete when there is feedback.
- **Verbal communication** is the exchange of ideas through spoken expression in words. It is a medium for communication that can entail using the spoken word, such as talking face-to-face, on a telephone, or through a formal speech; similar communication can occur through writing.
- **Non-verbal communication** involves the expression of ideas, thoughts or feelings without the spoken or written word. This is generally expressed in the form of body languages that includes gestures and facial expressions and, where appropriate, touches.
- **Both verbal and non-verbal** communication is important in palliative care.



## Key Aspects that Should be Targeted by Communication in Palliative Care

### These Cover:

- All aspects which make an individual complete, i.e. psychological, spiritual, social, cultural and physical aspects;
- Prognosis and goals of care, as these are essential for quality care;
- Disclosure, diagnosis, prognosis, transition to palliative care and the holistic care plan;
- A patient's fears and concerns;
- Disease progression and end-of-life care issues, such as the use of aggressive treatments in the end-of-life stage, decisions on readmission, review of medications, family rituals and the family's role;
- Patient and family styles and practices for coping with grief, loss and bereavement, and the support required from care providers;
- Discussions about the future, as this is vital if patients are to be permitted the dignity of deciding how to spend their remaining time
- The beliefs and values of a child patient and their family regarding death and dying, and assistance to prepare and plan for death by discussing expectations in order to reduce fear and encourage involvement;
- End-of-life issues and the anticipation of the death of a child patient, each being honestly discussed with the child and their family.
- The opportunity to say goodbye and express last feelings and wishes.
- Bereavement counselling and support for children.



## 4.2.5 Communication Skills

### When the Health Care Worker (HWC) is the Sender:

- Recognize that communication starts with the self, identifying your own barriers and baggage.
- Be prepared by having the correct facts and, if possible, a suggested plan of action.
- Demonstrate honesty, consistency, and trustworthiness.
- Speak with confidence and believe your own message.
- Persevere.
- Think before you speak.
- Do not talk down to the patient or relatives.
- Create a comfortable atmosphere conducive to communication.
- Bring barriers into the open.
- Do not share your own feelings of sadness or hopelessness.
- Move at the person's own pace. Do not force a person to listen to more information if he or she is not interested or ready for it.
- Check that the message is received and understood.

### When the HCW is the Receiver:

- Listen well and actively (more on this below).
- Show persons that you enjoy their humour, but avoid making culturally inappropriate jokes.

**Active listening:** this can be defined as hearing with interest and attention, and understanding verbal and non-verbal messages that patients and their families are communicating. The indicators of attention are summarised as "ROLES":

- Relax
- Openness
- Lean forward
- Eye contact
- Sit near (comfortably near).
- 

**Check understanding** through paraphrasing and summarising the patient's story, and identifying and reflecting the person's feelings and emotions from the story.

**Ask questions:** focus on questions that are purposeful to the patient and the care provider. They should aim to:

- Get information
- Assess knowledge
- Direct and focus decisions
- Get a deeper understanding of the person's problem

You are not listening to me when ...	You are listening to me when ...
<ul style="list-style-type: none"> <li>• You do not care about me.</li> <li>• You say you understand before you know me well enough.</li> <li>• You have an answer for my problem before I've finished telling you what my problem is.</li> <li>• You cut me off before I've finished speaking.</li> <li>• You finish my sentence for me.</li> <li>• You feel critical of my vocabulary, grammar, or accent.</li> <li>• You are very eager to tell me about something.</li> <li>• You tell me about your experience, making mine seem unimportant.</li> <li>• You are communicating to someone else in the room.</li> <li>• You refuse my thanks by saying you haven't really done anything.</li> </ul>	<ul style="list-style-type: none"> <li>• You come quietly into my private world and let me be.</li> <li>• You really try to understand me even if I'm not making much sense.</li> <li>• You grasp my point of view even when it's against your own sincere convictions.</li> <li>• You realise that the hour I took from you has left you a bit tired and drained.</li> <li>• You allow me the dignity of making my own decisions, even though you think they might be wrong.</li> <li>• You do not take my problem from me, but allow me to deal with it in my own way.</li> <li>• You hold back your desire to give me good advice.</li> <li>• You do not offer me religious solace when you sense I am not ready for it.</li> <li>• You give me enough room to discover for myself what is really going on.</li> <li>• You accept my gift of gratitude by telling me how good it makes you feel to know you have been helpful.</li> </ul>

*(Source: Hospice Palliative Care Association of South Africa, 2005)*

- Prioritise issues
- Set the pace of the dialogue with the person seeking assistance
  - Show that the care provider is trying to understand the person and the problem better.
- Use mainly open-ended questions, i.e. those that are thought provoking, that invite a person to talk and explain a situation, and that offer the opportunity for a variety of responses. Such questions might be 'What makes you feel bad?', 'How did you feel when you were diagnosed with cancer?' or 'What worries you the most?'
- You can use some closed-ended questions if necessary: these are brief and restricting and are used to obtain facts rather than knowledge of feelings – for instance, 'Does this part of your body hurt?'
- Avoid leading questions: these suggest a preferred answer or desired response – e.g. 'You must be feeling a lot of pain, mustn't you?'

- When answering questions:
  - Understand that behind every question is a story; therefore be honest and give accurate answers
  - Give correct information
  - Provide clear and simple information
  - Check for understanding or misunderstanding
  - Respect and reinforce important information.
- Use positive attitudes:
  - Non-judgmental: treat people as they are, with respect and dignity, and avoid condemning or criticising them.
  - Confidential: the care provider should not reveal any information that they get from their patient unless consent is obtained from the patient. Every patient has a right to confidentiality and should feel secure as they communicate.
  - Empathetic: put yourself 'in the patient's shoes' by understanding and accepting their situation.
  - Caring: this means giving attention or being concerned about someone's well-being. We show care by being approachable, welcoming, showing interest, etc. It entails making the patient feel at home and responding with interest to what they are saying.

3 Use language and media that children understand according to their age – e.g., drawing, pictures, music, dance and drama, or stories.

#### 4.2.6 Communicating with Children

It is important to note that communication with children

- Uses an honest and open approach as the basis of all communication with a child and their family;
- Enables parents to be central to a child's well-being; and, where possible, they, or a designated carer, are present and involved in all aspects of the child's care, guided by the age and wishes of the child;
- Provides information to a child and their family about the signs and symptoms of approaching death in a manner appropriate to their individual needs and circumstances.
- 

#### Process of Communicating with Children;

- a) Introduce self as the person who talks to & helps children
- b) Take some time to get to know the child (play a game, talk a bit)
- c) If child is not verbalizing, divert & introduce child to other materials in the room that can be used for communication

- d) Allow child to explore toys/activities/room at his/her own pace
- e) Ask about the demographic data of child (name, age, No. of siblings, school, favorite food, the parents, best friends)
- f) Don't feel rushed when working with the child. If you are impatient, the child will sense this!
- g) Use of self by adjusting to child's physical level
- h) Utilizing play, drawing & other art mediums
- i) Observe what toys the child is handling
- j) Ask open-ended questions regarding the toys and regarding what you observe the child doing with the toys (What is happening there?)
- k) Actively participate with the child in playing with toys
- l) Notice the theme of the child's play (e.g. themes of nurturing and aggression)

## Summary

- Paediatric healthcare providers already possess skills in communicating with children
- Take time to get to know the child at the beginning of treatment and in an ongoing way
- Don't feel rushed in the process of getting to know and treating the child

### 4.2.7 Breaking Bad News

The following steps to breaking bad news about an illness are helpful:

- Prepare well. Know all the facts before meeting the patient/family.
- Ensure patient is not alone.
- Prepare the environment as well
- Review how much the patient already knows by asking for a summary of events. You can ask, 'Can you bring me up to date me on your illness and how things are now?'
- Check that the patient/family wants more information and how much more. You can say, 'we have more results now. Would you like me to give you an update on what we know? I will go step by step and you can stop me whenever you want.'
- Indicate that the information to be given is serious. You can say, 'I am afraid it looks rather serious,' and then allow a pause for the patient to respond.
- Encourage expression of feelings – this is the key aspect in terms of patient satisfaction with a session.
- Give more information if requested, step by step and in simple language.
- Listen to concerns and ask questions. You can say, 'what are your main concerns at the moment?' or 'What does this mean to you?'

- Wind down the session by summarising issues that are raised and plan with the family the next steps.
- Make yourself available to discuss the illness further, as needed.
- This process can be adapted when breaking news of the death of a loved one.
- [When breaking bad news to a child, try to do it in an age-appropriate manner.](#)
- [Never underestimate what a child knows and can understand.](#)

#### **4.2.8 Consequences of Ineffective Communication in Palliative Care**

- Not communicating accurate essential information to patients may provoke greater problems.
- Protecting patients from the reality of their situation often creates further problems and can lead to inconsistent messages being given by other members of the inter-disciplinary team.
- Hiding the truth often leads to conspiracies of silence that usually build up to a heightened state of fear, anxiety and confusion, rather than provide one of calmness.
- Poor communication is a threat to patient care and can lead both to mistrust and to a source of staff stress.
- Communicating effectively is essential for engaging the patient and their family in their care.
- Not communicating about the nature and seriousness of an illness can lead to a lack of planning for the future – e.g. not writing a will, not planning who will take care of the children

#### **4.2.9 Special Considerations in HIV&AIDS**

- A diagnosis of HIV presents the affected individual with the prospect of a life-threatening illness along with the stigma associated with the disease.
- There are strong emotions associated with HIV&AIDS which increase anxiety and therefore impact on effective communication – e.g. the fear of rejection by others, the fear of infecting others, anger and a sense of betrayal, a sense of shame for having contracted the disease, worry about how to cope, worry about the family.
- Disclosure of their status is an important topic to explore with patients – they may be trying to maintain a position of respect with their children, or be afraid of being abandoned if the family finds out their status.
- Adherence to the specified drug regimen is key to the success of ART, and good provider–patient communication is key to adherence.

- Communication issues that are key to successful adherence include:
  - Proper education and counselling before initiation of ART
  - Information on HIV and its manifestations, benefits and side effects
  - Involvement of peer support in the patient's treatment
  - Psychosocial support to minimise stigma
  - Culturally appropriate adherence programs.
- Support groups across the African region have proved to be successful in providing emotional and peer support, and in helping individuals to cope with HIV&AIDS.
- Disclosure is a particular challenge with children and adolescents, with their carers often not wanting them to know their diagnosis.
- Adherence in children, particularly if they are not aware of their illness, can be a challenge.

## Important note

Most attempts by service providers to protect patients from the reality of their situation create further problems for patients, their relatives, and their friends. Realistic hopes and aspirations can only be generated from honest disclosure. The extent to which patients and families cope with information relating to illness largely depends on how effectively it is delivered and the relationship created between them and the care provider. Considerable suffering is caused by poor communication; much of this is avoidable.

## UNIT 4.3: COUNSELING



**Time: 4 hours**

### **OBJECTIVES:**

By the end of this module participant will be able to:

1. Explain the concept of counseling
2. Discuss counseling skills
3. Describe the counseling process
4. Highlight client counseling issues in regards to HIV&AIDS and cancer
5. Discuss care and support for caregivers.
6. Demonstrate appropriate skills in counseling patients with HIV&AIDS, cancer and their families

## COURSE NOTES

### 4.3.1 Concept of Counseling

#### **Definition**

Counseling is a professional relationship between a client and the counsellor to help the client deal with a difficult situation.

Counseling is a structured conversation between people that assist one participant to work through particular problems or conflicts, explore feelings and find ways to resolve or cope with them. Counsellors encourage people to recognize and develop their coping capacity, so they can deal more effectively with problems.

## Qualities of an effective Counsellor

- **Trustworthiness:** keep confidentiality.
- **Self-Awareness:** Professionals are aware of their own attitudes, values, and beliefs. In addition, they show openness and respect for the values and beliefs of others.
- **Non-Judgmental:** Professional workers should accept that the life choices of the patient may differ from their own and accept their feelings of judgment but do not allow the judgment to affect their care.
- **Professional:** The services providers do not become socially involved with their patients and caregivers' emotion. This is primarily to protect the health care worker to be emotionally affected. Health care workers should treat all patients equitably.
- **Ethical:** Being ethical includes being honest with patients and making decisions in their best interest. Professionalism and ethical behaviour helps patients feel safe and secure.
- **Empathetic:** Empathy is the capacity for understanding the feelings, thoughts, and experiences of another person without having them explicitly communicated.
- **Knowledgeable:** The services providers need to be well informed about cancer or HIV&AIDS in order to be able to communicate their knowledge to patients. However, need to use simple terms they can understand.
- **Culturally Competent:** Culturally competent professionals respect the culture and religion of patients and accept that their patients' practices may differ from their own. Effective health care professionals are careful not to impose their personal values and beliefs on patients.

### 4.3.2 Counseling Skills

- **Active Listening:** Active listening involves carefully noticing and attending to both verbal and non-verbal messages. The counsellor needs to show their client that they are listening through: nodding, sitting with the patient and making eye contact. The counsellor's job is to have the client do most of the talking.
- **Understanding and Empathic Responding:** is a smart responding process, understanding the real emotional state, or point of view of the patient. The counsellor confirms in words the emotional state that is being communicated through means of verbal and non-verbal language and empathic responding involves showing appreciation for another person's, thus encourage them to take active part in the counselling.



- **Maintaining Confidentiality:** The patient needs to feel that information they share will not be shared with others without their consent. It is the counsellor's role to prepare the patient to be able to communicate the diagnosis to the relevant people. The counsellor also can help the family members to cope with the news of the patient's disease.
- **Psychosocial needs assessment:** The psychosocial needs assessment helps the health worker or counsellor provide appropriate counselling. Also at each visit, they should assess the patient's psychosocial needs and share the information with other counsellors in the palliative care team.

### 4.3.3 Counselling Process

There are three stages of the counselling process;

#### 1. Exploration

##### **Building a Therapeutic Relationship**

It is ultimately the genuine relationship between the healthcare worker and the patient that not only creates positive change and growth in the patient's life but also assist the patient to adhere and improve efficiency of other therapies. A therapeutic relationship develops through the following stages:

**Relationship Building:** Building the relationship should happen since the first visit. The health care worker should to greet patients by name, be warm and friendly, and take a few extra minutes to talk informally at the beginning of the visit. This builds trust and rapport in the relationship.

- a) **Identifying Patient Concerns:** Next, the provider can ask about the patient's concerns. Ask questions that make the counselling as a normal talk, listen to the problem described by the patient, ask clarifying questions.
- b) **Exploring Options:** Once patients' needs and concerns have been identified, their options can be explored. Help the patient to identify his or her own possible responses or solutions to the problem.

#### 2. Understanding

Once clients have understood their problems, they have to be helped to determine and consider the different options available solve them.

#### 3. Action

Help the patient to decide on a solution, and summarize their planned next steps with them.

#### 4.3.4 Client counselling in issues in HIV&AIDS and Cancer

- i. Preparing to disclosure illness to family, loved one: the health care worker assist the patient in disclosing their cancer or HIV diagnosis to their loved ones.
- ii. Counselling on treatment interventions: various interventions (ART for HIV&AIDS patients, chemotherapy, radiation or radiotherapy for cancer patients), treatment goals and adherence's important role.
- iii. Positive living counselling
- iv. HIV prevention counselling (especially for sexually active people).
- v. Counselling for caregivers of patient
- vi. Support counselling for family members.
- vii. Preparing client for death and saying goodbye
- viii. Bereavement counselling for the patient and the family

#### 4.3.5 Counselling Skills and Techniques for AIDS and Cancer patients

##### Role play guide

Based on the information below, counsel the patient/client on the appropriate use of the prescribed medicine using the 13 points of the Patient/client medication counselling checklist

Maria is a 35 year old mother of 4 who has just been started on ART with Kaposi sarcoma. She comes to the pharmacy today to pick up her oral analgesics. Maria reports that her pain persists despite the DF118 that she has been taking as prescribed (highest safest dosage and frequency). She works as a house help and commutes daily to work on a matatu. She gets to work at 6am and leaves at 8pm. After processing the following prescription please counsel her on how she should take her medications.

Discuss Maria's management.

##### Key Issues to Observe

- 13 point counselling checklist
- Medication taking times- Young mother with very many children, long working hours, stressed life, nutrition?

- Adherence/Reminders e.g. Alarms-mobile phone, radio news, Mosque times
- Drug boxes e.g. containers
- Treatment Buddies/ husband? - Maria married?
- Discuss major side effects of the drugs, D-D interactions
- Additional protection use i.e. Condoms
- Screening, prophylaxis and treatment of symptoms
- Family counselling/disclosure
- Partner counselling and testing

## Rx

Stop the DF 118

To Start her on Oral Morphine

Laxative -Bisacodyl

Haematinics

Contraception

Stavudine 30mg Bid

Lamivudine 150mg Bid

Efavirenz 600mg OD

## Observation Checklist for Role Play

1. Introduce yourself
2. Identify who is being counselled
3. Check what the patient or his/her representative already knows about the medicines:
  - a. *What did the doctor/nurse tell you the medication was for?*
  - b. *How did the doctor/nurse tell you to take the medicines?*
  - c. *What other information did the doctor/nurse tell you about taking this medication?*
4. Make sure the patient or his/her representative understands how these medications work  
(Not a cure, only suppresses the virus, can still infect others, can still get sick from other illnesses)
5. Ask for patient's questions and concerns
6. Give the name of medicine and describe appearance  
(Show the patient the identifier code on solid dosage forms and show the label, if possible open package and show the tablets. Refer to patient counselling info)

7. Name the route of administration
8. Give directions/instructions  
Explain to the patient or his/her representative the directions they should follow (number of pills/analgesic, amount of fluid, when to take, not to share/miss dose, not take more or less, missed doses to be taken soonest or skip and go to regular dosing schedule, no double dosing. Continue taking even when feeling better, otherwise medicines may not work and are limited. Do not stop taking drugs without doctor's knowledge).
9. Give information on the possible drug interactions (herbs, other medicines)
10. Give information on the side effects of the medicines
11. Give instructions on how the medication should be stored
12. Check the understanding of the patient or his/her representative by asking them to repeat back to you key information. Remind them of information they left out
13. Final check for questions and concerns

## UNIT 4.4: SPIRITUAL AND CULTURAL ASPECTS IN PALLIATIVE CARE



**Time: 2 hours**

### **OBJECTIVES:**

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

1. Describe spirituality
2. Discuss common aspects of spiritual care
3. Discuss task of spiritual care
4. Discuss the fears of death
5. Explain effects of culture in palliative care

## **COURSE NOTES**

### **4.4.1 Spiritual and Cultural Care**

#### **Overview**

The spiritual and cultural aspects of holistic palliative care are very important. All HCWs can reach into the spiritual aspects of themselves to draw on the sensitivity and compassion needed to share with patients and their families what is important to them in facing chronic illness, death, and loss.

#### **What is Spirituality?**

One way of thinking of spirituality is as a sense of relationship to a transcendent dimension or something greater than oneself. Another view is that it is a person's relationship with a supernatural being, whether known as God, Jesus Christ, Mohammed, Buddha, or simply the Supreme Being. Spirituality can be a lifelong relationship with that dimension or being which takes on even more meaning in times of crisis and when approaching old age and death.

For many, existential questions are mainly expressed in a formal religion through belief in a deity, the theology of the religion, the concept of an afterlife, and the rituals and practices of the religion used to express those beliefs. Religions provide a way of incorporating spiritual beliefs into everyday life by offering a structured means for communicating with the Divine. They feature a system of ritual observances and a code of conduct, which regulates an ordered existence.

Many religions are practiced in Kenya, including christianity, islam, traditional African religion, Judaism, Hinduism, Buddhism, the Baha'i faith, and numerous others. Health care workers (HCWs) must be sensitive to the cultural and spiritual differences between themselves and some of their patients, and be respectful of those differences while providing care. It is never appropriate to assume that they understand what a person believes or practices because they 'know' that particular religion. It is best to ask the patient or family member what his or her particular beliefs and practices entail.

Whatever form it takes, spirituality can help patients cope with the uncertainty of their illness, instil hope, bring comfort and support from others, and resolve existential concerns, particularly the fear of death. It is important that HCWs accept and honour all approaches to existential concerns. This requires open-mindedness, cultural sensitivity, and a willingness to learn from the life experiences of others

Certain African spiritual beliefs emphasize a sense of belonging — to the soil, to one another, to oneself, to God, and to ancestors (or 'living-dead') who are believed to be with God and benevolent to their families, clans, communities, and society. Prayer is considered an important ritual which is viewed as a real 'telling it to God'. For the traditional African person, spirituality encompasses all of life. The holistic nature of African culture, which does not distinguish the 'sacred' from the 'secular', results in an intertwined belief system. This sense of integration can be used to illustrate the connectedness of all life — including the sick and the healthy, the living, the 'living-dead', and the yet-to-be-born. These links help the patient maintain a sense of identity, even in the face of sickness and death. They also provide a sense of continuity in the culture and of one's personal heritage that yields feelings of self-worth, community, God, and the connections between the good in this life and the good in the afterlife.

Dying at home is important for some people because of the belief that the body is commended to the ancestors. It also allows family and community members to keep the family company during the mourning period.

It is important to understand the concept of a 'happy death'. This is when the dying person is rather old; has ensured the family lineage through children and even grandchildren; has been adequately cared for by all relatives, friends, and community; has had time to reconcile with family members, the community, and beyond; has been

able to express his or her will to specially trusted friends; has been able to feel that he or she is fully loved and treasured by all who have tried to save his or her life; and has accepted that he or she will be leaving this life to join the ancestors (living-dead).

For those left behind, it is important to preserve and fulfil cultural values and ceremonies for the terminally ill, and provide proper funeral rites for loved ones who will be left behind in the extended family, clan, and community. It is also important to foster a deep and central sense of God, spirituality, community, abundance, and joy.

## Spiritual Care

The basis of spiritual care is compassion and being present to our patients in the midst of their suffering. This allows connection to them as individuals that helps to provide hope and comfort to our patients. We can help our patients heal by providing them with the opportunity to find a sense of resolution and perhaps peacefulness by discussing issues of suffering, spiritual values, and conflict.

At its core, palliative care recognizes that emotional and spiritual healing can occur even when a physical cure or recovery is impossible. Although illness may disrupt a person's life, it can also offer the opportunity to see life in a different way. Many people with serious and terminal illness talk of seeing a richness and fullness in life that they had never seen before. Some people find new priorities and appreciation for aspects of their lives they never noticed before.

The combination of good clinical/technical care and psychosocial/spiritual care provides the best chance for healing at any stage of illness. For the dying, healing or restoration of wholeness may be manifested by a transcendent set of meaningful experiences while very ill, and by a peaceful death. In chronic illness, healing may be experienced as the acceptance of limitations.

The holistic approach to end-of-life spiritual care addresses the innermost feelings, thoughts, values, joys, and fears to achieve peace, harmony, and proper relations with oneself, relatives, the community, the living and the living-dead (ancestors), the entire cosmos, the transcendental or supernatural powers, and God.

For spiritual care to be relevant and effective, it should capture correctly the inner feelings, worries, fears, and thoughts of the sick person and all related to him or her. An African proverb says, 'illness and death are two things which no person can ever become familiar with' Each person's illness is seen as unique, even if it resembles another's illness. Each death is also seen as unique.

## 4.4.2 Common Aspects of Spiritual Care from Major Religions

The three major religions in Kenya are Christianity, African traditional religion (ATR) and Islam. These religions share several principles, which include all loving, all compassionate, All-powerful Creator-God. All three religions are also based on a belief in a monotheistic divinity, a Supreme Being or Creator-God. They attribute the highest and best to God, using names that express God's love, power, wisdom, compassion, forgiveness, giving, guidance, and sustenance. During illness and nearness to death these titles, attributes, and powers of the Creator-God are invoked to offer praise and petitions on behalf of the sick person.

### 1. Just and Merciful Judgment

All three religions believe in a final judgment before God following a person's death, though each considers the judgment to take different forms. In the ATR, the people left behind mainly give judgment. When the community judges the deceased's life to have been good, exemplary, generous, responsible, and supportive of the values of the community and culture, that person is identified as having been a good person who will be included among the good living-dead (ancestors). Christianity holds that the judgment is mainly based on the Ten Commandments and salvation through Jesus Christ. Each person is to be judged at a final Day of Judgment that determines either eternal bliss or damnation. Islam believes that immediately after a person's death, angels come down to hear and record what people say about the dead person, which they present to God within 40 days after the death.

### 2. The Resurrection of the Dead

A central belief of Christianity and Islam but vague in ATR, is that human life does not simply end at death but continues in a spiritual form that at the end of time will be reunited with the physical body for eternal life with God and all the ancestors. Christianity and Islam have been massively embraced in Africa in part because of their teaching on the resurrection of the dead and the everlasting life of joy in heaven. These beliefs are important to the spiritual care of the sick and the dying and in their relatives and communities. The hope and assurance they offer are strong enough to calm down excessive fear, worries, helplessness, and despair. They also help to unite the living with the ancestors and God.

## The Importance of Prayer

It can be said that prayer is the heart and soul of proper spiritual care. But prayer must be appropriate and relevant to the situation of the sick and his or her family and friends. Prayer can be in words, but words that carry deep meaning. If the sick person is to join in the prayer, it should be brief and precise, such as: God loves me; God is with me and



for me; God is my life and healer; God helps me endure this pain; God drive all fears from me; God do not let anything divert me from you; and God in your loving hands, I commend my total self.

### 4.4.3. Tasks of Spiritual Care

The tasks of spiritual care are the same within most religious contexts. HCWs are encouraged to determine the wishes and practices of each patient and community for whom they provide care.

In general, to provide effective spiritual care as part of palliative care, one must do the following:

#### Transcend Religious Denominations

It is possible to provide spiritual care based on shared principles that transcend particular religions or branches of a religion. In general, God is perceived as the supreme healer and doctor. Both modern scientific medical specialists and traditional medicine men and women are seen as agents of the supreme doctor and healer. In taking any medicine, a sick person usually prays to God for its effectiveness. Even when medical providers fail to discover the real cause of the disease, it is believed that God knows the cause and is able to cure or heal any disease. The sick person and family still think and believe that God can and often intervene directly to heal the terminally ill.

**Spiritual care:** To ensure that spiritual healing takes place in a holistic way, the sick person and family can be urged to feel the presence of God and utilize that presence to call upon their inner religious energies and values in these moments of suffering, worry, and fears. At these moments, spiritual caregivers should never abuse their role by presenting to the sick person an image of God of anger, revenge, and justice-without-mercy-and-compassion. This should not be a time to create yet more fears in the sick that can lead to despair, self-hate, self-blame, and self-condemnation.

#### Provide Pastoral Counseling

Although the role of spiritual care provider may be distinct from pastoral counsellor, the same individual can fulfil both roles. Pastoral counselling becomes part of spiritual care when it is based on a person's spiritual, religious, and cultural needs and responds to the deep-rooted questions and anxieties of the sick person and the family.

**Spiritual care:** Spiritual care should be a committed, friendly, and wise accompaniment of the sick from the beginning to the end of their journey. It requires a relationship with the sick and the people connected with him or her. Spiritual care providers should

possess a deep sense of God, of the sacred, of spirituality, and above all of love for the sick in carrying out their holistic service. A genuine ecumenical spirit and inter-faith dialogue and cooperation are much needed in spiritual care. Any adequately trained pastoral agent or hospital, hospice, or caring staff can and should undertake the pastoral counselling and spiritual care of the sick and their families. There should be well-planned coordination of spiritual care in every medical unit, religious bodies, communities, and even families that are looking after the sick. It is important to use great sensitivity in providing spiritual care to sick people of different religions, cultures, and backgrounds.

### **Define the Category of Disease**

Some people believe that there are categories of diseases, which often are reduced to four main ones: African disease, foreign disease, chronic disease, and plague. When sick, the individual and his or her relatives and community begin with this analysis or diagnosis. It is essential first to acceptably categorize the disease. An identified African disease is mainly dealt with using African indigenous medicines and medicine men and women. Modern scientific medicine and medical professionals are consulted to address a foreign disease. Both traditional modes and modern scientific treatment are often used simultaneously to address a chronic disease. A plague that kills many people suddenly, whether it is cholera, smallpox, or measles, is often seen as coming from malevolent forces within or without the community. The traditional indigenous medicines and practitioners mainly deal it with.

**Spiritual care:** At this initial stage, the only spiritual care to provide is in trying to understand the preoccupations of the sick person and the family. When adequately provided, this care can save the life of the sick and help the relatives and community to take the proper action in a holistic way.

### **Identify the Cause and Causer of the Sickness**

The central focus in spirituality on life and its preservation means that when life is threatened there is a wide and serious search for the cause and causer. Two opposing forces, the pro-life and anti-life, are believed to be operating. Such questions as, 'Why me?', 'Why our family?', and 'Why now?' are fundamental. Nothing is believed to simply happen by chance. Although some modern HCWs may consider this questioning to be primitive or due to ignorance and illiteracy, their view cannot end the questioning simply by dismissing it. Moreover, such a view is not sensitive to the cultural perspective of the person being cared for.

**Spiritual care:** Adequate spiritual care will help to properly address the ‘why’ questions of the sick and his or her people with reasonable, positive, and convincing answers that can remove any hatred, unwarranted suspicions, and dangerous divisions in the family and community which may result from this search for the external cause and causer of the illness. The key here is to build on religious and cultural values which emphasize peace of mind and heart, harmony in the community, and values of forgiveness, reconciliation, and courage in facing the illness without the disruptive hunt for the suspected causer of the illness.

## Involve Every Concerned Person

The principle of the centrality of life requires that everything possible should be done to preserve life, even when all signs are that a particular life cannot be saved. This communitarian concern to prevent death and protect life is the reason everyone close to the patient will offer suggestions of what else to try or which medicines to offer. Death is the most feared event for most people, although they see it every day. It must be prevented at all costs. Even when the sick person may seem reconciled to death, everyone around the person will continue struggling to save his or her life—even at the very last moments of that life.

**Spiritual care:** Intensive, empathic, and understanding spiritual care at this point should touch on the innermost feelings and values that point to a better future life with the ancestors. Spiritual care should connect the life on earth with the life after death. Religious and cultural beliefs in this matter are of utmost importance, both to the sick person and his or her relatives and community.

## Foster Peace and Harmony in the Sick Person and Family

Understanding the concept of ‘happy death’, described above, is a key to providing the spiritual care that a person who is sick most wants.

**Spiritual care:** This stage is the essence of spiritual care. It is easier to offer spiritual care to older people than to younger individuals or children. In each case the spiritual care must address the specific situation and people concerned. At this stage it is important to highlight the religious and cultural beliefs and values of the patient and his or her community. This is not an easy task, as it demands an adequate understanding of the proper situational context of all sick persons and their relatives and communities. It is essential at this stage to properly understand peace, harmony, reconciliation, and forgiveness—and to ensure that no dying person leaves behind un-peace, un-harmony, serious divisions, and unforgiving people.

## Address Core Spiritual Challenges

There are central issues that challenge virtually everyone afflicted with life-threatening illness, and the spiritual care provider can help the patient address them and reach a point of peaceful acceptance.

**Spiritual care:** The HCW or spiritual caregiver must take account of the patient's beliefs, values, and practices. One important example is to note that every person who visits the sick is almost culturally bound to volunteer yet another possible medicine and another medicine man or woman or another modern doctor or hospital. Spiritual care should never give despair to the sick and relatives; on the contrary, it should provide hope—not necessarily of a prolonged physical existence, but of continued life even after death. Spiritual care is much needed at such moments to avoid confusion in the mind of the sick person and to prepare him or her for the inevitable event of death

### 4.4.4. Fear of Death

All human beings have a fear of death. Death 'steals' the best property and quality we have in life, which is life itself. It shatters all our dreams, visions, and plans in life. It separates us from our dear ones, whose lives were inseparable from ours. There is also the fear of the unknown and the type of life awaiting us after death. We also worry about how we have conducted ourselves in our earthly lives and what legacy we are leaving behind us.

**Spiritual care:** The care provider can help calm the patient's fear of death, responding to the anxieties of both the dying person and the relatives. It is also useful to draw upon the sick person's religious and cultural values and inner energies, including encouraging their hopes for the life after death.

#### Example

For Christians, Christ's passion and death are the centre of spiritual care. Death is seen as the last and fiercest struggle any human person will one day face. Those facing this struggle need the greatest support from all who care about them. In this struggle there are moments when sick people may feel abandoned by God. They need to hear God's whisper; either from within their own heart or from a spiritual carer that God is fully with them even at this difficult moment, still loves them, and is not going to abandon them. It is important at this moment to emphasise the Christian beliefs in the resurrection, the life hereafter of joy and celebration with the ancestors.

## Care for the Family

Guardians of others are concerned for the care of the family as they confront their own struggle with illness and death. They are worried for those directly under them, but also for their family's future, property left behind, and plans that may be left unfinished or not even started.

The care provider has the role of adequately and holistically addressing this major concern with the patient. A widow who has been the sole supporter of her children can never simply be consoled by the promise of God's care over the orphans. Spiritual care demands more than providing comfort or admonition. It involves the relatives and community in finding real solutions which can help calm down the dying person's worries.

### 4.4.5 The Role of Culture in Palliative Care

#### Definition

Culture refers to learned patterns of behaviours, beliefs, and values shared by individuals in a particular social group. It provides people with both their identity and a framework for understanding experience. In its broadest sense, a culture is a group of people with similar ethnic background, language, religion, family values, and life views. Spirituality is a predominant aspect of African cultures. The entire universe is seen as a living system with an interconnection through a living spirit, of the individual, the family and community, the environment, and the world beyond the grave. For the most part, the multicultural and pluralistic societies of Africa, made up of members of different ethnic, racial, religious, and social groups, live side by side and maintain their own values and traditions.

When interacting with people from a different culture, unfamiliarity may create an attitude of superiority and viewing persons from another culture as being ignorant or inferior. It is important to approach people from another culture or ethnic group with respect and humility and a desire to understand their culture and perspective. This is particularly important in the health care setting and especially in palliative care where patients and their families are anxious and fearful. These emotions also act as barriers to communication and the caring HCW is sensitive to these issues.

### 4.4.5.1 African Cultural Traditions

#### The Concept of 'Home'

In African tradition, home does not merely mean the physical structure in which a person lives but also the biological, sociological, and spiritual roots of the individual. After birth the child is kept with the mother in seclusion until the umbilical cord falls off. The cord is buried in the ancestral home and symbolizes the link between the individual, the community, and the ancestral land. People should be buried in their places of birth, as the grave is the home from which the bones of the deceased are believed to speak. The grave is the home but the spirit is everywhere. Those buried away from their homes are believed to have been deserted by their clan and this can bring problems to the clan.

#### The Role of the Ancestors

Every member of a family is considered sacred and will after death become one of the ancestors. The ancestral spirits have a responsibility of protecting and disciplining their descendants. They show their displeasure to their descendants by creating illness or misfortune. They also look after the family, give people guidance, bring them luck, and look after the crops. Death is not seen as the end of life but as physical separation with the deceased joining the ancestral world.

#### Understanding of Illness

Western cultures identify the cause of illness as a physiological insult due to degeneration, infection, or other specific physical causative agent. Certain Kenyan cultures define health not only as the absence of disease but also as the balance between the individual, the community, the environment, and the spiritual world. Illness is caused by imbalance of these systems. The elders can identify the cause of the imbalance and will advise as to the most appropriate intervention to restore the balance, which may include western medicine, herbal treatments, or sacrifice to the ancestors

### 4.4.5.2 Addressing Cultural Differences in Communication

#### Discussing Illness, Prognosis, and Death

For HCWs to share bad news with patients of certain ethnic groups can cause harm if not done in a way that recognizes cultural values. In fact, even raising the possibility of a bad outcome can be seen as wishing that outcome on the person. This makes the

important task of pre-bereavement counselling difficult because talking of a patient's impending death may be seen as causing the death. The sensitivity and words used in the palliative care setting are important. If it is recognized that the 'day of departure' is near, African tradition teaches patients to accept the situation, examine what they are going to leave behind, and consider the world they will be entering. Instead of referring directly to death and dying alternative expressions are used.

## **Translating between Languages**

Translation between HCW and patient can be a source of communication breakdown. Patients who do not understand the HCW's language often rely on relatives and family members to act as translators. Families sometimes want to shield their loved ones from serious diagnoses not because they are in denial but because they wish to protect their loved ones from the emotional impact of 'bad news'.

## **Family Spokespersons**

Some patients and families expect HCWs to discuss health concerns with the family spokesperson, usually a son, a daughter or an older member of the family and not directly with the patient.

## **End-of-Life Preferences**

In some Kenyan cultures, patients are not likely to communicate treatment preferences, complete advance directives, and withhold/withdraw life-prolonging treatments in the face of futility. In fact, patients are likely to ask for a temporary discharge so that they can consult traditional healers or ask to be allowed to go to their villages to die so that they can be buried next to the graves of their parents and other family elders.

## **Sexual Diversity**

Miscommunication is not only limited to differences in ethnicity. Even in Kenya, where HIV is primarily transmitted through sexual contact between men and women, HCWs may be caring for men who have sex with men. HCWs are often uncomfortable with sexuality in general, and when they must deal with sexual diversity, their discomfort and sense of judgment may make it difficult for their patients to talk openly about real issues surrounding their illness and how it affects their lives.

## Non-verbal Communication

Misunderstandings in communication sometimes arise through the cultural differences in non-verbal cues. Western-trained HCWs may have adopted Western customs and may have become less sensitive to traditional Kenyan customs.

It is important to respect the patient's wishes for a same-sex care provider if she or he feels strongly about it. Although Islam does not prohibit examinations or treatment by the opposite sex, we recommend that same-sex care providers make any procedures involving physical contact.



## UNIT 4.5: LOSS, GRIEF AND BEREAVEMENT



**Time: 2 hours**

### **OBJECTIVES:**

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

1. Describe the meaning of loss in relation to palliative care
2. Explain grief in relation to palliative care
3. List types of grief
4. Discuss bereavement in relation to palliative care
5. Outline the grief process
6. Outline grief process in children
7. Discuss phases of addressing grief and bereavement

## COURSE NOTES

### 4.5.1 Meaning of Loss and Grief in Relation to Palliative Care

#### Definitions

##### **Loss**

It is not only the loss of life but also loss of friends, dignity, self-esteem, strength social life, job etc.

##### **Grief**

Grief is the normal, dynamic process that occurs in response to any type of loss. It encompasses physical, emotional, cognitive, spiritual, and social responses to the loss. It is highly individualized, depending on the person's perception of the loss, and influenced by its context and concurrent stressors.

**The Grief Process**

The grief process occurs in phases ranging from shock, denial, and anger bargaining depression, and acceptance and healing.

**Mourning**

Mourning is often used interchangeably with grief, but mourning more specifically refers to the public expression of grief. This public expression (perhaps crying or wailing) does not necessarily relate to the significance of the loss; it is usually related to cultural and religious values and encourages social support for the mourner. While we grieve internally we mourn externally

Complicated mourning arises from an interrupted or obstructed grief process, and can result in potentially harmful outcomes, from somatic discomfort to chronic emotional distress, and even the possibility of death. Many of the risk factors that can lead to complicated mourning apply to AIDS-related deaths.

**Anticipatory Grief**

Grief begins as soon as a loved one develops symptoms perceived as life threatening, rather than beginning only at the person's death. This has been called anticipatory grief. Although both the person with AIDS and his or her carers experience anticipatory grief, it does not replace the necessity of grieving after the death. Studies of anticipatory grief have been inconsistent in determining whether grieving before the death shortens the bereavement process afterward or eases the pain of grief.

Anticipatory grief includes changing assumptions; adapting to role changes; balancing the need to stay separate from, yet involved with, the patient; and experiencing feelings of sadness, depression, and anxiety. Anxieties at this time typically revolve around the future care of children, especially if the person with AIDS is a single parent. The practical issues of life take precedence — how to feed the family, get the person to the toilet, and prevent the neighbours from finding out about the illness.

If the illness is prolonged, the period of anticipatory grief may become problematic. Those caring for the person with AIDS may emotionally withdraw too soon and experience ambivalence about the length of the illness and care giving responsibilities. This can lead to feelings of guilt during the illness and bereavement. Another complicating factor is that because the caregivers often are also HIV-positive, they may be confronting their own health challenges and mortality in addition to the threat or the prospect of losing a loved one.

## Effects of Stigma on Anticipatory Grief

People can only complete their unfinished business — whether practical, emotional, or spiritual — if they are aware of the life-threatening nature of their own or their loved one's illness. But in some cultures it is taboo to talk about death and dying, and this belief must be respected. Whilst some people in urban areas may need the opportunity to return to their rural family home to die, others may believe that talking about death will hasten its arrival.

## Facilitating the Anticipatory Grief Process

The palliative care team should be aware of the process and common themes that emerge during anticipatory grief because their outcomes may have an effect on caregiving and the emotional status of the person with AIDS. Team members can assist individuals in handling their anticipatory grief in ways that enable them to take care of themselves and their loved one, including:

- Helping to address practical issues, such as food, accommodation, and care for their children
- Identifying and legitimizing feelings of sadness, anger, guilt, and anxiety
- Encouraging expression of feelings in privacy
- Enabling them to complete unfinished business
- Encouraging them to live fully and enjoy life whenever and wherever they can

## Life Review and Memory Work

As people face their death, they want to know they will be remembered and that their life has had meaning. Engaging patients and caregivers in life review and memory work are effective interventions in coping with anticipatory grief. This can include using religious rituals, meditation, photography and/or videos, and journeys (one last trip to a favourite place) as therapeutic tools. Tradition in Uganda and elsewhere requires that the close family gather around the bedside of the dying person. Instructions are given for burial and the rituals to be followed. Any important 'last words' will be said.

In some communities health workers assist parents to create memory boxes that contain important legal documents and significant items about their lives and family history for their children to have after the parent's death. Documents include children's birth certificates, family photographs, drawings, simple wills, family trees, and other items for children to open up and appreciate later. The box can be of cardboard, wood, or metal, according to availability, and can be decorated on the outside.

## **Nature of the Relationship between the bereaved and the deceased**

Generally the greater the bond between the deceased and the bereaved, the greater the grief experienced. The type of bond (parent, child, partner, and sibling) does not necessarily indicate the intensity of grief; every relationship is unique. However, the death of a child is usually considered a high risk for the bereaved parent(s). An ambivalent or co-dependent relationship with the deceased can also complicate the grief process, as the bereaved may face intensified emotional responses.

## **Cultural Influences in Mourning**

The palliative care team should be familiar with the different cultures and belief systems within the areas they serve. In sub-Saharan Africa these professionals and lay workers will often be members of the same communities, so will have this understanding. Overall it is important for community health workers to be culturally sensitive and respectfully acknowledge the client's expertise and knowledge of his/her own body, circumstances, and culture. By asking clients to enlighten them, health workers can help empower clients and give them a sense of control in a situation where they face increasing loss of control.

The funeral is an important event. The tradition in many cultures is that everyone's hair is cut, but this practice is now changing. Many families pay into traditional burial societies and will receive a pay-out for funeral costs. Others are prepared to run into huge, even crippling, debt to be satisfied that the person who has died and the ancestors will be pleased. The palliative care team must be mindful of traditional rights of succession in assisting the dying person. For example, in some societies when a mother has died and young adult children are living in the dwelling, a family member on the mother's side may arrive and claim the home as his property. This may or may not be a problem, depending on the individual circumstances.

## **Personality Traits and Coping Style**

The personality traits and coping style of the bereaved will also impact on the bereavement period. There is no 'right' or 'wrong' way to grieve (as long as it is not harmful to the bereaved or another); the key is to find what works for that particular person. Some people will never shed a tear publicly, while others will cry every day for months. Talking about the loss and expressing feelings related to the death can be very healthy for some people, yet threatening for others. For example, someone who deals with grief by accomplishing tasks may not find it helpful to be part of a bereavement support group that encourages expressions of feelings.

**Bereavement** is the state of having suffered a loss and incorporates the period of adjustment in which the bereaved learns to live with the loss.

### **Bereavement Overload**

The excessive number of AIDS-related deaths in some communities can cause what is often called ‘bereavement overload’, which can lead to unhealthy physical, emotional, and spiritual responses. Besides the deaths of many loved ones and friends, the bereaved may also experience other losses, including loss of their community, meaning and purpose, privacy, or their role in society. Coping with bereavement overload and multiple losses increases the risk of a complicated grief process.

## **4.5.2 Grieving in Children**

Children whom a single-parent mother was caring for and whose relatives are not available, unable, or unwilling to help them may become a child-headed household, with or without accommodation. These children need support and assistance from state and welfare organizations. Many areas in sub-Saharan Africa do not receive enough practical assistance from non-government and faith-based organizations. In the past, the extended family would have done their best to care for orphans within the family. But with the high level of unemployment and poverty, fear of HIV&AIDS, and fewer adults alive to care for children, many extended families have reached their limit.

## **4.5.3 Ways of Addressing Grief and Bereavement**

### **Stages, Phases, and Tasks**

#### **The 4 tasks of Mourning from Worden (1991)**

William Worden created a theory called “Tasks of Grief” which are the experiences that we go through after the death of someone we care about.

1. To accept the reality of the Loss:
2. To experience the pain of Grief:
3. To adjust to the new environment where the deceased person is missing:
4. To reinvest energy in life, loosen ties to the deceased and forge a new type of relationship with them based on memory, spirit and love:

Recent models of bereavement describe grief as a dynamic process in which certain themes can be distinguished and personal growth and transformation can emerge as possible outcomes. Accommodation is perhaps a more appropriate goal of the grieving process rather than the traditional focus on resolution, recovery, or completion. Accommodation implies an active process of adapting to fit specific circumstances, rather than a linear process with a final endpoint.

Traditional bereavement models usually describe grief that results from a single loss, but the experience of bereavement overload because of multiple losses from AIDS challenges these frameworks.

We use William Worden's 'tasks of mourning' below to illustrate the grief process. Worden intentionally uses the phrase 'tasks of mourning' to emphasize that dealing with grief takes effort; hence 'grief work'. Worden acknowledges that the tasks do not have to follow a specific order and that people can work on more than one task at a time.

### **Task 1: Accept the Reality of the Loss**

The first task of mourning is to acknowledge and accept the reality that the person is dead and will not return.

This can take time, as the bereaved often experience a period of numbness, shock, and disbelief even if the death was expected. The bereaved may experience a period of searching or yearning for their loved one. Some people report that they expect to see their loved one when they arrive at home, calling out before remembering that the person is gone. Others find themselves continuing their old routine, such as setting the table for two. The bereaved may even refer to the deceased loved one in the present tense or use the present and past tense together in the same conversation.

Traditional rituals such as funerals or memorial services can help people accomplish this task. This public good-bye helps people confront the finality of the death. Often the first visit to the cemetery reinforces the finality of the loss as well. The primary aim of grief support at this task is to help people accept the reality of the loss in their own time and at their own pace. It may take days or weeks for the reality to be accepted, even longer for it to be fully absorbed.

### **Task 2: Experience the Pain of Grief**

The second task of mourning is to express the pain of grief in a healthy way. The pain of grief includes physical, emotional, behavioural, cognitive, spiritual, and social responses to the loss. This task is crucial because if the bereaved cannot, or does not, acknowledge the pain of grief in some way, these responses could manifest themselves in unhealthy ways. Coping with the pain of grief is unique for each individual. Sleep disturbances and appetite changes are the most common behavioural responses.

The cognitive responses to loss may be the primary way some people experience grief. Initially many bereaved report a fear of 'going crazy', education and normalization of the grief process may help assuage this fear.

Spiritual responses to loss are also highly individual. Even those who have a strong

spiritual or religious belief system may not be comforted by their beliefs. One of the crucial aspects of the spiritual response to loss is the ability to make meaning from the experience.

The social response to loss is often overlooked. But in AIDS-related deaths, people may be coping with social isolation due to stigmatization.

### **Task 3: Adjust to the Loss**

The third task of mourning is to develop the skills and fill the roles needed to move forward without the physical presence of the deceased.

This can usually begin only after several months of dealing with the loss. It may include adjusting to living alone, being a single parent, getting a job, learning to manage finances, or taking on household tasks. For those dealing with HIV themselves, it can also mean needing to find other caregivers.

Part of adjusting to the loss is facing all the significant 'firsts' that occur in the first year of bereavement.

### **Task 4: Reinvesting Energy From the Deceased into New Life**

The fourth and final task of mourning entails transferring the emotional energy invested in the relationship with the deceased into new, healthy approaches to life.

Reinvesting the emotional energy into new life may include gestures such as considering the deceased's perspective in a difficult situation or wearing a locket with a picture of the deceased. Others may reinvest this energy outward in socio-political activity such as becoming active in an AIDS organisation or creating a memorial for the deceased. In general the signs that bereaved people are learning to accommodate their grief include:

- A return to good health (or their health status before the death of their loved one)
- Acknowledgment of the reality of the loss
- Redefined identity
- Emergence of new skills or roles
- Establishment of or reconnection with a social support system
- Ability to cope effectively with temporary upsurges of grief
- Comfort with the quest to find meaning
- Personal growth/transformation

It is important to understand that those who grieve the death of a loved one never truly 'get over' the loss. Even after people accomplish the tasks of mourning, the pain of the loss is still present though hopefully less intense and more manageable.

#### 4.5.4 Supporting the Bereaved

Members of the palliative care team can reach out and support the bereaved in a variety of ways. Reaching out to the bereaved: Acknowledge the loss, share memories of the deceased, give permission to grieve, and do not take sides in family disputes.

Assessing the bereaved person/family's physical/situational needs:

- Acknowledge and assist when possible with practical difficulties, such as assisting with developing income generation skills or registering children's births if they are unregistered.
- Networking with other resources and organisations:
- Visiting the bereaved/family:
- Providing details about the deceased's illness and treatment, as appropriate:
- Taking cues from the bereaved about their wishes to remain in contact (or not)
- Educating the bereaved about 'normal' responses to grief:
- Encouraging good self-care:
- Encouraging the use of ritual:
- Helping the bereaved recognize opportunities for personal growth:
- Keeping the professional's grief separate from the bereaved client's:



## UNIT 4.6: SUPPORT FOR CARE GIVERS



**Time: 1 hour**

### **OBJECTIVES:**

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

1. List who the care givers are in palliative care
2. Discuss the issues that might affect the care givers in palliative care
3. Discuss the needs of the care givers in palliative care
4. Describe the support interventions for care givers in palliative care

## COURSE NOTES

### 4.6.1 Overview of the Scope of Caregivers

#### Definitions

Caregivers are people who provide ongoing assistance or support to patients. Caregivers may be healthcare providers, friends, family members or neighbours or a combination. They are valuable resources in palliative care. In practice, care givers needs have often been neglected by health and social service agencies and their role in caring has generally been taken for granted. As a result, caregivers are often very stressed, under-trained, and physically and mentally tired.

### 4.6.2 Issues Affecting Caregivers

#### Psychosocial Characteristics of Patients and Caregivers

- People with HIV&AIDS, cancer and other life-limiting illnesses often suffer from emotional distress and social problems related to their disease because they know that their life is shortened and in poorer quality.

Some of the patients may be elderly with age related special needs. Therefore, the patient is usually emotionally depressed and has related social problems. These common problems can include fear of illness and treatment interventions, reduced desire to live, fear of death, guilt, fear of being punished, reduced self-esteem, fear of isolation and loneliness, anxiety about the future and the future of their family, fear of loss in income and poverty, loss of opportunities for children, and loss of social status.

- Caregivers or family members and other loved ones often face many difficulties in providing care for cancer and AIDS patients. This can be related to sadness of losing their loved one, lack of training and skills in providing care, worry related to financial concerns and the future welfare of the family, social isolation and loss of social status. Especially for those caring for a child with a Life threatening illness, it can be very difficult for caregivers to cope; they will require significant support.

**Role of psychosocial support:** Psychosocial care is to respond to the emotional and psychosocial needs not only of the patient but also of the patient's family. It also provides support beyond death of the patient through the bereavement process of the family.

**Role of the palliative caregiver:** The role of the palliative caregiver is to assist patients and families in developing healthy coping mechanisms provide emotional support and improve self-confidence and self-reliance, help to improve relationships between patient, family, friends and peers; and referral to essential social and economic support services.

### 4.6.3 Needs of the Caregivers

#### Psychosocial

Use the following questions are useful in assessing the psychosocial needs of caregivers:

- Because of the time you spend with the patient you do not have enough time for yourself?
- Stressed between caring for the patient and trying to meet other responsibilities (work/family)?
- Stressed between caring for the patient and trying to meet other responsibilities (work/family)?
- Angry when you are around the patient?
- The patient affects your relationship with family members or friends in a negative
- That your health has suffered because of your involvement with the patient?

- That you do not have as much privacy as you would like because of the patient?
- That your social life has suffered because you are caring for the patient?
- That you have lost control of your life since the patient's illness?
- Do you need more information about caring for patients?
- Do you think the patient needs more than you can provide?
- What can help you do a better job in caring for the patient?

## Work Overload

The strains on those caring for people with HIV&AIDS or cancer are enormous. Much of the care provided is by lay caregivers within families and communities. The quality of care they provide and the ability to do so over a sustained period depend on the protection of their own well-being and morale. Some of the caregivers in the Kenyan community are old people who are taking care of grandchildren orphaned by AIDS. Care for the caregivers is rarely given the priority it deserves, and "burnout" is a serious problem.

## Burnout

If the caregiver identifies with any of the following symptoms, it may be necessary for respite time away from the care-giving role:

- Irritability, anger
- Emotional numbing - lack of pleasure
- Withdrawal from others - avoidance of patients and problems
- Irrationality, mood swings or depression
- Poor sleep, fatigue
- Poor concentration
- Resorting to alcohol or drugs

### 4.6.4 Supportive Interventions

At palliative care facilities (Hospital, Hospice and Home-based Care Teams), caregivers should be provided with:

- Training on caring skills
- A safe environment
- Chances for regular group discussion to discuss staff stress issues
- Advice for managing workload
- Measures to prevent work overload

## Prevention of Burnout

- Be confident in their skills and resources to care for the patient and family;
- Define for themselves what is meaningful and valued in care-giving
- Discuss problems with someone else;
- Be aware of what causes stress and avoid too much exposure to the stressful stimulus;
- Use strategies that focus on solution to problems rather than emotions;
- Change approach to care giving, such as divide tasks into manageable parts (small acts of care), learn to adjust to the pace of care giving - relinquish the need to control outcomes. Act as a facilitator for care rather than taking responsibility for everything;
- Share problems, experience and joy with colleagues;
- Practice self-care by making time regularly for relaxing and enjoyable activities and getting appropriate rest and nutrition.
- Arrange a bed in the hospital or hospice (if any) for fixed schedule respite.

## For Family

- To train family members take care of the patient;
- To prevent infection (including HIV and OIs);
- To have confidence in their skills to care for the patient and family;
- To define for themselves what is meaningful and valued in care-giving;
- To recognize that anger from the patient toward the caregiver is not directed at them personally but may be part of coping strategy;
- To develop a system of sharing the workload between caregivers or family members in order to provide the main caregiver with breaks

## UNIT 4.7: HUMAN SEXUALITY IN THE CONTEXT OF PALLIATIVE CARE



**Time: 1 hour**

### **OBJECTIVES:**

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

1. Discuss sex, sexuality and sexual health.
2. Explore self awareness on sexuality
3. Discuss client concerns in relation to sexual functioning

## **COURSE NOTES**

### **4.7.1 Overview on Sex and Sexuality**

In Kenya the culture strongly influences sexuality perspectives. To provide holistic care to HIV&AIDS and cancer patients, we need to understand that sexuality influences and is influenced by the biological, psychological, sociological, and spiritual aspects of being. Our patients do not leave their sexuality behind when they seek our services. But sexuality, which is central to their quality of life, remains unattended to by health professionals, intervening professionals, and family carers. Many health care workers (HCWs) do not consider the patient's sexual health until the patient brings it up. This is perhaps due to the fact that sexuality is a private issue in most cultures, and even more so in Kenyan cultures.

### **4.7.2 Essentials of Sexual Counselling**

#### **Definitions**

The words sex and sexuality are used—interchangeably and often incorrectly—to define the different aspects of sexual being.

The word sex is commonly used to identify biological male or female status. Sex is also defined as the physical activity in which people touch each other's sexual organs, and which may include sexual intercourse. Human beings express themselves sexually from birth to death.

**Sexuality** pertains to all those things that relate specifically to being a woman or a man. It is subject to life dynamic change as a function of total personality. It includes body image, self-esteem and how we would like others to see us. It involves more than sexual desires, activity and orientation. It encompasses touching, intimacy, and the physical closeness of others, and can be an expression of warmth and caring, relationships and gender roles.

**Sexual orientation** refers to whether a person is attracted to a person of the opposite sex (heterosexuality) or the same sex (homosexuality) or both (bisexuality), and whether a person feels that his or her gender role (male or female behaviour) is consistent with his or her biological sex (male or female).

### 4.7.3 Preparing Health Professionals to Address Patient Sexual Needs

HCWs need to allow their patients the opportunity to express the physical and emotional pain of their sexuality. A debate on sexuality in HIV&AIDS needs to be raised in open forum, through appropriate media. At the same time, good role models among men should be identified and invited to assist in raising awareness among other men. There is need to create openness around sexuality in life-threatening illness. Suggested steps for HCWs to address the discomfort of sexuality include discussing the issue with colleagues, sharing experiences of working with patients having such discomfort, identifying those colleagues who feel comfortable discussing sexuality, acknowledging cultural aspects in the work setting, agreeing on ways to facilitate communication with a patient or partner regarding issues of sexuality, and arranging a date to review and reflect on any new approach to sexuality.

NB. Consideration should be given to the gender while dealing with the human sexuality in regards to palliative care.

### Self-awareness

HCWs need to be able to deal with issues of sexuality before they can help their patients. The process of developing awareness of our own feelings about sexual organs, relationships, and roles contributes to understanding and self-comfort. Those who are comfortable with their own sexuality will be more comfortable with another's.

This concept is new to the Kenyan context, although the traditional puberty rituals bringing a woman or man to adulthood include educating them about sexual roles and traditions with the belief that the woman must give pleasure to the man and that the man has no reciprocal obligation. These rituals separate girls from boys, so they learn not to discuss sexuality with one another. Sexual development and needs are rarely

discussed in the family. HCWs need to reflect on these things, learn to assist others from their own experiences of cultural practices, and be able to evaluate the sexual practices that can bring problems during illness.

Health providers need to provide information about potential sexual problems to their patients more frequently. In one study, only 30% of patients were given any information about potential sexual problems—though 40% indicated they would have liked such information. It is important to acknowledge the sensitivity of the topic and its importance in planning future care. It is important for HCWs to inform patients that sexuality is an important and recognized part of their care, and that it is appropriate to talk about or ask about any concerns they may have. Simply asking and listening can be reassuring.

The partner and family are important in facilitating psychosexual adjustment and reducing feelings of isolation and abandonment. Without communication and understanding, even the strongest of relationships can be destroyed. This is true even in other African societies, where families fall apart due to lack of communication, openness and understanding. In a study of women's experiences, one woman was quoted as saying, 'I think sexual adaptation depends a lot on the support women get from their husbands. If they can reassure you that whatever happens they'll still love you just as much, or you're just as important, you're just as complete a person as you were before'.

## **Gender, Sexuality, and in HIV&AIDS, Cancer and Other Life Threatening Illnesses**

Gender is the socially constructed roles and responsibilities assigned to women and men in a given culture or location and societal structures that support them. It defines the division of roles by sex, determined by any given society and dictated by cultural, religious or other values that have little to do with the anatomy or genetic make-up of a person.

The words sex and sexuality are used—interchangeably and often incorrectly—to define the different aspects of sexual being.

The word sex is commonly used to identify biological male or female status. Sex is also defined as the physical activity in which people touch each other's sexual organs, and which may include sexual intercourse. Human beings express themselves sexually from birth to death.

Sexuality pertains to all those things that relate specifically to being a woman or a man. It is subject to life dynamic change as a function of total personality. It includes body image, self-esteem and how we would like others to see us.

It involves more than sexual desires, activity and orientation. It encompasses touching, intimacy, and the physical closeness of others, and can be an expression of warmth and caring, relationships and gender roles. Sexual orientation refers to whether a person is attracted to a person of the opposite sex (heterosexuality) or the same sex (homosexuality) or both (bisexuality), and whether a person feels that his or her gender role (male or female behaviour) is consistent with his or her biological sex (male or female).

### **Women's Vulnerability**

- A culture of silence surrounds sex dictating that 'good' women are expected to be ignorant about sex and passive in sexual interactions. Thus women may be uninformed about risk reduction or disempowered with regard to negotiating safer sex.
- Traditional norms of virginity for unmarried girls increase young women's risk of infection by restricting their ability to ask for information about sex out of fear that they will be thought to be sexually active.
- Virginity also puts young girls at risk of rape and sexual coercion in high-prevalence countries because of the erroneous belief that sex with a virgin can cleanse a man of infection and because of the erotic imagery that surrounds the innocence and passivity associated with virginity.
- Economic dependency increases women's vulnerability to sexually transmitted infections including HIV. Women are more likely to exchange sex for money or favours and less likely to negotiate safe sex or leave an abusive or risky relationship.
- Violence against women contributes both directly and indirectly to women's vulnerability to HIV.

### **Men's Vulnerability**

- Men are expected to be more knowledgeable and experienced about sex. This prevents men from seeking information or admitting their lack of knowledge about sex or protection, and results in their experimenting with sex in unsafe ways, and at a young age, to prove their manhood.
- Believing that variety in sexual partners is essential to men's nature reduces the effectiveness of prevention messages that call for fidelity in partnerships or a reduction in the number of sexual partners.
- Cultural norms that emphasize men's sexual domination over women implicitly accept violence against women and encourage homophobia. The stigma associated with homosexuality results in secrecy and denial of risk of infection.
- The expectation that men are or should be invulnerable contrasts with the expectation that men should protect themselves from potential infection and encourages the denial of risk.



## 4.7.4 Coping Mechanisms

### Communication Strategies

Research suggests that many HCWs receive inadequate training, so they are embarrassed to discuss sexual issues and feel the issues are irrelevant to illness. Nurses, however, are ideally suited to carry out the role as assessor, educator, confidante, and sometimes counsellor.

Times of crisis, such as new diagnosis, recurrence, or treatment setbacks, may not be the most appropriate time to discuss sexual issues. The literature does not suggest the best time for such discussion, though there is agreement that discussion should be a routine part of care at diagnosis, treatment, and follow up. The assessment is important to meeting the patient's needs. One useful strategy is to move gently from less sensitive topics to issues that are more sensitive.

Sex is about communication. But communication is often lacking in sexual matters in African marriages and couples. While one partner may see the lack of sex as a positive aspect of the relationship, the other may not agree unless they talk to each other. Improved communication is a prerequisite for both partners to cope with the challenges ahead. The caregiver needs to identify the sexual concerns of the patient and refer to the appropriate professional

### Interventions

- Helping individuals feel accepted as sexually worthy, loved and wanted
- Helping individuals increase their sexual self-esteem by maintaining their appearance
- Clarify misinformation and providing information and maintaining patients confidentiality
- Ensuring people with advanced HIV&AIDS are not denied having their sexual needs met

## UNIT 4.8: COMPLEMENTARY THERAPIES IN PALLIATIVE CARE



**Time: 1 hour**

### **OBJECTIVES:**

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

1. Define complementary medicine
2. Discuss different types of complementary medicine
3. Discuss the role of complementary medicine in Palliative care

## **COURSE NOTES**

### **4.8.1 Definition of Complementary Care**

#### **Overview**

Complementary care is care that is given alongside western medical treatment and is used to enhance well being and improve the effect of medical treatment. Many types of complementary care are available. In the African setting, where most families affected by HIV would not have funding to pay for complementary therapy, some complementary therapies can be taught to family members and community caregivers. As it is impossible to list all available complementary therapies, this chapter describes some of those that are being used in the Kenyan settings that may be effective in the palliative care of people with HIV&AIDS.

Complementary therapies are used to control symptoms and enhance quality of life. They are promoted neither as cures for disease nor to be used in lieu of mainstream therapy. Rather, complementary therapies are applied in an adjunctive fashion to reduce pain and other symptoms. They are non-invasive, comforting, effective, and inexpensive'.

Complementary therapies, when used competently and with sensitivity, can enhance the quality of the patient's life and help the family. Family members can be taught complementary techniques such as massage and play therapy, which strengthens interpersonal bonds and helps the family members feel that they are doing something to help their loved one.

## **Complementary Care, Western Medicine, and Traditional Medicine**

It is important to differentiate between complementary therapies and traditional medicine and to specify how they each relate to Western medicine.

### **Complementary Care**

Within the field of western medicine, the general term complementary medicine refers to therapies that are used alongside western medical care to enhance the well being of the patient. The term alternative medicine refers to a number of ancient systems of healing based on concepts of human physiology that differ from those understood by modern science. The term alternative medicine is also used for any therapy that the patient chooses to use instead of, rather than along with, western medicine.

### **Traditional Medicine**

In the African context, and in this manual, traditional medicine refers to the ancient systems of healing practiced within African cultures by indigenous practitioners who have been trained in these systems. Traditional healers and other traditional practitioners are professionals who have been trained in the traditions and who practice within the community alongside western-trained medical providers. Patients and families may seek the services of traditional healers in addition to or instead of western medical practitioners.

### **Western Medicine**

The term is used in this manual to describe the system of healing that has developed within Western culture that is based on concepts of modern science. It includes medicine as practiced by trained and licensed physicians, nurses, and other allied health professionals.

### **Difference Between Complementary Care and Traditional Medicine**

Complementary care usually refers to therapies adopted by Western medical practitioners to enhance and support the well being of the patient, especially in palliative care. Many of the techniques have been borrowed from ancient systems of healing within other cultures, such as Reiki, a Japanese tradition. However, they have usually been imported into other cultures and are practiced separate from their original cultures.

Traditional medicine, on the other hand, refers to healing practices that are indigenous to the cultures in which they are being practiced. The theoretical systems on which they are based are therefore inherent in the culture and beliefs of the people seeking treatment.

## Advice to Caregivers

When using complementary therapies it is important to make certain they are culturally and spiritually acceptable to the person with HIV& AIDS, cancer and other life threatening illnesses and the family. Also, it is important that the person's medical provider knows about the complementary therapies being used if there is any chance they may interact with medical therapies. Some herbal or homeopathic remedies may affect medications being prescribed.

Children infected or affected by HIV&AIDS often lack stimulation at home because their parents are ill. A combination of complementary therapies that stimulate the senses, such as aromatherapy, massage, and the use of music and colours, may promote their sensory development. Simple multi-sensory toys can be made from cloth of different texture, lights, and musical instruments. Children respond well to complementary therapies, which may also be helpful to the family or guardians and the caregiver.

### 4.8.2 Therapies that have a role in palliative care

#### Aromatherapy

Aromatherapy is the art and science of using essential oils to balance, relax, and stimulate the body, mind, and spirit. Aromas often recall memories of the past and as such may release emotions from past experiences. The oils may be used in a massage of the whole body or a part such as the hands, infused into a warm bath, or used as part of an inhalation or to fragrance a room. Each of the oils has a specific effect on the person. Lavender oil can be used to relieve stress and to relax the person, eucalyptus oil to relieve coughing and congestion, and lemongrass to be a stimulant.

#### Colour Therapy

Colour therapy uses colours to stimulate, energize, or relax the patient. The colours may be in the person's clothing or in the room. It is thought that yellow stimulates the mind and the emotions; blue and green are calming and relaxing; red is energizing.

## **Pet Therapy**

This makes use of animals to comfort patients and help them relax. A gentle, older animal that is comfortable with people should be used. Dogs and cats are the most commonly used pets but people may also enjoy watching the antics of a variety of other animals and birds.

## **Creative Therapies**

### **Art Therapy**

Art therapy allows the person to express emotions and fears that they may not be able to express in words. Adults as well as children enjoy drawing and the use of colours. Much may be read into what has been created, but where possible, it is best to get the person to describe and interpret the picture.

Art therapy is often used with children. The decrease in the use of bright colours, which children usually favour, may indicate decreased physical and emotional energy. Children who are terminally ill often show common features in their artwork. Objects on the page tend to move toward the upper left-hand quadrant of the page. The child often uses pictures to depict rain, clouds, or snow to indicate that they are feeling overwhelmed. A shining sun is often depicted shining nearby — a sign of hope. Changes in body image may be shown in the figures that are drawn by children.

### **Music and Dance Therapy**

Music offers the opportunity for creative acts. Group music and/or dance therapy promotes socialization and the understanding that one is not the only person who is ill and that expressions of fears and concerns are shared. Music has a powerful effect on the emotions, and may relax or energize the person. Techniques such as song writing, putting new words to a familiar tune or song, and visualization through music or guided imagery, may encourage a person to release his or her fears through a creative and therapeutic act.

Older children and adults may express their sexuality through dance and through the words they put to music.

### **Play Therapy**

Children communicate through play. They use imaginary thinking to animate their toys and puppets. Thus play is a very effective tool to use when communicating with a child in any setting. Play in the home setting can identify problems within that setting. Some specific ideas include: puppets to communicate with the child, soft toys to comfort, balls to make a safe and non-threatening link between the child and the provider, board games to promote expression of feelings, anger and fear, and team games with other children to help the child to socialize.

## Touch and Energy Therapies

### Massage and Therapeutic Touch

Massage makes use of the hands to stimulate and relax the body and the mind. Oils may be used at the same time and it may be combined with aromatherapy. Children respond well to the effect of touch.

Therapeutic touch uses the dynamic energy field around the body to facilitate healing of the body, mind, and spirit.

### Reflexology

Reflexology is a natural healing art based on the principle that there are reflexes in the hand and feet that correspond to every part of the body. Stimulating and applying pressure to the feet or hands increases the circulation and promotes specific bodily and muscular functions. The therapeutic effect of touch enhances the reflexology treatment. Some people are very sensitive to having their feet touched or it may not be seen as culturally acceptable in all cultures. In these cases reflexology on the hands may be more acceptable. Community caregivers can be taught reflexology, as it has no cost implications whatsoever after the initial training.

### Reiki

Reiki is a Japanese form of natural healing based on the application of the Universal Life Force Energy. The hands are used above the body to link this energy to the body.

## 4.8.3 Other Examples of Complementary Therapies

### Homeopathy

Homeopathy is a system of medicine based on three main principles.

1. Like cures like. If your common cold has the symptoms of mercury poisoning, the mercury will be used in the medication to cure the cold.
2. The Single Dose theory provides for one remedy for all the symptoms shown.
3. Homeopathic drugs are considered to be safe as they contain natural ingredients. They work with the immune system and do not further suppress it, they are not addictive, and the effect is holistic.

Herbal remedies are often used in homeopathy. Because of the manner of working of homeopathic medications, they may take longer to show an effect.

## **Prayer and Meditation**

The naming of this as a complementary therapy is controversial, but in many parts of Kenya this is seen as the greatest form of support for the individual and a way of bringing a peaceful acceptance of the illness and the progression, both for the patient and for the family members. Faith plays a very strong role in the lives of many people in Africa.

## **Psycho-neuro-immunology**

This practice is based on the understanding that stress suppresses the immune system. Stress affects most if not all of the neuro-endocrine functions. People with HIV&AIDS, cancer and other life threatening illnesses often have many fears and concerns that cause stress. When they have their stress relieved through therapies such as reflexology and aromatherapy, this may have a positive effect on the immune system.

A form of stress relief that has been shown to be effective is the identification of a wish, goal, or dream for the patient. The wish may be to celebrate an upcoming holiday or to see a loved one again. Once this is granted, it gives the person something to look forward to, to then enjoy, and to remember with delight. This seems to have an immune-boosting effect. Any activity that promotes hope would seem to have a similar effect.

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# Pediatric Palliative Care

## Module 5



**Time: 3 Hours**

### **OBJECTIVES:**

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

1. Outline the developmental stages in children
2. Describe the assessment and management of pain in children
3. Discuss HIV&AIDS management in children in palliative care
4. Discuss cancers management in children in palliative care
5. Describe Palliative Care in the critically ill child
6. Discuss prescribing and dispensing for palliative care in children
7. Outline nutritional management in the critically sick child in palliative care
8. Describe communication process with children and families in Palliative Care

### **Course Outline:**

- Introduction
- Developmental Stages in Children
- Assessment and Management of pain in children in palliative care
- HIV&AIDS management in children in palliative care
- Cancer management in children in palliative care
- Common symptoms in the critically ill child

- Palliative Care in the Critically Ill child
- Prescribing and dispensing for palliative care in children
- Special consideration in HIV & AIDS
- Nutritional management in the critically sick child in palliative care
- Communication process with children and families

## UNIT 5.1: CLINICAL ASPECTS IN PAEDIATRIC PALLIATIVE CARE



**Time: 2 hours**

### **OBJECTIVES:**

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

1. Outline the developmental stages in children
2. Describe the assessment and management of pain in children
3. Discuss HIV&AIDS management in children in palliative care
4. Discuss cancers management in children in palliative care
5. Describe Palliative Care in the critically ill child
6. Discuss prescribing and dispensing for palliative care in children

## **COURSE NOTES**

### **5.1.1 Introduction**

#### **Focus on Children**

Children are legally not able to make their own decisions and need help from a responsible adult. A young child may not be able to understand how and why a life can change within serious illness and what death means. The child will understand as they grow up as they are learning and growing all the time. Most children involved in palliative care may realize that they may not achieve what they want in life making it very frustrating. Children may not be able to express their feelings or say what they need so expression of complicated feelings comes with maturity. Children may not be able to describe their physical pain. School and friends are very important for children and if they are not involved it can be very upsetting.

## The Needs and Rights of Children

Children are our future and whether healthy or sick they have their rights. Some basic needs of all children include to be loved, to be forgiven, to be heard and believed, reassurance, to have hope, to feel safe and secure, to know they are important to others, to belong, being part of living and dying, to know oneself, to be involved in issues concerning their health and to be treated as children and not like adults.

Children's rights include the right to life, survival and development, right to protection from all forms of maltreatment by parents or others responsible for their care, right to develop in a family environment, and, right to participate and express his or her opinion freely in matters that concerns them.

## Palliative Care for Children

Definition; This is an active total care of the child's body, mind, emotions and spirit which also involves giving support to the family .It begins when an illness is diagnosed for which there is no cure(chronic illness). It continues regardless of whether a child receives treatment directed at the disease and includes the assessment of a child's physical, emotional and social distress and helps to reduce these as much as possible. It uses a Inter-disciplinary approach of the health professionals and involves the family and mobilizes community resources.

## Identifying Children for Palliative Care

Palliative care in children should begin on diagnosis of a life threatening illness such as HIV and cancer. The child and his or her family need immediate and continuous physical, emotional care and support to put days into the child's life. The child needs help with pain management and other symptoms. Early diagnosis of the illness helps the child get the best care. The clinical and laboratory diagnosis should be confirmed.

## Home Based Care

This is any form of care given to sick children living with chronic illness in their homes. It can mean the practices people might do to take care of themselves, or care given to them by family, volunteers, members of NGOs or by health care workers. The care is aimed at meeting their physical, emotional and spiritual needs and is supervised by existing support systems in the community.

Children like to be at home where family and friends can be around them. Home care allows for the family to continue daily activities. It is much less expensive because there are fewer costs for transportation and hospital care. It helps to show people that a child who is sick and is need for palliative care does not have to be isolated.

The health care professional needs to know what is right and what is wrong when working with children and families.

## **Ethical Considerations;**

### **Do no Harm**

What is easier may be harmful in the long run. It may not be wise for a parent to withhold the prognosis of the illness to the child or the rest of the family. It is important to be guided by always acting in the best interest of the child. One really needs to think about the child and his or her family and discuss all issues with them, no matter how hard that is.

### **Privacy**

Children and families have a right to privacy and they do not have to give up their privacy when they accept help from others. The family has a right to refuse help or entry into their home by a care rat any time. Sometimes children and families need to be on their own and it may be hard for them to say so. Always ask if a visit is convenient. Remember that the family may not always feel that they need help form others.

### **Dignity and Respect**

Children and families have the right to be treated with dignity and respect. Each person needs to be viewed by you as a human being unlike any other, with his own dignity, worth, value and ways of doing things. There will be differences between what a carer may think is 'right' and what the family members believe. Their views and beliefs must be respected without taking away support.

### **Confidentiality**

Information about the family and patient should only be shared with health personnel and only when necessary for patient care. You need to tell the family what will happen.

## **5.1.2 Developmental Stages in Children**

The developmental stages of children are some of the determinants of how they understand their needs, understanding of death, and ways of grieving reaction to difficulty or hardship that they undergo.

### **Infants (age 0-1):**

- Children do not communicate nonverbally at this age.
- Adults should use simple language, terms, voice and tone that show the love, and touch and caress.

- Need as much consistency as possible in caretakers, setting, and daily routine.
- Will understand and be affected by the (showed) sadness of the parents or caretakers.

### **Toddlers (age 1-3):**

- Continue to need as much consistency as possible in caretakers, setting, and daily routine.
- Adults should give simple explanations, be clear and consistent, and prepare the child just before a medical procedure.
- Will be affected by the sadness of the parents or caretakers
- Have no concept of death.

### **Pre-School Age Children (age 3-6):**

- Understand the world by interweaving fact and fantasy (“magical thinking”).
- Need as much consistency in daily routine as possible.
- Understand death as reversible: a “temporary departure” or “long sleep”.
- Are egocentric and are likely to feel responsibility for their illness and for the sadness or death of a parent. Thus, it is important to explore the child’s understanding of the cause of death, correct misconceptions, and dispel guilt.
- When a parent dies, the child may interpret the sadness of the surviving parent or caretaker as disappointment in the child’s behaviour. Thus, it is important to explain simply that the child is loved and that the parent or caretaker is sad about the death.

### **School-Age Children (age 7-12):**

- Thinking is concrete, no abstract reasoning.
- Child begins to understand cause and effect.
- Understand death as irreversible.
- Evaluate for fears of abandonment, destruction, or body mutilation. (need to assess the child’s thoughts by inviting the child to share their thoughts, fears, and sadness when he/she is ready)
- Be truthful and open about treatments or about a parent’s illness or death without giving too much detail.
- May see treatments as punishments. Thus, reassure the child that treatments are not punishments.
- Wish to understand and control what is happening around. Caregivers should offer choices to give the child a sense of control.

- After a parent's death may return quickly to their usual activities and to being with best friends. Such activity helps the child to cope with the loss.

### **Adolescents (age 13-16):**

- Are capable of abstract thoughts. Cultural specificity begins at this age.
- Undergo dramatic physical change and are very self-conscious.
- Begin to challenge parental values, separate from parents by developing peer-group identity.
- Allow expression of anger.
- Allow privacy and reasonable independence. Maintain access to peers.
- Provide clear, honest, direct explanations.
- May have very complex relationships with and feelings toward both a dying parent and a surviving parent. This may make communication and grieving more difficult. May turn to a non-parental adult to share sadness. It is important for an adolescent to have an adult with whom he/she can remember a dead parent, whether that adult is the surviving parent or another adult.
- Is at risk for developing depression. Signs may include guilt feelings, suicidal ideation. Depression requires treatment.

## **5.1.3 Assessment and Management of Pain in Children in Palliative Care**

### **5.1.3.1 Assessment**

Pain can be defined as what the child says hurts and occurs because of disease, injury or worries. Pain is not only an indication that something is wrong. Depending on previous experience of pain, this will be different for each child. It can mean physical or emotional suffering, or any sharp feeling of agony. It is usually not of our choice, and causes generate distress. In palliative care we talk of total pain, looking at all kinds of pain that can be in the body and mind. Pain can usually be treated and controlled. Caregivers needed to know how to help people deal with pain.

Children with life threatening illnesses like HIV and cancer do experience pain at certain times, but they do not have to suffer from pain. Pain can be managed to make the child comfortable and pain may get worse due to the fears that the child may have

- Physical (on the body)
- Social (who is he losing or missing)
- Emotional (feelings)
- Spiritual (fears about what happens later)
- Remember to listen to what the patient says about pain



**Signs of Pain**

- Crying
- Groaning
- Restlessness
- Withdrawal-cannot play • Sweating
- Holding or protecting the painful area
- Refusal to eat

**Pain Assessment in Children**

- Begin with direct observation of the child and reports from parents or other adult caregivers.
- Notice body position, spontaneous movements, level of arousal, and interaction with others.
- In preverbal children, crying, irritability, withdrawn or depressed affect, tense body position, facial grimacing, or fearfulness can indicate pain or nausea.
- Ask (even very young) children if and where they hurt before trying to examine them. Can use “Wong-Baker Faces Scale” or the 0-10 scale to assess pain.
- Physical examination, or even anticipation of physical examination, can cause a child to start crying. Once the child is frightened and crying, it is difficult or impossible to determine areas of tenderness and to complete the physical exam. To reduce the child’s fear, ask him/her to tell you as soon as something hurts.
- Neuropathic pain may have associated motor or sensory changes.
- Involve the parents and ask what they see or think about the child’s pain
- Ask the child to tell about the pain if possible
- Ask the child to point to where it hurts
- Ask the child to draw what the pain feels like
- Is it worse when the child moves
- Find out what makes it better or worse
- How strong is it?
- Is it sharp or squeezing?
- Watch communication and behaviour with parents and siblings or other responsible adults
- Use a body chart and ask the child to mark where the pain is

**Uncontrolled Pain Will Lead To:**

- Breathing problems; the child will breathe quickly and not deeply enough if he or she is in pain
- Withdrawal
- Difficulty in thinking about or seeing things clearly

Pain will wear a child down and so pain medication needs to be given regularly. Giving injections for pain relief is not always the best option since injections leave the child sore. Some children hide the pain to avoid being injected and analgesics should be given orally at the right time and in the correct amount.

## Important note

Keep a diary or a notebook to keep a record of the child's behavior, reaction to medication, eating, sleeping and playing habits.

### Myths and Misconceptions about Pain

- Newborns and young children do not feel pain because their bodies are not mature
- Young children do not remember pain and they forget their pain. Pain will not have lasting effects on them
- Active children are not in pain
- Sleeping children are not in pain
- Children do not feel as much pain as adults
- Children cannot describe pain (FALSE BUT TRUE IF THE CHILD IS TOO YOUNG TO TALK)
- Parents always know how to get rid of their pain
- Children need to learn to tolerate a little pain
- If a child not crying he is not in pain
  
- Pain should be treated as soon as possible and should be taken seriously especially in children who are HIV positive. Pain can be much more than physical pain and can be made worse by feeling lonely and worrying about what will happen.

### Barriers to Pain management in children

- Lack of communication
- Fear of side effects of analgesics
- Fear of overdose
- Fear of addiction (in case of drugs like morphine)
- Fear of hastening the child's death with medication like morphine
- Lack of money to buy medicines
- Belief that pain and suffering is part of being sick
- Belief that God will intervene and some religious say you should not medicate children
- Refusing to believe that the child is in pain because then that means something worrying
- Not knowing it can be helped

**Things that Make Pain Seem Better for Children**

- Toys pictures around them and can be home made and personal
- Company of others
- Comforting behaviour e.g. being carried on the back
- Telling stories
- Playing with friends
- Making or playing with toys, e.g. dolls made out of straw or clay
- Make-believe and fantasy games
- Reassurance that adults will do us as much as possible to help ease the pain
- Listening to music, poems, nursery rhymes
- Singing
- Drawing, painting, colouring
- Relaxation exercises, e.g. deep breathing, stroking, etc
- Being quiet and restful
- Change of environment
- Treating the pain with medicines

**5.3.5.1 Management of Pain in Children in Palliative Care**

The right drug should be used at the right time and the strength should be titrated to the intensity of pain using the criteria of the WHO pain management ladder. The doctor or palliative care nurse should prescribe the drug.

It has to be the right drug, the right dose that is individually calculated, given at the right time by mouth, that is:

- By the mouth
- By the clock
- By the ladder
- For the individual

**Morphine**

It is a drug that is given to control moderate to severe pain and when correctly used, it is the best pain control drug. When used well, morphine can help a child live as full a life as possible. Doctors, clinical officers and palliative care nurse can recommend it. A child who needs morphine will need to be regularly checked by a nurse. Speak with the nurse at your clinic to find out more.

**What to do with newborn babies**

Newborns can also feel pain and often suffer because of their inability to communicate. Take the child to the health facility or doctor if you are worried  
Give the medicine prescribed by the doctor or nurse by mouth every 4-6 hours

Observe the child for any reaction

Report to someone who can help if you are worried about the baby's condition

Feeding should be encouraged

#### **What to Do With Children Who Talk**

Reassure the child that something can be done to help the pain

Massage the painful area gently

Use a cloth, warmed in hot water and squeezed out, for swelling in the joints and boils.

Remove it before the cloth gets cold. Cold towels are used on fresh sprains

Use the right drug and dosage as written by the doctor. Usually the doctor prescribes

Paracetamol for pain and the child may take liquid medicine using a measure to control the correct dosage

Refer to the clinic if the pain is getting worse

### **5.1.4 HIV&AIDS Management in Children in Palliative Care**

#### **What is HIV&AIDS?**

HIV stands for Human Immunodeficiency Virus (HIV)

Human=People, Immunodeficiency=The body lacks the ability to fight infections

Virus=Infection, AIDS stands for Acquired Immune Deficiency Syndrome

Acquired= you get it from somewhere, not born with it

Immune = Body's defence from infections, Deficiency = Lack of immune system

Syndrome=Many diseases at the same time

The virus stops the body's defence system from working properly. HIV destroys the cells in the body whose job it is to fight off infection. These are sometimes known as CD4 cells which have a very important role in defending the body against infection.

#### **Understanding Symptoms of HIV&AIDS in Children**

Jumping to conclusions about who does or does not have HIV promotes stigma.

The following are clues about that a child has HIV in their blood:

- Failure to thrive (this will also happen in a child who does not get enough to eat)
- Weight loss
- Long lasting diarrhoea
- Thrush (white spots) in the mouth especially if it lasts for more than 30 days
- Skin rashes
- Sore ears with discharge especially if it lasts for more than two weeks
- Severe childhood illness like measles

- Fever (hot body) especially if it lasts as long as 1 month or comes and goes over this time
- Delayed development (slow to sit, crawl, walk, talk)
- A cough or pneumonia which does not get better with the usual medicine
- Crying and irritability because the child is not feeling well
- Seems weak and without energy
- Does not seem interested in playing with other children
- Paleness, either in the palms of hands, or the face
- Swollen glands in the neck

### Key Points:

- Children with HIV may look healthy for many years
- The longer a child has HIV, the more likely the immune system will be damaged, leading to infections or tumours
- Germs that are around us all the time cause opportunistic infections. Usually these do not make us sick when our immune system is working well, diarrhoea and fungal infections
- Once infected, HIV remains with the child or adult for life
- It is important to know that a child has HIV as soon as possible so you can provide the best support, care and treatment and give the child a good quality of life for as long as possible.
- The term AIDS is a collection of signs and symptoms which show a person infected with HIV is very sick, because they have many infections at the same time. The body is weakened by HIV and is no longer, or is not able to protect itself from infections like pneumonia, skin diseases, TB
- However it is important to remember that these signs and symptoms can also be present in children who are NOT infected with HIV making a diagnostic HIV test mandatory.

### Transmission of HIV in Children

HIV cannot be transmitted through:

- Ordinary social contact-shaking hands, hugging, cuddling, playing , etc
- Coughing and sneezing
- Using the same cups, cutlery and food
- Sharing the same toilet
- Animal and pets
- Mosquitoes and other insects
- Sharing baths, showers and buckets
- Swimming pools

Compared to several other viruses, HIV is a virus, which is not easily passed on through casual contact, as it cannot live outside the body for long. However, once HIV is living in the body, it remains there forever and cannot be cured. HIV is found in many body fluids and is mostly transmitted through the following fluids:

- Semen
- Blood
- Vaginal fluid
- Breast milk

This means that the most common ways in which we catch HIV are

- Unprotected sexual intercourse with someone infected which is the most common cause with women being at higher risk than men although both are at risk. HIV is passed through the exchange of semen and vaginal fluid.
- Mother to child during pregnancy, delivery and breastfeeding where HIV is passed through breast milk and blood
- Contact with infected blood and blood products through cuts in the skin when people:
- Share unsterilized sharp objects such as razor blades for piercing ears, shaving or ritual markings (HIV is passed through blood that has HIV in it)
- Shared needles commonly seen in people who abuse drugs given by injections e.g. drug users
- Receive transplants from infected organs such as kidneys, heart or any other part of the body

## Mother to Child Transmission

This is a common method of preventable HIV infection among children in Kenya. All babies born of HIV in infected mothers have HIV antibodies to the HIV virus. Antibodies made by the body against HIV cannot be developed by the baby until the baby is 15 or 18 months old. It can therefore be confusing to test babies less than 18 months old because the antibodies present in their blood are those of their mother. If the mother has had the HIV virus for a long time or if she gets infected while pregnant or breastfeeding and is unwell, there will be a greater chance of the baby being infected with the HIV virus. All expectant mothers should be encouraged to test for HIV during pregnancy and take ARTs if prescribed. All couples should be tested for HIV to be sure that their baby is born HIV free. Men should go with their wives to the antenatal clinic to be tested together for HIV, so that they can make choices together about their yet-to-be born baby and how best to protect the baby from getting HIV. Further protection includes having all children immunized against childhood illnesses such as measles, poliomyelitis, etc.

**Key Points:**

- HIV is spread through blood, semen, vaginal fluid and mother to child in or after pregnancy
- Only HIV positive mothers give birth to HIV positive children
- Not all the babies born to HIV positive mothers are infected with HIV. About one third of babies born to HIV positive mothers are HIV positive
- HIV can be transmitted through breast milk, especially 'first milk' after birth
- It is difficult to confirm HIV in children less than 18 months old because they carry the mother's antibodies, not their own
- There are services available to prevent mother to child transmission in Kenya and all women and men planning or expecting a baby are encouraged to go to their local community NGO or health facility for more information

**Universal Precautions in Paediatric HIV**

Basic steps to control infection are often referred to as 'Universal Precautions' and are important because any person may carry a number of infections including HIV. A person, who is ill with any disease, particularly if they have HIV, is more likely to contract diseases that a caregiver might have. Therefore, these steps that are taken by the people providing care are meant to protect the care provider, the sick person and the rest of the family.

**How can we Protect Children and Carers from Infection?**

- Practice good hygiene for everyone by washing hands before and after caring activities. Treat all people with respect and care no matter what their HIV status is
- Cover all open wounds and cuts with a plastic-covered bandage if you have one. Otherwise clean the wound carefully and cover with a clean cloth and avoid direct contact
- Wash hands under running water
- If you have severe eczema or other skin problems that are weepy, avoid infecting others by rubbing your skin against theirs
- Teach children to NEVER pick up condoms

Do not panic about catching the HIV virus otherwise that fright may lead you to act with prejudice, discrimination and poor judgement. You should use the same plates and cups with people who are infected. Children too can say hurtful things to other children as they are observant and can sense resentment or other negative attitudes. Be aware of how you and others are feeling and reacting to HIV&AIDS in order to prevent stigma, and face the future together as communities and families.

## Clinical Signs and Symptoms for HIV in Children

It is not possible to be certain that the child has or does not have HIV infection without a HIV test. The clinical signs and symptoms vary for child to child and include common childhood illnesses such as diarrhoea, measles and respiratory infections. Some illnesses may be severe, frequent and chronic. A serious bacterial infection happens often such as septicaemia, meningitis and abscesses.

## Testing for HIV in Children

Caregivers must know the HIV status of the child to help them take better care and support of the child to improve the length and quality of life of the child (including ART). It is in the best interest of the child to be actively involved as much as possible in decision making about being tested for HIV. It is hard for adults to think that a child has a right to think that a child has a right to be involved in this decision. Talk about this with the adults in the family.

## HIV pre-test Counselling

You need to think about HIV in a child if:

- One or both parents are HIV positive
- One or both parents have died
- One or more siblings have been diagnosed with HIV infection
- The child has been sexually active or sexually abused
- The child has symptoms or signs that make you think they may have HIV infection

(Remember: It is essential to know if a child has HIV sooner rather than later as the child will respond better to medical care and treatment, including ART, the earlier and less symptoms they have when diagnosed).

VCT centres are available countrywide in Kenya but the family needs to carefully discuss and agree about testing the child for HIV infection. This is pre-test counselling and should be carried out by someone that has some knowledge and experience in counselling.



Pre-test counselling should correct information on HIV&AIDS and the test in a way that will be understood by parents and the child regardless of the age of the child. In Kenya, the age of consent for HIV testing is 18 years and children must be tested with the consent of their parents, guardian or carer. Remember that children of different ages will have different worries as a young child might be afraid of needles and possible pain.

Discuss with the family what would happen if the child tested HIV positive and how they might feel about the results. Explain what it means to have a negative HIV test and what should be done to keep the child HIV negative. Discuss the options available if the child tests HIV positive and the local availability of medical care that could greatly enhance the child's length and quality of life (including adherence to cotrimoxazole prophylaxis, nutritional support and ARTs) remember to discuss how and to whom these results will be given.

Families should not be forced to go mandatory testing it would be better to continuously do pre-test counselling so that when the family makes up their mind they will put into practice the information given to them effectively. The counsellor must however think about the child's welfare as he or she respects the parents' rights. What and how the child is told will depend on their age and understanding as well as maturity. When the child is very young, only the carers will be aware of a child's diagnosis. As the child grows older, especially if they are on ART, they will require more information and 'disclosure' of their HIV status. This can be one of the most difficult issues for carers to address, and more specialized support and training should be provided on this topic for both the carer and the children living with HIV as they grow up.

Every young child should be remembered that even very young children can understand issues around their diagnosis, illness and management, even if not able to understand what HIV means. Use age appropriate language to explain things to the children whatever their age, to help them be involved and build their understanding of their chronic condition from diagnosis onwards. Teenagers need to be given time and respect and as much counselling as they need to think about being tested.

### **Why it may be helpful to have the test**

An early diagnosis may help the child get the special care and support that he or she needs which may include ARTs, prevention of opportunistic infections and common infections

The child will get a chance to talk about their illness and about any worries and fears, perhaps with others in a support group. Support groups can be helpful for adolescents. Knowing about illness can help parents understand why their child is often sick and how best to care for the child. It may stop parents from spending a lot of time and money looking for a cure and understand why medicines do not always work well,

rather than believing that they are no good.

Knowing about the illness helps the child understand and co-operate in taking medicines, eating certain foods and understanding any changes in lifestyle.

### **How is a HIV Test Done?**

Some blood is taken and tested to see if it has antibodies to HIV and there are two methods of testing which include ELISA for HIV which can only be done in the laboratory and take a week or more to give results while the Rapid Testing methods are simpler, quicker and can be done in the clinic setting. A small amount of blood is taken from the fingertip and the results are ready in ten (10) minutes.

### **ART for children living with HIV&AIDS**

**(ART=Antiretroviral therapy/ARV=Antiretroviral drug)**

Available sites offering medical care and treatment for children living with HIV changes with time but is now available as part of the National ART scale up in Kenya. ARVs work by stopping the growth and multiplication of the HIV virus and it is essential that the drugs are taken every day as prescribed for life if they work well for a long time. Although these drugs do not cure HIV infection, they stop the HIV virus from progressing and allow the body to build up its defences to infection, making children feel better and preventing them from getting sick.

ARVs may not be suitable and available for all children living with HIV immediately, but carers need to understand that it may now be possible for sick children to access home based care services and medical services that can greatly improve their quality of life and help them recover from life threatening illnesses. ARVs are not a cure and may not be suitable or available for all children, it is essential to be able to manage complete care of the child with HIV as a chronic illness who has symptoms and/or is very sick or dying.

## **5.1.5 Cancer Management in Children in Palliative Care**

### **What is Cancer?**

Cancer is an abnormal growth of cells and the reason that this happens is not clear. This collection of cells is called a tumour, which the healthy immune system can sometimes fight against when the abnormal growth happens. Tumours can be harmless (benign) or they can be dangerous (malignant) called cancer. Harmless tumour cells can take up space in the body but are usually not dangerous and cancer tumours spread into surrounding areas and all the cells can go into the blood and then move around the body to other areas where they can keep growing.

The place where cancer starts is called the primary cancer and it spreads to another part of the body it is called a secondary cancer.

Some names of cancers that you may have heard of:

- Carcinoma-cancer of the skin or the linings of organs; breast, bowel, uterus, lungs, stomach or bladder
- Sarcoma-cancer found mainly in bones or muscles
- Leukemia-cancer of blood cells

The following can help in the diagnosis of cancer:

1. Physical examination
2. Blood tests
3. X-rays and scans (ultrasound scan, CAT scan and MRI scan)
4. Biopsy-taking a piece of tumour to be examined in a laboratory

Cancer can be treated by:

- Surgery- an operation to remove the tumour or diseased tissue
- Radiotherapy-special x-rays to kill cancer cells
- Chemotherapy-special drugs to kill cancer cells

Some children have all these treatments or sometimes only one or two depending on the type or stage of cancer. A child will often feel worse during treatment because of the damage done to the cells.

#### **What Increases a Person's Chance of Getting Cancer?**

- Too much red meat
- A diet with little fibre or roughage
- Tobacco, smoking, chewing or snuff
- Excessive alcohol consumption
- HIV&AIDS can allow cancers to grow because the body cannot fight against them
- Unprotected sex with many partners increases the risk of catching the HIV virus that cause cancer of the cervix or neck of the womb
- Hepatitis B can lead to liver cancer
- Untreated infection from the bilharzias snail

#### **Some Common Cancers In Children That You May Come Across:**

- Wilm's tumour-kidney cancer
- Non-Hodgkin's Lymphoma- a cancer of a type of immune system cells known as lymphoid tissue (glands) in certain areas of people's bodies e.g. the neck or armpits

- Kaposi Sarcoma- a type of cancer that can occur anywhere in the body but it usually shows as dark patches on the skin, in the mouth and inside the stomach
- Leukemia-cancer of the blood cells
- Squamous cell carcinoma- a cancer that mainly affects the eye

**You Cannot Get Cancer By:**

- Contact with someone else with cancer
- Getting it from your parents
- Witchcraft
- Coughing or spitting

**What to Look Out For:**

- Change in toilet habits e.g pain on passing urine (water) or stool
- A sore that does not heal
- Unusual bleeding from anywhere
- Any new moles or warts that grow fast or itch
- A cough that will not go away or hoarseness of voice
- Weight loss
- A thickening or lump in the breast or anywhere in the body

**Cancer and HIV&AIDS**

Some cancers have become more common in people living with HIV&AIDS including children. Most cancers related to HIV are very difficult to treat because the body cannot find a way to stop the growth of cells. We do not know that we have cancer until it is very big and it may be too late to treat.

**5.1.6 Common Symptoms of Critically Ill Children**

These symptoms are seen in children who are sick from other causes as well as HIV infection

**1. Loss of Appetite**

When a child has lost appetite, the child will not want to eat and this may be due to many causes: e.g.

- Medicines that the child is taking
- The illness is getting worse
- Fever
- Sores in the mouth, throat or on the lips

**Management**

- Ask the child what he or she would like to eat and give small meals often if child will take them
- Do not force the child to eat or give too much food at once
- Encourage the child to drink sips of nutritious fluids often
- Keep the gums, teeth and tongue clean and the lips moisturized
- Keep the child as pain free as possible
- Refer to the clinic or doctor if the condition continues for more than two(2) days

**2. Nausea and Vomiting**

Nausea is when there is a feeling of wanting to vomit but no vomiting takes place. This can easily be missed in children who may not talk about it. Watch for signs. The child may not want to eat and not want to be near food. Some causes of nausea include;

- Medicines that the child is taking
- The illness is getting worse
- Fever
- Vomiting happens when a child brings up food and fluid from their stomach and its causes can be the same as those for nausea and vomiting.

**What to Do:**

- Keep the home clean and attend to any bad smells. Avoid cooking near the child.
- Use herbs in the house, for example wild mint, to make a nice smell
- If the child vomits, give oral rehydration therapy according to the directions on the ORS sachet.
- Ask how the child feels after taking medicines
- Encourage small frequent meals

**3. Oral Thrush**

White patches on the tongue and inside the mouth. It is a fungus that comes when our immune system is not working well

**What to Do:**

- Avoid sugary and spicy foods
- Clean the mouth with bicarbonate of soda paste
- Give the child plain yoghurt, sour milk, pineapple chunks or raw tomatoes to eat. Use homemade sour milk as this has live bacteria that destroys the fungus

- Children can be given cinnamon or ginger tea or traditional non-alcoholic drinks made from fermented maize or sorghum
- Apply small amounts of gentian violet to the affected areas
- Take the child to the health facility, doctor or nurse if it carries on
- Do not attempt to remove the patches by using your fingers as this will cause more damage

**Bicarbonate of soda paste to help prevent mouth infections:**

Mix two (2) teaspoons of bicarbonate of soda and enough warm water to make a paste(like toothpaste)

Clean the mouth and brush teeth with the paste

## 4. Dehydration

This is when the body loses a lot of fluid through passing diarrhoea and or vomiting and is classified in three (3) categories:

**No Visible Dehydration: Signs**

- Level of consciousness-Alert
- Eye sunkeness-Eyes not sunken
- Ability to drink-Normal and not thirsty
- Skin pinch (turgor)-Skin returns back to normal immediately

**Some Dehydration: Signs**

- Level of consciousness-Restless and irritable
- Eye sunkeness-Sunken eyes
- Ability to drink-Eager and thirsty
- Skin pinch (turgor)-Skin returns to normal slowly, about less than two(2) seconds

**What to Do:**

- Give the child small sips of water or ORS
- Refer to the clinic or hospital for management of severe dehydration

**Severe Dehydration: Signs**

- Level of consciousness-Lethargic or unconscious
- Eye sunkeness-Very sunken
- Ability to drink-Poor or unable
- Skin pinch (turgor)-Very slow return to normal takes more than two(2) seconds

**What to Do:**

- Refer to the clinic or hospital for management immediately

## 5. Diarrhoea

Diarrhoea is passing of soft or watery stools many times a day and is common in HIV infection. It may be caused by:

- Unsafe water
- Consumed rotting food
- Stomach infections
- Some medicines may not agree with some people resulting in stomach upsets
- Foods that disagree with the child (sometimes milk and fatty foods)

**What to Do:**

- Give plenty of fluids and if possible the ORS
- Always boil drinking water for 5 minutes
- Give water that rice has been boiled in
- Keep the home clean, wash cups, spoons and dishes in hot soapy water
- Avoid fatty foods, milk, spices, sugar and dishes in hot soapy water
- Prepare soft foods, for example, mashed potatoes, pumpkins, soft meal or sour porridge
- Clean the child's bottom carefully after every loose stool
- Refer to the health facility, doctor or nurse if it carries on

## 6. Constipation

Constipation is a condition when the child is unable to pass for several days or passes hard stools that are painful. It can be serious if left untreated and may be caused by:

- Eating too little fibre, including too few vegetables or locally available wild fruits
- Not drinking enough water
- Some medicines may cause constipation such as painkillers that have codeine in them
- Being bedridden for a long time with no exercises predisposes to constipation

**What to Do:**

- Make use the child drinks plenty of fluids
- Give the child fruit and vegetables such as spinach. Porridge made from wild fruits has good roughage
- Help the child to move around to get exercise

- Make a small suppository (i.e. a small piece shaped like a pellet with one narrow end) from the solid soap and push it into the rectum. Be gentle and take care not to injure the child.

If none of the above helps, refer to a health care worker for assistance.

## 7. Fever

Fever is when the body temperature is higher than normal and is usually due to infection anywhere in the body. Do not let your child's temperature stay high as it can be very dangerous and can cause fits.

### The Child May:

- Feel hot and damp to touch
- Be restless, moving a lot
- Be sweating and shivering
- Be confused, not knowing where he or she is not saying things that do not make sense.

### What to Do:

- Take off any clothes and blankets and use a cloth to cover the child
- Open windows and doors to allow air into the room
- Use a fan if available and you can use a small basket or tin plate to fan the child by moving it quickly near the child's face and body
- Cool the child down by using a warm damp cloth to wipe the skin and do not use a hot or a cold cloth

Give paracetamol 8 hourly daily in the following doses if available:

Age group	Dosage
Children who are small for age	7.5 - 125ml syrup
Children under 5	125 mg
Children 5-10 years	250 mg
Children over 12 years	500 mg

If the temperature does not come down quickly enough get the child to a health facility.

## 8. Fatigue

This is weakness of the body and the child may just sit or lie down much of the day as doing even little household chores will tire him or her. The child's arms and legs may get floppy and the lack of energy may be caused by:



- The illness getting worse
- Poor nutrition
- Anaemia
- Hopelessness and sadness

**What to Do:**

- Encourage the child to eat small and tasty foods
- Encourage the child to drink plenty of nutritious fluids
- Keep the child company
- Consult the doctor or nurse if there is no improvement

## 9. Coughing and Breathing Difficulty

The child may take short frequent breaths and breath fast and is usually due to infection anywhere in the body. Being breathless is frightening to the child and family. Since breathing means living, breathlessness can mean the opposite. Coughing may go on for a long time and the child may struggle to catch his breath.

**What to Do:**

- Do not leave the child alone
- Reassure him or her that you will do what you can to help him or her
- Open windows and doors to let in fresh air
- Sit the child up if possible
- Lean the child forward with his or her head resting on his arms at shoulder level on the small table, box or folded blanket
- Place a hand on the ribs to make coughing easier
- Gently pat the back to encourage coughing and help get rid of mucus
- Give cough medicine or guava or gum leaf tea
- If coughing or breathing difficulty continues, take the child to the health centre.

## 10. Edema

When the body is not working well and does not get rid of fluids normally, these fluids start to build up in the legs and feet. These symptoms can be caused by:

- The illness stopping the body from working normally
- Not eating enough protein-rich foods
- Heart or kidney problems
- An infected wound on the leg

**What to Do:**

- Gently massage from the toes up the legs using petroleum jelly or a body lotion
- Stop adding salt to food and use lemon juice instead
- Feed the child a high protein diet with eggs and meat if available
- Keep the legs raised on pillows or blankets
- Ensure that the child does not stand for long periods

**11. Insomnia**

The child may be restless at night, waking up often or may not sleep at all and this may be due to:

- Untreated pain or uncontrolled symptoms such as itching
- Hunger and or thirst
- Feeling uncomfortable because the child needs to pass urine or stools
- Fear of what is happening or that he or she may die or fear of being alone
- Bad dreams

**What to Do:**

- Ask the child why he is she is not sleeping
- Tell bedtime stories or sing comforting songs
- Cuddle or carry the child on your back to the provide comfort
- Let the child know you are nearby
- Sit with the child or share the same room
- Do what you can to lessen the child's pain or discomfort and help the child use the toilet before going to bed
- Talk with the child about his or her fears and you may choose to do this in the daytime
- Ask others in the family, perhaps a brother or sister to sit with the child

**5.1.7 Palliative Care in the Critically Ill Child**

The care of a seriously sick child is demanding for everyone involved and is accompanied by sadness when the child is dying or after they have died. This sadness can sometimes take a toll on the body and manifest itself as a heavy feeling in the heart or stomach, feeling tired, sick, headaches and no energy at all. This could continue for months or years and may be a cause of concern because it seems that the sadness has gone on for too long and other people may think that one should be able to cope much better than there are currently coping. Each person should work out for him or herself whether there is a reason for these feelings and if one is worried, look for help from a good friend, the church or good listener. If you are helping to take care of ill children, always work with everyone in the family if possible.

Common symptoms of critical illness

You will see many symptoms showing that the child is very ill which include:

- Fever
- Irritability
- Vomiting
- Loss of appetite
- Loss of energy
- Complaining of pain or feeling ill

## Critical Illnesses Commonly Found in Children Living with HIV

If you know that the child is HIV positive, you must be aware and recognize these signs and symptoms, as these serious illnesses are much more common in children living with HIV. If any child (including children known to be HIV negative or whose HIV status is unknown) experiences these signs and symptoms, you must seek urgent medical attention.

### 1. Pneumocystis Pneumonia

**What it is:**

- Dry cough that does not get better
- Breathlessness
- General weakness
- Loss of appetite

**What to Do:**

- Take the child to the local health facility as soon as you can
- When the child is discharged:
- Make the child comfortable in a sitting position by using pillows or blankets to do this
- Encourage the child to drink lots of fluids
- Encourage the child to drink lots of fluids
- If the child is on cotrimoxazole or any other medication give the medicine (tablets or syrup) at the same time every day
- Explain clearly to the child and others in the family what is happening
- Keeping the child company by playing with the child, read and tell stories
- Encourage the child to eat fruit and vegetables in a well balanced diet

## 2. Tuberculosis

Tuberculosis is an airborne disease, which means that one can get lung tuberculosis by breathing it in. TB can develop in the lungs (pulmonary tuberculosis), in the bones, in the muscle covering the stomach or other parts of the body. Diagnosis of TB in HIV positive children can be difficult as some of the symptoms are similar to other conditions.

### What it is:

- A cough that carries on for two or three weeks or longer that brings sputum (spit) from the chest
- Sweating, especially at night, due to fever when the body feels hot and it can also occur during the day
- Weight loss even if the child is eating well
- Loss of appetite and refusal to feed
- Glands become swollen around the neck, head or under the arms
- Feeling unwell-lack of interest in playing or reading

### What to do:

Take the child urgently to a local health facility. The child may be admitted to hospital and nursed in isolation away from other but will receive free treatment

Follow the nurse's or the doctor's instructions for taking the medicine in order for the medicines to work properly. Remember the TB drugs may be of several types of tablets, which must all be taken all the time.

After three (3) days of taking this medicine the child is no longer infectious but the child will have to carry on taking the medicine for as long as the doctor says. The only way to find out if the child is still infectious is to test the sputum for TB bacteria. The length of time on treatment will vary and it is important to do just as the doctor or nurse says. The health worker may wish to see that the medicine is taken each time and is called Directly Observed Treatment (DOT).

There are several ways to help a child with TB while you wait for child to get to the clinic and also when the child gets home:

- Make sure there is enough ventilation in the house
- Give the child a high protein diet with eggs, milk, meat and beans
- Feed the child lots of fruits and vegetables
- Keep the child exercising, even gently
- When the child gets home, give the medicines at the same time every day
- Keep the child alert by reading to him or her or telling a story

- Support the parents and family members by sitting with the child at times and asking how everyone is managing
- Look out for any reaction to the drugs. If the child has a rash or starts to vomit take the child to the clinic
- Encourage the family members to go for TB screening themselves

### 3. Meningitis

This is an infection of lining of the brain

**What it is:**

- Bad headaches that do not stop
- Fever
- Nausea and vomiting

**What to Do:**

Take the child urgently to the local health facility and the child may be admitted until the illness is under control

Give the child Paracetamol if you have it available, to help the headache

### 5.1.8 Prescribing and Dispensing for Palliative Care in Children

Children who are living with cancer or HIV will often need to take medicines every day and medicines should be provided by a hospital or clinic with clear instructions.

**The Instructions Should Include:**

- When to give the medicine
- How much is to be given
- Whether the child needs to eat food before taking the medicine
- How to store the medicine

**Remember!**

- Children do not usually like taking any medicines and may become upset
- Children find it difficult to swallow tablets. Syrups, suppositories, ointments and creams may be easier for them
- Some children will vomit or spit out the medicine soon after taking it
- Persuade children to take medicines rather than force them
- Avoid mixing medicine with food, as this will put the child off eating

## Sample Drug Chart

Medicine	Use	Amount/ How Often	Time	Month	Date	Date	Date	Date
				July	1st	2nd	3rd	4th
Paracetamol	Pain	2mls 4 hourly	6 a.m.					
			10 a.m.					
			2p.m.					
			6p.m.					
			10p.m.					
Liquid Paraffin	Constipation	5ml at night	10p.m.					

Make sure that you tick when the drug has been given so that you do not forget it has been taken. There are also many herbal remedies that carers can use at home and are different views on how well these remedies work, but carers have reported that some of these remedies seem to bring relief to adults and children with HIV, cancer and other life threatening illness. If the child does not improve after taking them, he or she should be taken to a health facility for further management.

## Special Medical Treatment for Children Living with HIV or AIDS related illnesses (opportunistic infections)

### Cotrimoxazole

It is used for chest infections and diarrhoea and is often given to prevent infections. The child should take a daily dose as prescribed and other drugs are given for prevention of thrush and brain infections.

### Antiretroviral Therapy (ART)

ARVs are medicines used to help people with HIV&AIDS fight the growth or multiplication of HIV in the body.

ART is the correct provision as a total package of ARVs with adherence support and all appropriate care e.g. nutrition, infection control, treatment of opportunistic infection as well as testing and counselling

There is a lot to talk about this treatment so we need to know what it means and ARVs have the ability to fight mechanism that allows the HIV virus to multiply in the body.

Three or more medicine are used together to make one ARV tablet and this controls the spread of HIV in the body and makes the immune system stronger and this is NOT a cure for HIV or AIDS but it may help the child

- Live longer
- Fast stronger because the immune system works better
- Lead a normal life and go back to school
- Eat better
- Have fewer hospital visits

**There are some challenges that have to be met when taking ARVs:**

- They do not cure HIV, so the child remains HIV positive
- If the drugs are not taken absolutely correctly at the right time every day for the rest of the child's life, they will not work properly. When one never fail to take the medicines correctly this is called adherence
- They are not easily available and are very expensive. However, you may be able to register with a program where you can get the drugs for free. Ask your health worker for details
- They must be given (prescribed) by a doctor and carefully followed up regularly
- They must be taken for the rest of one's life and this can feel like too much of a burden
- The virus in the body can learn to fight against the medicines if they are not taken correctly
- Some people can react badly to the medicines e.g. some children can develop a rash or a neck ache and this can make a child want to stop taking the medicine

**What to Do:**

- Explain that it is normal for people to feel tired when they start ART and this because the body has to get used to the new medicine
- Check for the signs that are worrying and for the one that will be short lived. They need to be taken in the right way at the right time and with the right foods every day. Not everyone improves when they take these drugs and some people feel no different and others may feel worse. If you are worried about the child's condition and you think the child is not benefiting from the medicine report this to the doctor or another medical person.

**Things to Do And Think About Before Starting The Child on Art If There is A Choice To do so:**

- There are ART sites in Kenya established by NASCOP that offer ART for children
- Find out where the treatment centres are in your area

- Who will pay for the tests and treatment?
- Will someone be able to continue paying for these for the rest of the child's life?
- Is there support in the family to help the child take the medicine properly, fill in the drug chart, and explain to the child why she or he is taking medicine?
- Will there be support for the whole family and this is an important responsibility for everyone
- Think about setting out a support group for children on ART to talk about what it is like for them. Use drama drawing and other ideas for working with children that are in them manual
- Refer to the subtopic on nutrition to be prepared for how best to feed a child on ART

### **Understanding HIV Progress (Staging) and When To Start Art**

We are guided by the WHO to help people understand how the HIV progresses in stages and will explain each stage and what to look for. It is very important to seek help at all stages and children should take vitamins throughout the illness and to follow the nutrition guidelines in this manual.

#### **Stage One**

- This is the earliest stage of HIV infection
- The HIV virus is killing the cells that protect the child from diseases therefore the child will not have any visible signs or symptoms in this stage

#### **Stage Two**

- The child may show weight loss and the immune system is not working the way it should
- He or she may have a sore throat, head and chest colds, a cough that may produce sputum (spit) and breathing may be difficult. All of these may occur often
- A painful burning rash (herpes zoster) may appear in urine, anywhere in the skin, the mouth or under the nails
- Ideally the child should start ARVs from the time of diagnosis

#### **Stage Three**

- There is a big loss of weight and failure to grow
- The child may not spend much time playing with others because he or she will be tired and feel unwell
- He may suffer from chronic diarrhoea, thrush in the mouth and fever for longer than one month
- He or she may catch tuberculosis (TB)
- The child will benefit from ART as any of these can make him or her feel very ill



**Stage Four**

- The child will be seriously ill
- She or her spends longer in bed than normal and does not play much
- There may be breathing difficulties due to head colds and lung infections
- There will be visible and serious loss of weight in the child. Infections that do not normally cause problems for a healthy child will make this child seriously ill
- The child will benefit from ART
- This staging helps us have an idea of how far then HIV may have gone in the child and to seek help to find out which treatments will be best for the child you are looking after.
- What happens next?
- The doctor may want to take blood for certain tests to check that the child is ready for ART and sometimes the doctor will just ask questions and not do a blood test.

**5.1.9 Special considerations in HIV&AIDS**

- HIV has become a major cause of infant and child morbidity and mortality in Africa.
- 95% of children with HIV are infected by vertical transmission from mother to child. Therefore HIV&AIDS in Africa is a multi-generational disease of families, in which the disease affects everyone in the family.
- Support for children must be delivered as a comprehensive package within the context of family-centred care.
- Making a diagnosis of HIV in children in resource-limited settings is a challenge, especially in very young children, because of limited laboratory resources and the high cost of tests. Health professionals are therefore often reliant on clinical signs and symptoms.
- Younger children with HIV have different OIs than older children – as they get older they develop disease conditions caused by the reactivation of previous infections, as is often seen in adults.
- Treatment protocols vary from country to country, and in many countries it is difficult to get paediatric formulations of medicines.
- HIV&AIDS will impact on an HIV-positive child's development, with growth, motor skills, cognitive ability and socialisation all potentially being affected.
- The impact of the disease will depend on the developmental stage at which symptoms present.
- Parents tend to want to protect their children from the knowledge of their disease, yet evidence suggests that children allowed pertinent information and knowledge are better able to 'own' their disease, adhere to medication and deal with the discomfort of interventions etc.

## Important note

- Children may respond differently to medications and dosages.
- Neonates, very young and very small children may require smaller doses of medication than their weight would suggest.
- Malnutrition and dehydration, as well as opportunistic infections, are often the most life-threatening conditions requiring immediate treatment.
- Paediatric formulations are more accurate for children than tablets that need to be divided.

## UNIT 5.2: NUTRITIONAL MANAGEMENT IN THE CRITICALLY SICK CHILD IN PALLIATIVE CARE



**Time: 1 hour**

### **OBJECTIVES:**

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

1. Discuss nutritional Management of the Critically sick child in palliative care

## COURSE NOTES

### 5.2.1 Introduction

#### Why is Nutrition Important?

Good nutrition is key to good health and adequate nutrition is especially important for young children to ensure they grow properly develop their immune system and are able to fight infection; this is especially true for children infected with HIV. Children living with cancer also need to give their bodies' good food because when the body is strong it will fight cancer. Taking ARVs can affect food intake and cause nausea or diarrhoea and these should be treated quickly so that the child is able to eat gain as soon as possible. Good nutrition also increases tolerance of ARVs drugs.

*If a child is still well, give plenty of varied and balanced food; if the child is ill, give more fluids and balanced small frequent meals*

If the child is not well he or she will not want to eat because very ill children refuse food. Look for clues that show he or she wants to eat if he or she cannot talk. Give plenty of fluids including milk, fruit juices and supplement fermented food drinks depending on the child's age and tolerance. Good communication with the child helps to ensure that the child eats what he can. However, in the final days or hours of life the child may refuse to eat completely. Do not force- feed the child and do not panic. The body does not need as much food at that time so you should continue to be supportive to the child. Look for ways to make him comfortable rather than worry about food.

## Why Children with Cancer or infected with HIV need extra nutritional care?

- Their weak bodies cannot fight infections that cause diarrhoea
- The body is trying to fight the cancer or the HIV virus
- Poverty can mean poor quality food is given
- A high temperature uses up the body's energies and prevents good appetite
- Throat infections make swallowing hard
- Worry about the illness
- Taking many different drugs can affect the appetite and stomach actions
- It is important that food is selected carefully to include all food groups to produce a well balanced diet. This will give the body its best chance to stay well

Early diagnosis and timely intervention with good nutrition will give the child an opportunity to thrive

### 5.2.2 Nutritional Management in the Critically Sick Child

#### A Balanced Diet

A healthy balanced diet is one that provides the right nutrients (carbohydrates, fats, proteins, vitamins, minerals and water) in the right proportion, combinations and is safe and free from germs and harmful substances.

- No food contains all the nutrients our bodies require
- When planning a meal take at least one food item for each group
- Always vary food items during different meal times
- A variety of locally available foods taken in the correct amount and proportion will give you a healthy diet
- Drink plenty of clean, safe water

**Energy Giving Foods (Carbohydrates):** Grains e.g Rice, Millet, Potatoes, Wheat, Maize meal, Whole wheat bread, Oatmeal, Pasta, Cassava, Sorghum

**Body Building (Proteins):** Beans, Groundnuts, Milk and milk products, Sesame, Peas, Lentils, Peanut butter, Meat, Fish, Eggs

**Protective Foods (Vitamins and Minerals):** Fruits and vegetable both provide the body with protection against the infection.

**Recommended Fruits and vegetables:** Indigenous fruits, Mangoes, Bananas, Watermelon, Guava, Apples, Pears, Plums, Pineapples, Green, white and yellow vegetables are sources of minerals and vitamins. Yellow vegetables are rich in vitamin A that increases the body defence system. Select from yellow, white and green vegetables regularly:

Yellow –pumpkin, carrot, butternut

White-Cauliflower, white cabbage, onions

Green-Spinach, pumpkin leaves or any dark green leafy local vegetable

**Fats and Oils:** Vegetable oil is preferred such as sunflower, groundnut oil, over animal fats

## To Keep a Sick Child Well Nourished

- Prepare fibre rich foods such as soft porridge with peanut butter, potatoes yam and millet. Give plenty of nutritious fluids and water, as this will help the child's stomach to work well
- Select locally available foods in season from all groups above
- Feed the child what he or she likes although do not give too much cakes and sweets
- Give small meals throughout the day- at least five meals a day
- Try as much as possible to prepare fresh foods for each meal but in case you have to use food left over
- Heat leftovers for 5-10 minutes to kill any germs before giving food to a child
- Safe food is easier for an ill child to eat

## Special Information about Babies up to 6 months

Breast milk is still the best milk with which to feed babies. Mothers need information during pregnancy so that they can make informed decisions on infant feeding methods. From birth, the baby's weight should be monitored closely at a health facility to ensure that feeds are adequate and to get medical advice and support. Mothers who are HIV positive may be worried that they can pass the HIV virus to the baby through breast milk and will want to know what choices they have.

### Exclusive Breastfeeding

Breastfeeding is still the best way to feed babies even for HIV positive mothers though there is a chance that she could pass the HIV virus to the baby

- Breastfeeding is still the best alternative because it protects babies less than six (6) months old who may die from infectious diseases like diarrhoea
- In certain areas where hygiene is poor and infections are more common in

- children, breast milk is hygienic and nutritionally sound
- There is also the advantage of cost. It is cheaper than formula milk

But there are some important things to remember.

- The mother should feed her baby with only breast milk and nothing else, not even water, for the first six (6) months
- Mixed feeding with other foods and liquids together with breast milk before six (6) months will increase the risk of diarrhoea. More important, research shows that it increases the risk of passing HIV virus to the baby. If breastfeeding is chosen, it needs to be breast milk only.
- The baby needs to be fed whenever he or she gets hungry. Make sure that the child is well attached to the breast to prevent breast and nipple problems. Stop breastfeeding immediately at 6 months and start with other foods and milk products and do not give breast milk again.
- HIV positive mothers who choose to feed with replacement foods must be aware that they should NOT breastfeed of HIV to their babies, mothers should either feed their babies ONLY breast milk or ONLY replacement feeds and NOTHING ELSE for the first six (6) months of life (including water, juices, porridge). Mixed feeding can create tiny holes in the baby's gut that allow the HIV virus to enter the baby's body.

**Hygiene:** The importance of good personal and environmental hygiene in reducing the occurrence of diarrhoea and other infections cannot be overemphasised. The following are some of the basic hygiene measures one can take when preparing food.

**Hand washing:** Washing your hands properly is one of the MOST EFFECTIVE ways of preventing transmission of infections.

**Food Safety:** Be especially careful in preparing food and cleaning utensils because babies are more likely to get sick than adults if food is contaminated

- Certain formulations may require refrigeration, which may be a challenge in many areas.
- Always know a child's weight because this is the basis for deciding on dosages.

## UNIT 5.3 PSYCHOSOCIAL ISSUES IN PAEDIATRIC PALLIATIVE CARE



**Time: 1 hour**

### **OBJECTIVES:**

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

1. Discuss Nutritional Management in the Critically sick child in palliative care

## COURSE NOTES

### 5.3.1 Communication with Children and Families in Palliative Care

#### Psychosocial Support

The term “psychosocial support” (PSS) has been mystified as something very technical as can only be done by people who have received training. However, as shall be shown the term can be broken down and this helps to see that it is nothing new but a something that has always been done by our society and has to be strengthened.

PSS is defined as an “ongoing process of meeting the emotional, social, mental, spiritual and physical needs of a child”. This is done through ongoing care and contact with the child”.

The term can be broken down into three parts and these are

**Psycho** - this refers to anything that involves what an individual feels, thinks and their emotions

**Social** – this refers to the community in which the individual lives and the various players that have contact with them. These include relatives, teachers, classmates, friends, church members and neighbours.

**Support** – this refer to how an individual is assisted by their people surrounding them to face challenges that affect their emotions, feelings and thoughts

## Communicating with Children

### Self-awareness

It is important to note that communication with children;

- Uses an honest and open approach as the basis of all communication with a child and their family;
- Enables parents to be central to a child's well-being; and, where possible, they, or a designated carer, are present and involved in all aspects of the child's care, guided by the age and wishes of the child;
- Provides information to a child and their family about the signs and symptoms of approaching death in a manner appropriate to their individual needs and circumstances.

### Process of Communicating with Children;

- Introduce self as the person who talks to and helps children
- Take some time to get to know the child (play a game, talk a bit)
- If child is not verbalizing, divert & introduce child to other materials in the room that can be used for communication
- Allow child to explore toys/activities/room at his/her own pace
- Ask about the demographic data of child (name, age, No. of siblings, school, favourite food, the parents, best friends)
- Don't feel rushed when working with the child. If you are impatient, the child will sense this!
- Use of self by adjusting to child's physical level
- Utilizing play, drawing & other art mediums
- Observe what toys the child is handling
- Ask open-ended questions regarding the toys and regarding what you observe the child doing with the toys (What is happening there?)
- Actively participate with the child in playing with toys
- Notice the theme of the child's play (e.g. themes of nurturing and aggression)

## Summary

- Paediatric healthcare providers already possess skills in communicating with children
- Take time to get to know the child at the beginning of treatment and in an ongoing way
- Do not feel rushed in the process of getting to know and treating the child



## Grief in Children- basic guidelines for care

- It is important for grieving children to continue age-appropriate activities. Family time and daily routines should be protected (if possible).• Children should be encouraged to tell a trusted adult everything they hear about the parent's illness or death. It is important to be honest with children without overwhelming them. In general, children's questions should always be welcomed.
- Memory times (boxes, books, gifts from parents) help children to maintain a spiritual connection to their dead parent. Such memory items can help a child to grieve, to make sense of the loss, and to develop and maintain a sense of identity and roots. They can include photos, letters, family stories, diaries, tape or video recordings, and souvenirs.

### 5.3.2. Differences Between Children and Adults' Palliative Care

- An understanding of developmental issues is essential when providing children's palliative care.
- Infants and young children are completely dependent on adults and so depend on other people to make decisions for them.
- As children grow and develop, their capacity to care and to decide for themselves increases. Therefore care that is appropriate for a child of 11 may be inappropriate two years later.
- The natural desire of family and carers to protect a child with a devastating illness can lead to that child feeling stifled.
- The child's developmental level will particularly influence:
  - The communication of wishes, fears and symptoms
  - Their understanding of illness and death
  - An assessment of symptoms
  - The management of symptoms
  - Decision making
  - The importance of play as a means of understanding the world
  - The importance of school

## Important note

- Children's understanding of illness, dying and death changes with their developmental stages, and the healthcare worker's approach will therefore need to change at each developmental stage.
- The healthcare worker should have a paediatric palliative-care guideline to refer to for pain and symptom management –
- Adolescents and young adults usually have sexual needs that should be discussed openly.
- Children are often very resilient and respond quickly to palliative interventions.
- All children have similar needs regardless of whether they are healthy or ill – treat the child as normally as possible.

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# System Strengthening In Palliative Care

## Module 6



**Time: 6 Hours**

### **OBJECTIVES:**

By the end of this module, the participants should be able to:

1. Identify resources needed in palliative care
2. Describe the services provided in a palliative care program
3. Discuss the systems necessary for running a palliative care program
4. Outline the structures needed in palliative care settings
5. Discuss resource management issues in a palliative care program
6. Explain supportive supervision in palliative care program
7. Discuss monitoring and evaluation of palliative care program

### **Course Outline:**

- 1. Resources needed in palliative care
- Basic services in palliative care program
- Systems in a palliative care program
- Structure requirements in a palliative care program
- Resources management in palliative care
- Supportive supervision in palliative care
- Monitoring and evaluation of palliative care programs

## UNIT 6.1: RESOURCES AND BASIC SERVICES IN PALLIATIVE CARE



**Time: 1 hour**

### **OBJECTIVES:**

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

1. Define a resource
2. List the different types of resources that are required in the pc
3. List the range and types of services in the palliative care
4. Discuss methods of delivery of services to the community level
5. Explain the different components of palliative care

## **COURSE NOTES**

### **6.1.1 Types of Teams in Palliative Care**

**Multi-professional team-** Incorporates the expertise of members from several disciplines/professions

**Inter-disciplinary team-** Different disciplines in health working together for the achievement of the best quality of life for the patient and family

Some members of a palliative care team include; doctors, pharmacists, nurses, clinical officers, nutritionists, counsellors, social workers, spiritual leaders etc

### **Models of Teams In Palliative Care;**

#### **Home Care Teams**

They make home visits, monthly day cares, visit local hospitals and work with community vigilantes to identify clients for cancer and HIV. They also do outreach programs and roadside consultations and train health professionals.

**Outreach/Mobile Teams**

Outreach teams expand the geographic area of a program can cover. The palliative care team travels to a centre beyond their catchment's area limit and spends the day seeing walk-in patients. They also may go to the homes of those too ill to reach the centre.

**Roadside Clinics Teams**

Roadside clinics can allow the team to see more patients in a day or to see patients outside the program's catchments area. This method often leads to the development of a more formalized outreach clinic.

**District Palliative Care Teams**

District Health care teams are inclusive in composition. They are headed by a palliative care coordinator and set up services and training for the district. They also spearhead drug availability with the District officials.

**Hospital-Based Palliative Care Teams**

These are teams, which see referrals in the hospital, commence on treatment, and then communicate with teams or caregivers in the community to provide a continuum of care. They assess the patient whilst they are in hospital and advise on the continuum of suitable palliative care after discharge to the community. They have a wide mix of health professionals. The nurse is the link between the hospital-based palliative care team and the home care program, maintaining daily contact with the other members of the palliative care team and ongoing liaison with the home care team. The team gives individualized holistic care to the patient and provides the family with information regarding basic nursing care, infection control, nutrition, and medication. Introductions are made to relevant community services such as home-based or day care programs.

**Role of Volunteers**

Most palliative care programs cannot survive without volunteers from the communities to supplement the services of paid staff. While volunteers are vital in providing care in SSA, it is both unrealistic and unethical to expect impoverished people from resource-constrained communities to work without some kind of incentive. Stipends for travel and meals are commonly provided to volunteers, but the time has come to also give serious consideration to linking HIV&AIDS service delivery to job creation.

**6.1.2 Resources Needed in Palliative Care**

Materials: includes goods and services e.g. drugs, palliative care equipments and machines, data tools, computers, physical structures, food(nutrition), nursing materials(gloves etc), stationery, beddings and beds, sanitary items,

**Money:** Refer to financial resources like:

- Supply costs
- Running/operational costs
- Capital outlay e.g. assets costs
- Administrative costs
- Insurance costs

**Time:** Work plans for specific areas. Annual, monthly, weekly and daily work plans

**Man power;** e.g human resources

### 6.1.3 The Range Of Services

Health care systems exist to address the prevailing needs of individuals, families and communities, and as such should form part of a dual continuum of care. On the one hand it is important for individual patients and families to have access to a continuity of care that addresses the entire disease spectrum. This includes care from pre-diagnosis through the asymptomatic and symptomatic phases of infection, the prevention and treatment of opportunistic infections and HIV, pain and symptom control, care at the end of life, and bereavement care. On the other hand, a continuum of services that allows for easy access across a variety of settings is vital for the well being and optimal management of people living with HIV&AIDS.

In addition to benefiting individual patients and families, this dual continuum offers considerable advantage for the entire community in terms of equitable access to quality care coupled with an uncomplicated and effective referral system. It also impacts positively on an array of HCWs—from grassroots level of community caregivers and lay counsellors to teams of multidisciplinary professionals and managers.

#### **Inpatient Hospital Care**

As in other parts of the world, people traditionally seek hospital care for serious health conditions. The role of hospital care, however, remains crucial to individual, family, and community health. Budget constraints challenge hospitals to be less rigid and to use their resources optimally. This care includes chemotherapy, psychotherapy, nursing care etc

#### **Discharge Planning and Referral to Community-Based Services**

Careful discharge planning with integration of patients and families into any existing network of community care should be required in policy and practice. In the case of home-based care, a written referral form should include:

- Consent from patient and family
- Documented diagnostic evaluation
- Treatment regimen



- Confidentiality of HIV status and other medical conditions
- Patients and families should also be given:
- Accurate information (ideally a brochure) regarding the likely intensity of care and social support provided by the home care program (to avoid unrealistic expectations and disappointment)
- Where possible, an initial supply and assurance of continued access to medication
- Where possible, supplies such as soap, dressings, and gloves

### **Outpatient Services**

Ideally people living with Life threatening illnesses and their families should have ongoing access to medical care whilst at home, at an outpatient clinic. This may be situated either within the hospital or at a location closer to where they live, such as a primary health care clinic.

## **6.1.4 Methods to Deliver Palliative Care at the Community Level**

- Home care services
- Outreach/mobile services
- Roadside clinics
- District PC teams
- Hospital-based palliative care services
- Palliative care teams grafted onto support organisations
- Day care
- Community-based care-givers link
- Inpatient hospice
- Small homes for care (using relatives to care)
- Caring teams from faith-based organisations (FBOs)

## **6.1.5 Components of Community-Based Home Care**

To provide effective palliative care, a community-based home care program should include:

- Proper pain and symptom control
- Effective management of OIs, including prophylaxis and treatment
- Culturally-sensitive holistic care that addresses the devastating nutritional, educational, financial, social, emotional, and spiritual needs of people with HIV&AIDS and their families
- Early identification and optimal support for, or placement of, orphans
- Effective networking with relevant CBOs and FBOs as well as traditional healers and community leaders.
- Professionally supervised and trained lay community members, employees,

- and volunteers, to provide services
- A caring for caregivers component
- Bereavement support and follow up
- Program monitoring and evaluation

## Training Component

It is vital that community caregivers receive proper training to equip them to provide a high standard of care.

## Transference of Skills

### **From professional to nonprofessional staff:**

This is the transference of skills to lay community caregivers. They are trained to perform tasks usually assigned by qualified professional members of the interdisciplinary team and are supervised by a professional nurse.

### **From rehabilitation professionals to nurses:**

Rehabilitation health professionals (e.g., occupational and physiotherapists) are scarce, making it necessary for those who are available to teach their skills to the nurses who are taking responsibility for patients. There are simple, cheap locally-made aids that can really improve the quality of life of a disabled person and their carer.

### **From doctors to nurses and clinical officers:**

In Kenya, doctors are few but are also the only prescribers of certain drugs, including morphine. For people in all communities to have access to effective pain management, nurses and clinical officers need to be trained and certified to prescribe morphine.

## Professional Supervision

People selected from the local community are trained as community caregivers. These caregivers live and work in the community and are the foundation on which home-based care programs are built. Trained care-gives must be professionally supervised. This hones their skills and empowers them to demonstrate and teach basic hands on quality care to the family and immediate neighbours. Professional supervision ensures that patients receive adequate clinical care including pain and symptom control, effective management of OIs and appropriate referral.

This recent development does, however, further accentuate the need for the professional supervision of community caregivers. Professional supervision is also necessary for the sake of the caregiver and forms the foundation on which the provision of care for the caregiver is based.

## **Caring for Caregivers**

If caregiver burnout is to be prevented, it is crucial for a caring for caregiver component to be included in HIV&AIDS programs, in particular home-based care. Home care programs serve poor communities whose members are coping with an excessive quantity of loss and grief. This stressful working environment is typically aggravated by a lack of adequate welfare infrastructure and referral options. Caregiver stress is compounded when clients are predominantly young adults and children with whom the caregivers identify

## **Poverty Alleviation and Orphan Care**

Aspects of community development and poverty alleviation are invariably interwoven into the delivery of community-based care. Thus the family depends on the extended family for financial security in a crisis. Often the breadwinner is the patient or the carer and this leaves the rest of the family in a crisis for school fees or for food. Some programs set aside small funds to meet these essential social needs for their clients. Such funds are often distributed from the nurses in the program. There is also often a need to plan for the care and placement of orphans and vulnerable children. Staff should have up-to-date knowledge on services for vulnerable children as well as the availability and criteria of welfare grants, if any apply in their country. Improving quality of life is one of the primary tenets of palliative care.

### **Networking with Other Services**

The palliative care team, such as orphan care and school fees, cannot easily take many of the holistic aspects of support on. In this case, there must be networking with and links to all organisations in the community that provide needed services.

### **Traditional Medicine**

Traditional healers are more abundant and far easier to access than western health care professionals. Including them in the program as networking partners is one way of ensuring that people living with Life threatening illnesses and their families receive culturally sensitive care.

### **Links between Care and Prevention**

Linking home-based care to HIV&AIDS prevention and care has been a significantly satisfying prospect for HCWs, who are able to teach infection control and encourage and support patients with HIV&AIDS in regard to divulging their status. Proper linkages are therefore necessary

## UNIT 6.2: SYSTEMS IN A PALLIATIVE CARE PROGRAM



**Time: 1 hour**

### **OBJECTIVES:**

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

1. Identify issues that affect the drug policy and medication availability
2. Identify the different systems in a palliative care program
3. Outline policy areas that govern the provision of palliative care
4. Describe the role of the government in provision of palliative care
5. Describe the role of the community in PC  
Outline the structure of National Policies in palliative care program

## COURSE NOTES

### 6.2.1 Systems in Palliative Care

Effective palliative care system requires the following;

- Financial management systems: well documented financial policies and procedures, financial manuals, financial/accounting tools
- Administrative systems: how are responsibilities and roles/authority distributed?
- Policy (guidelines and regulations)

Rules governing provision of PC services are non-existent at the moment.

All **programmatic issues** that need to be highlighted include.

- a. Program- set up of palliative care services
  - Stand alone set up guidelines
  - Integrated/affiliated set up guidelines
- b. Standards of service
  - Training

- Medication policies e.g. opioids How to procure, supply, store, dispense, prescribe,
- Human resources policies
- c. Monitoring and evaluation policies
- d. Management of programs (board overseeing the running, management issues, roles of GOK- Asking government to allocate funds/Resources for PC at national level)
- e. Role of community in provision of PC services e.g. HBC, sensitization, resources mobilization, ownership enhancement, Guidelines on how the PC services are managed

## Referral Systems

- Internal- linkages, interactions
- External -networking, affiliations, collaboration and partners, inventory and database for referral, referral tools,

## 6.2.2 Issues That Affect Drug Policy and Medication Availability

### Health System Issues:

- Shortage of trained staff, especially in rural areas (doctors, assistants, nurses, pharmacists, drug regulatory, patent officers, therapists)
- Erratic drug supplies
- Limited distribution
- Lack of regulation during distribution
- Confusing procedures
- Inaccessibility (many patients are too ill or poor to travel to health services)
- Uneven distribution of services (patients are often reluctant or afraid to travel, experience language barriers, or fear the unknown)
- Limited access to voluntary HIV counselling and testing (VCT)

### Social Issues:

- Stigma and discrimination
- Lack of knowledge
- Denial of diagnosis
- Misinformation
- Inadequate integration of traditional healers into comprehensive care

**Educational Issues:**

- HCWs lack knowledge of palliation and symptom control
- Use, scope, and side effects of ART
- Treatment of opportunistic infections (OIs)
- Patients and carers fear that using opioids for analgesia will cause addiction and/or abuse
- Patients and carers lack knowledge of symptom control
- HIV transmission and symptoms
- Scope of ART

### 6.2.3 Role of Government in Provision of Palliative Care

**Local Government**

Education and support of local government officials aids planning and informed decision-making about drug requirements, the allocation of the drug budget for other health problems, and the balance between prevention and treatment of OIs, ART, and palliative care.

**Policy Makers**

Educating policy makers is critical to improving drug access, especially access to morphine.

Policy makers should be educated in the clinical uses of drugs and in any legislation or policies that limit or prevent access.

**Research**

Policy should encourage research, both in clinical practice and in methods of delivering service

### Formation of National Policy for Palliative Care

This is not currently available in Kenya. A national policy on palliative care should include ensuring access to oral morphine (addressing fears, e.g. who can prescribe it, ensuring a cheap and reliable supply). The absence of national policies and government officials' lack of understanding about the importance of palliative care were contributing issues in a number of countries.

### 6.2.4 Structure of National Policies for Palliative Care

National Policy Should Include:

1. Goals and priorities
2. Guidance on integration with other policies and guidelines
3. Development of national guidelines

4. Generic drug quality assessment
5. Resources to allow accurate and continual quantification of requirements
6. Measures to assure uninterrupted drug supply (predicting demand)
7. Effective integration of communities, private health sector, donors, and traditional practitioners, including traditional birth attendants
8. Continual evaluation and adaptation of guidelines as appropriate
9. Monitoring the rational use of ARVs and other drugs
10. Ensuring proposed projects are viable
11. Education of:
  - o Health personnel
  - o Caregivers
  - o Patients
  - o Community

## Access and referral process

Services should be available and accessible to all clients. The referral process should be well organized. There should be guidance for use of resources and storage of the same.

## Treatment Guidelines

National guidelines are essential. Guidelines aid in:

- Rational drug use
  - o Only necessary drugs
  - o The correct drug for the condition
  - o The correct dose
  - o The correct length of time
- Drug procurement: Care plans can be used to negotiate reduced prices with pharmaceutical companies.
- Training of HCWs (standard clinical management protocols and limited number of drugs)
- Patient education
- Monitoring and evaluation

## Accountability

To ensure accountability records need to be kept throughout the whole supply chain: from importation, manufacture, wholesale, transportation, movement within health centres, supply or destruction of expired drugs.

## National Drug Laws

### National Drug Regulatory Authorities

Drug laws vary between different countries. In Kenya, the Pharmacy and Poisons Board (PPB) regulate their implementation. The PPB is responsible for drug evaluation and approval, and for guaranteeing the quality, safety, and efficacy of drugs registered within the country. Policies should ensure the PPB has adequate capacity. Drug laws need to be relevant and practical to clinical practice.

### Drug Classes

Nationally approved drugs are usually classified into different categories. Different restrictions as to who can prescribe, dispense, manufacture, etc., apply to the different categories. Morphine and other opioids are usually under the tightest restrictions in respect to who can handle it.

### Coordination and Quality Control

Coordination of procurement and quality control reduces the number of stakeholders and improves negotiation with industry. To assist in procurement in developing countries WHO provides up-to-date information on sources and prices of selected medicines and diagnostics for people living with HIV&AIDS.

They regulate;

- Importation
- Manufacture
- Transportation
- Prescribing
- Dispensing
- Drug Costs
- Patents and Intellectual Property Rights

## 6.2.5 Palliative Care Associations

### Overview

The concept of palliative care is dynamic, changing, and relatively new in many African countries. It requires collaboration and respect for each other as members of a team. Palliative care associations are central to the development of palliative care services within a region. The palliative care association is an important forum for members to meet and share ideas, challenges and best practices amongst themselves.



It is also a good place to meet with potential donors and departments of health and welfare. The associations' specific roles and responsibilities vary according to the region they serve, the resources available in the region, and the development of palliative care in the region.

Kenya Hospices and Palliative care Association (KEHPCA) takes lead in palliative care issues in Kenya. The association was formed to represent palliative care providers nation wide and is currently working closely with the Ministry of health (MOH), National AIDS Control Council (NACC), the National AIDS and Sexually Transmitted Disease Programme (NASCO), other NGOs and Community Based organizations to address issues of service delivery; advocacy; policy and capacity building in palliative care in Kenya.

It is a non profit marking organization, was registered in 2005 and set up a secretariat in 2007. The association's vision is: Quality Palliative care for all.

The common roles of palliative care associations include education, networking and support, setting standards, advocacy, and publications.

## Education

Education is key to the development of palliative care within the African region. This includes training health care professionals to a level of knowledge and skills that equips them to provide palliative care within their setting.

## Networking and Support

Networking is the process by which two or more organizations and/or individuals collaborate to achieve common goal. Networking is a vital function of palliative care associations. The ethical, technical and managerial demands of HIV&AIDS and other Life threatening illnesses are on such a scale that they can only be addressed by cooperating as much as possible.

A network is defined as:

- A group of organizations/individuals who come together to pursue joint goals or common interests
- A venue for social action through exchange and mutual learning
- Sustained through some form of communication
- Committed to a jointly developed structure and shared responsibility
- Based on member ownership and commitment to shared objectives and means of action

## Setting Standards

It is important to set and recognise standards for palliative care within countries, when initially developing services and when the services become more established and widespread through out the country. Palliative care associations are ideally positioned to set and monitor guidelines and standards for palliative care within their context. These include standards for staffing, clinical care (e.g., pain control), and philosophies of care.

## Advocacy

Palliative care associations have a mandate to promote palliative care in the local community by mobilizing and enabling health care professionals to impart knowledge to the community and the media, such as on the safe use of morphine. They also must advocate for the availability of palliative care drugs for all in need, and for affordable and appropriate palliative care to be incorporated into the whole spectrum of health care services.

## Publications

Most palliative care associations have some type of publication, whether an informal newsletter or a peer-reviewed journal. These publications provide important forums for exchanging and disseminating information and research and sharing best practices. They are also tools for communicating information about research projects, training programs, and funding opportunities, and are important in the associations' overall communications and advocacy efforts.

## Other Roles

### Fundraising

Support to hospices and palliative care units

Role of stakeholders and relationship

- Promote palliative care to other relevant national bodies
- Share information in with each other openly
- Involve patients and carers in developing services
- Facilitate creativity and empower change
- Reflect the views of individual hospice and palliative care providers

## UNIT 6.3: STRUCTURES IN A PALLIATIVE CARE PROGRAM



**Time: 1 hour**

### **OBJECTIVES:**

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

1. Define organizational structure
2. Discuss basic policies and procedures in palliative care
3. Explain the layout of the respective organograms
4. Discuss various structures in a palliative care set up

## **COURSE NOTES**

### **6.3.1 Organizational Structure**

This refers to models/settings/layouts e.g.

- Community based (community groups via support groups using community resources),
- Home based (in-home),
- Facility/ hospital (in patient or outpatient), hospice (in patient or outpatient)
- Mobile (camel, bicycle, motorbike, vehicles)

Administrative structure- government, community - referral mechanisms, linkage to facilities and program organograms as relate to palliative care

### **Defining Organizational Structure**

In the beginning, you may have only one or a few staff members. They may even all be volunteers. Regardless, you need to decide very early on what services to provide. This will guide you as to what professional staff you need to employ or have access to, what volunteer input you will require, and what other structure you need to put in place.

**Steps Include:**

- An organisational layout with clear reporting
- Job descriptions and letters of appointments
- A volunteer database organised in terms of expertise and availability
- A volunteer policy that covers how the organisation manages, protects, and supports its volunteers

### 6.3.2 Basic Policies and Procedures in Palliative Care

These will be added from time to time, and should include:

- Financial management and accounting
- Media
- Ethics
- Human resources
- General, such as motor vehicles and worker's compensation
- Lines of Communication

### 6.3.3 The layout of the Respective Organograms

**Organograms**

An organogram is a description of an organisation's structure, which reflects different departments. It is often referred to as the map of the organisation that outlines the various level structures.

Organisations need to clarify the roles of staff and identify, firstly, who their key players are and, secondly, how every other job title fits into the successful operation of the organisation.

Organograms also:

- Ensure that job functions, reporting, line management, and levels are defined correctly so that up-to-date job profiles can be put in place
- Assist with job planning and career development
- Help identify branching in or out of job families

An organogram development process has two phases:

**1st Phase:**

Development of a functional structure that reflects the functions of the various elements of the organisation

**2nd Phase:**

Develop positions for establishing the organisation structure. This structure reflects

the accountabilities and role designation of staff members and forms the basis for developing clear and specific job roles and profiles.

Once the development process is complete and the organogram is finalised, it must be kept updated regularly as changes take place. The organogram is a vital tool as well as a flexible document that is used in times of organisational change and restructure.

#### 6.3.4 Structures in a Palliative Care Set up

##### Grafting palliative care onto existing community-based support organizations

Many support organisations have networks into the communities and involve caregivers at the village level. Using these community-based organisations (CBOs) is obviously a way to rapidly scale up care of the critically ill and those at end of life within the community.

##### **Community Day Care**

Here, the community comes together and prepares a day for the patients receiving palliative care to meet together in a centre, which may be the community centre or a local church from where they receive their care services.

##### **Community-Based Caregivers Link**

Community caregivers or vigilantes are carefully selected and trained volunteers who identify and care for people within the community who are in need. They work closely with the formal palliative care team. Individuals doing this form of community work find even those who have not accessed health care in the past who now are dying of cancer or HIV&AIDS.

##### **Inpatient Hospice**

Inpatient units are ideally placed to provide intensive clinical teaching. They often develop protocols for treatment and care that are then rolled out to benefit the broader community.

##### **Small Homes for Care**

##### **Care By Faith-Based Organisations**

Many FBOs have developed caring groups ready to move in and assist with patients in the end of life. These groups work well when networking with other palliative care services in the area.

##### **Integrated Community-Based Home Care**

The collaborative model of integrated community-based home care involves not a single organization, but the collective efforts of many organizations working together e.g. A hospice works closely with government hospitals and primary health care clinics.

## UNIT 6.4: RESOURCE MANAGEMENT IN A PALLIATIVE CARE PROGRAM



**Time: 1 hour**

### **OBJECTIVES:**

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

1. Define resource management in palliative care
2. Discuss how to establish a palliative care unit based on available resources
3. Discuss the importance of record keeping

## **COURSE NOTES**

### **6.4.1: Resource Management in Palliative Care**

These include:

- Financial management
  - Accountability – control systems
  - Record keeping
- Human resource (HR) management
  - Capacity building
  - Motivation
  - Appraisal systems
  - Occupational hazards
  - HR Database
- Commodity management
  - Procurement
  - Distribution
  - Inventory maintenance
- Records keeping on resources
- Reporting on resources at different levels
  - Within the program
  - To partners/stakeholders

## Defining Organizational Structure

In the beginning, you may have only one or a few staff members. They may even all be volunteers. Regardless, you need to decide very early on what services to provide. This will guide you as to what professional staff you need to employ or have access to, what volunteer input you will require, and what other structure you need to put in place.

### 6.4.2 Establishing of a Palliative Care Unit Based on Available Resources

Starting a palliative care centre involves

- A vision and a passion to help which should be shared with others
- Formation of a steering committee as an oversight team to coordinate and monitor progress and later a board to be constituted
- Constitution that articulates the vision and goals of the institution.
- Cultivating teamwork, cooperation and respect which will form the basis for service delivery to patient and family.
- Capitalizing on natural talent and interests, cultivate good cooperative habits, and provide continual attention and training so that each member contributes to her or his maximum potential.
- Record keeping: Clinical records, Administrative and financial
- Management:
  - Strategic Planning (scheduled forecasting)
  - Accessing Funding
  - Financial forecast:
  - Budget
  - Grant writing
  - Monitoring and Evaluation: Internal and external audits of the standards of clinical care are imperative and should always be welcomed, as a learning process.
  - costing of services, and ensuring that each department is aware of them, promotes optimal use of whatever human and material resources are available.
  - Integrity and accountability which will give the institution credibility

### 6.4.3 Growth and Development:

Organizational growth depends on many factors, including:

- Managing, and not venturing beyond, your limitations
- Consulting with others who have walked the path before you
- Having a respectful and invitational management style

- Building teams and being willing to adapt them
- Being open to change and suggestions from staff and others.
- Developing skills and careers
- Nurturing staff and recognizing their achievements
- Focusing on sharing skills in training and discussion sessions
- Setting up mentorship for newcomers with more experienced staff
- Ensuring that each member of the team stays focused on their task of care for the patient and family.

## **Sustainability**

This worrisome task confronts top management in every sphere, whether a business or community-based organization. It is important to work at building respect and credibility locally, nationally, and internationally. The only way to do this is to conduct your affairs in a resolute manner, stay with your ideals and within your budget, and remain financially transparent.



## UNIT 6.5: SUPPORTIVE SUPERVISION, MONITORING AND EVALUATION IN PALLIATIVE CARE



**Time: 2 hours**

### **OBJECTIVES:**

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

1. Define supportive supervision
2. State the importance/benefits of support supervision
3. Distinguish between monitoring and evaluation
4. Discuss the importance of monitoring and evaluation in PC programs
5. Discuss types and qualities of monitoring and evaluation tools
6. Discuss monitoring and evaluation processes and activities
7. Discuss M, E & R Challenges in PC programs
8. Discuss the role of research in palliative care

## **COURSE NOTES**

### **6.5.1 Supervision in Palliative Care**

There is a need for a supervision checklist and guidelines that cover availability of service, quality, scope and competence of providers, gaps identification and quality of supervision.

#### **Definition**

Supervision is the overall range of measures to ensure that the caregivers involved carry out their activities effectively and efficiently and become better and more competent to carry out assigned roles. It entails enabling people to do their work in a better way. It involves the ability to see something from a higher level or the ability to see more than others. Supervision is for the purpose of promoting continuing improvement in service delivery.

## Supervision involves:

1. People in order to establish if they are doing their work well, their skills, attitude, interest and knowledge. Interventions are planned according to gaps identified.
2. Activities: to establish if activities are being correctly implemented; if everything is going as planned and whether tasks are well coordinated
3. Materials-Whether the required materials are available at the right time and whether they are being put to proper use.

## Role of the Supervisor

To enable staff:

- To manage the quality-improvement process;
- To meet the needs of their clients; and
- To implement institutional goals.

This approach emphasizes mentoring, joint problem solving, and two-way communication.

## Styles of Supervision

1. Traditional (Autocratic)
2. Facilitative (Supportive)

### Traditional (control) supervision

1. Focuses on helping staff solve problems through the use of quality-improvement tools.
2. Focuses on processes rather than individuals.
3. Assists staff in planning for future quality-improvement goals.
4. Is continuous and builds on past gains while setting higher quality-improvement goals.

### Disadvantages of Traditional Supervision

- It is superficial
- It is often punitive, fault-finding, and critical
- Focuses on individuals rather than on processes
- Focuses on control, not teamwork
- Emphasizes the past rather than the future
- Is not continuous

### **Facilitative Supervision**

It is a system of management whereby supervisors at all levels in an institution focus on the needs of the staff they oversee. Supervisors consider their staff as their customers.

#### **Benefits of facilitative (supportive) supervision**

1. Fewer problems to solve by yourself
2. Less need to provide technical assistance
3. Gain of good reputation
4. Being more welcome at sites
5. Satisfaction of success
6. More fulfilling job

The following are not included in facilitative supervision;

1. Hiring staff
2. Developing job descriptions
3. Conducting performance evaluations
4. Reprimanding staff
5. Firing staff

## **6.5.2 Monitoring, Evaluation and Reporting**

### **Overview**

Monitoring and evaluation (M, E & R) is critical for ensuring that successful interventions become part of an integrated health service. M, E & R offers powerful tools to ensure that funders, policy makers, implementers, and researchers remain abreast of the impact, efficacy, efficiency, and the overall success of a program.

### **What is Monitoring and Evaluation?**

Monitoring and evaluation form the essential elements of a control and reporting system.

Monitoring is an ongoing assessment of progress of implementation of planned activities to achieve goals and objectives. It helps to determine whether any change that has occurred due to a program has been worthwhile or effective.

Evaluation is a point assessment of actual progress towards goals and impact to target groups. It is scheduled (midterm or end term evaluation)

## Importance of M, E & R

It is important for organizations to assess whether and how well they are achieving their aims and objectives. M, E & R often is seen purely as a requirement of funding agencies and therefore as an external necessity. But the goals are much broader than that, and

should be seen as a strategic system for assessing organizational capacity and economic effectiveness and predicting future sustainability.

### **An effective M, E & R system gives palliative care organizations the ability to:**

- Evaluate how effectively they promote change.
- Monitor how efficiently they promote change.
- Foster public and political cooperation and support particular information needs for target audiences
- Equip managers with a tool to gain timely information on the progress of activities, allowing comparison of what was planned to what is occurring.
- Promote organizational learning and encourage adaptive management

### **Goals of M, E & R for Palliative Care**

- Achieving the best possible care for consumers/program improvement
- Measuring palliative care and training activity
- Cost effectiveness
- Feedback for staff (based on successes, achievements, needs, inventory of Palliative care and training successes within the region)
- Reappraising objectives
- Course correction and program improvement/improving efficiency
- Program decision-making—determining what works and what doesn't work (Fast-tracking and scaling-up effective programs)
- Learning from mistakes, training other programs in best practices and proven models in Kenya and beyond
- Accountability to donors
- Increased credibility to obtain additional resources
- Advocacy for funding/policy

## **6.5.3 Types and Qualities of Monitoring, Evaluation and Reporting Tools**

1. Formative assessments and research (concept and design)
2. Monitoring (monitoring inputs, processes, and outputs; assessing service quality)
3. Evaluation (assessing outcome and impact)
4. Cost-effectiveness analysis (including sustainability issues)

## Questions Addressed By the Different Types of M, E & R

- Is an intervention needed, e.g., palliative care?
- Who needs the intervention, e.g., people with HIV&AIDS or cancer?
- How should the intervention be carried out? For example what model of palliative care delivery best suits the need?
- To what extents are planned activities actually realized, e.g., has the palliative care service been set up?
- How well are the palliative care services provided?
- What outcomes are observed e.g. is there better pain control?
- What does the outcome mean e.g. what does it mean if pain is not controlled?
- Does the program make a difference?
- Should program priorities be changed or expanded?
- To what extent should resources be reallocated?

## M, E & R Frameworks

Different M, E & R frameworks exist and can be applied as appropriate.

### Monitoring, Evaluation, and Reporting (MER) Results-Based Framework

A results-based Monitoring, Evaluation and Reporting framework helps to see things within the larger picture and look at how a program's results contribute to achieving the highest level and longest-term impact that can be anticipated for an intervention—such as increasing access to quality palliative care. The MER system will mirror the expected program results at different levels when using a results-based framework.

In the MER, results are measured at different levels as follows;

- Inputs (results relating to provision of resources and processes)
- Outputs (results relating to short-term change effects and results sought)
- Outcomes (results relating to intermediate change and effects sought)
- Impacts (results relating to long-term change and effects sought)

### Participatory M, E & R Framework

A participatory M, E & R framework offers inclusive ways of assessing and learning from change. It also rethinks the issue of who initiates and undertakes the process and who learns or benefits from the findings. A participatory M, E & R framework works best at the community level.

Participatory M, E & R is based on four main principles i.e.

- Participation
- Negotiation
- Learning
- Flexibility

## A Framework for Clinical Audit

**Definition:** Clinical audit is a method of reviewing clinical practice against agreed standards of care to identify areas for improvement in the quality of care. It is a systematic critical analysis of the quality of clinical care, including the procedures used for diagnosis and treatment, use of resources and resulting outcomes and quality of life of the patient

## The Audit Cycle

- Choose Your Topic; For example for the management of AIDS-related pain; What should be happening?
- Criteria and standards e.g., is the WHO analgesic ladder being used?
- What is actually happening?
  - Data collection e.g. review of pain charts
  - Analysis and dissemination of results
  - Identify poor performance e.g., where the WHO analgesic ladder is not being used, implement changes e.g., teaching on WHO analgesic ladder
  - Re-audit performance

## Quality Improvement Framework

The quality improvement cycle provides an easy means of ongoing monitoring and evaluation. It is an ideal tool to collect, analyze, and process data, rapidly converting data into practice based on needs and identified constraints.

## M, E& R Tools

### Work plan

An M, E & R work plan needs to be flexible and show the steps used to document a program's activities and assess progress towards achieving its goals and objectives. An organization must be clear about what needs to be measured and how it will be measured.

**Indicators**

Definition: An indicator is a unit of information measured over time so that change can be documented. It gives specific information providing evidence of the achievement (or not) of results and activities. Required data for indicators can be measured using both quantitative and qualitative data collection methods:

1. Quantitative data documents numbers associated with programs and focus on what and how often different elements of a program are being carried out.
2. Qualitative data looks at how well elements of a program are being carried out. They can show change in behaviour or attitude

**Methods for collecting data for M, E & R**

- Structured or semi-structured questionnaires
- Structured or semi-structured interviews
- Discussions and focus group discussions
- Review of documents and existing data
- Logs or diaries
- Observation
- Off-the-shelf audit packages
- Satisfaction surveys
- Review of comments and complaints

**The Process of M, E & R**

Although different people will be involved in different types of M, E & R, it is important that all key stakeholders are involved to increase utilization of results. M, E & R will be carried out in different ways and may be done internally, by peers, or externally:

**Internal audit**

The hospice or palliative care organization should identify one or two people who are trained as assessors to carry out an internal audit.

**Peer review**

The regional or national organization should identify one or two people who are trained as peer assessors.

**External audit**

This would be carried out by the donor or an organization appointed by the donor with an agreed-upon notice period

Who does the audit and how it is done will depend on the M, E & R framework being used and who needs the information (e.g., program managers or donors) and what they need.

#### **When Should M, E & R Take Place?**

It is an ongoing process that needs to take place continually, with some indicators being measured more frequently than others.

#### **6.5.4 M & E Challenges in Palliative Care**

- Under- or over-doing it.
- Waiting until the last minute to set up a data system, enter, or analyse data
- The 'fear factor' e.g. will what they receive be affected by what they say
- Difficulties with memory or perceptions
- Challenging the notion of vigorous data collection, analysis, validity, and reliability by using a participatory M, E & R approach that incorporates different ways of looking at the data
- Difficulty in scaling-up the M, E & R process.
- The fine line between research and M, E & R.
- Defining what, exactly, to measure.
- Determining what we mean by quality palliative care, how to measure it, and whether it is the same everywhere.
- Ethical and cultural issues.
- Evaluation of the palliative care services by relatives of the actual person who received care and has died.
- The lack of M, E & R expertise within some of the palliative care organisations in the region and the need for technical assistance in this area
- Integration of M, E & R into palliative care services
- Concerns about the use and relevance of outcome scales within the palliative care setting

#### **6.5.5. Research in Palliative Care**

##### **Definition**

An attempt to increase the sum of what is known, usually referred to as a body of knowledge by the discovery of new facts or relationships through a process of systematic scientific inquiry, the research process

Research is about generating new knowledge

Evidence-based practice is clinical practice informed by the best knowledge available.



## Purpose of Research

- Research is there to investigate the underlying reasons for events.
- It has a key role to play within a continuous improvement process
- It sits alongside audit and development activity
- To identify gaps in knowledge
- To fill the gaps in knowledge
- To broaden our scope of understanding
- To discover new treatment, new techniques of clinical management
- To test effectiveness and efficiency of intervention
- To inform policy decisions
- To Improve quality of care

## The Research Process

Research is a systematic process. As such we may define a series of stages that we would expect to see in any research study. These may be considered as:

- Preliminary questions
- Defining the research question
- Evaluating other work in the field: reviewing the literature
- Designing the research study
- Collecting Data
- Analysis of the data
- Interpreting the results
- Dissemination of the results
- Implementation of evidence-based practice

## Types of Research Design

### Experimental

Examine and establish casual links between variables.

The researcher introduces and manipulates a variable and then measures its effects on another variable e.g. compare two treatments outcomes

### Survey

To obtain information from populations regarding the prevalence, distribution and interrelationship of variables within those populations

### Case Studies

Focus on specific situations

Researcher studies individuals, groups, or specific phenomena

## Data Collection Methods

### 1. Quantitative

- All approaches that can be quantified
- Technology for counting and measuring
- Physiological measurement
- Observational measurement, rating scales, check lists
- Questionnaires

## Data Analysis Techniques

- **Descriptive statistics** – which describe and summarise data e.g. frequencies, percentages
- **Inferential statistics** – which allow the researcher to infer whether relationships found in data e.g. cross tabulation, chi square, SPSS

## Data Collection Methods

### 2. Qualitative

- Interviews, observation
- Pictures, photographs, collages
- Videos
- Music
- Art
- Poetry
- Essays
- Diaries

### Data Analysis Techniques

- Transcriptions of interviews / Field Notes
- Categories, concepts, themes, patterns, trends, hypotheses and theories emerge
- Computerised data management packages e.g. ethnograph, QUALPRO, TAP

## References

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1. MOH (2005) Implementing Best Practices in Family Planning; Update Manual for Service Providers; MOH – DRH Nairobi, Kenya.
2. Nduba, S & Hebert I.V.A. (2005) Home Based Care Training manual for Health professionals as Facilitators and for Home Based Care givers; AMREF, Nairobi, Kenya
3. A Handbook of Palliative Care in Africa, 2010, eds. Julia Downing, Mackuline Atieno, Stephenie Debere, Faith Mwangi-Powell, Fatia Kiyange. African Palliative care Association
4. MOH – DRH (2006) Adolescent sexual Reproductive Health – A Trainers Manual for Health Service Providers; MOH Nairobi, Kenya



# Practicum Visit

## Module 7



**Time: 12 Hours**

### **OBJECTIVES:**

At the end of this unit the participants will be able to:

1. Participate in palliative care activities including care of terminally ill AIDS and cancer patients.
2. Identify strengths and weaknesses related to palliative care service delivery practices at the practicum site
3. Draw a list of appropriate recommendations to strengthen palliative care practices at the practicum site and for their facilities

### **Content:**

**Session 1:** Orientation to palliative care practicum

**Session 2:** Site Visit

**Session 3:** Plenary Discussion

**Session 4:** Attachment to a palliative care centre/hospice

SESSION 1: ORIENTATION TO PALLIATIVE CARE PRACTICUM

SESSION 2: SITE VISIT

SESSION 3: PLENARY

SESSION 4: ATTACHMENT TO A PALLIATIVE CARE CENTRE/HOSPICE



# Annexes

## Annex 1: Training Schedule

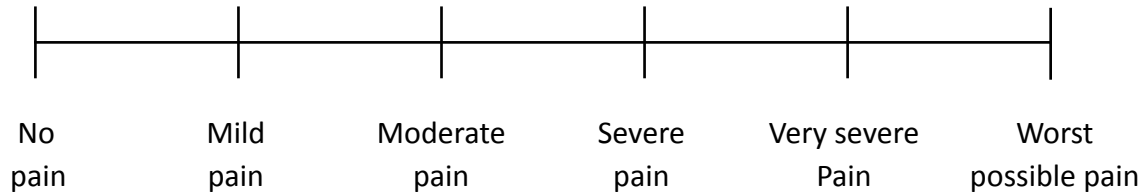
TIME	DAY 1	DAY 2	DAY 3	DAY 4	DAY 5
8.30-9.30AM	Introduction Expectations	Ethical issues in PC	Symptom assessment	Mental illness	Nutritional counselling
9.30 -10.30AM	Opening remarks PRE-TEST	Physiology and pathophysiology of pain	Symptoms management	Skin and oral care	Drug and Food interactions
<b>10.30- 11 AM</b>	<b>TEA BREAK</b>				
11-12 NOON	Concepts of palliative care	Pain assessment	Complications of chemo/ radiotherapy in PC	End of Life care	Concepts of psychosocial aspects of PC
12-1.00PM	Interdisciplinary team approach	Pain management (principles)	PC emergencies and management	Introduction to human nutrition	
<b>1.00-2.00 PM</b>	<b>LUNCH</b>				
2.00-3.00 PM	Resources and basic PC services	Structures in PC	Supportive M & E	Relation between nutrition and disease	Communication
3.00 -4.00PM	Systems strengthening in PC	Resource management	Research in PC	Clinical assessment and nutritional requirements	

TIME	DAY 6	DAY 7	DAY 8	DAY 9	DAY 10
8.30-9.30AM	Communication in PC	Spirituality in PC	Paediatrics (CLINICAL)	Paediatrics (SOCIAL)	PRACTICUM (Plenary) PRACTICUM (plenary)POST TEST
9.30 -10.30AM					
<b>10.30- 11 AM</b>	<b>TEA BREAK</b>				
11-12 NOON	Counselling	Support for carers	Loss, grief and bereavement	Human sexuality	<b>Closing ceremony</b>
12-1.00PM		Practicum		Complimentary therapies in palliative care	
<b>1.00-2.00 PM</b>	<b>LUNCH</b>				
2.00-3.00 PM	Counselling	Practicum	Practicum	Practicum	DEPARTURE
3.00 -4.00 PM					
4.00 -5.00 PM					

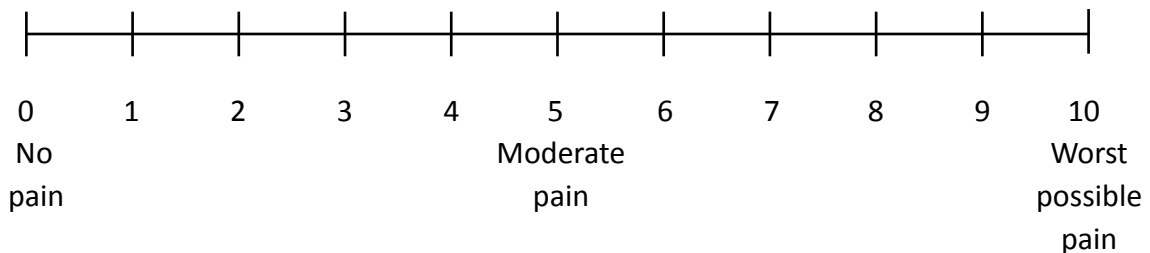


## Annex 2: Pain intensity scales

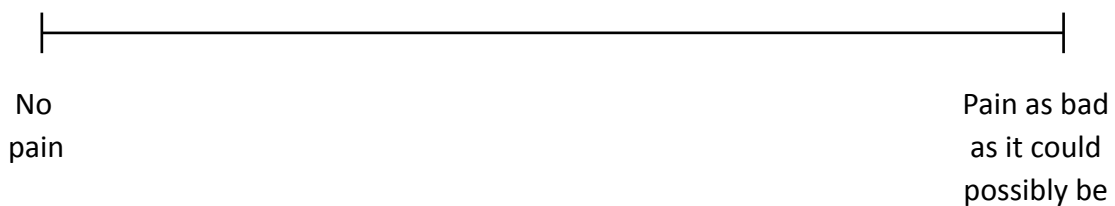
### Simple Descriptive Pain Intensity Scale<sup>1</sup>



### 0-10 Numerical Pain Intensity scale<sup>1</sup>



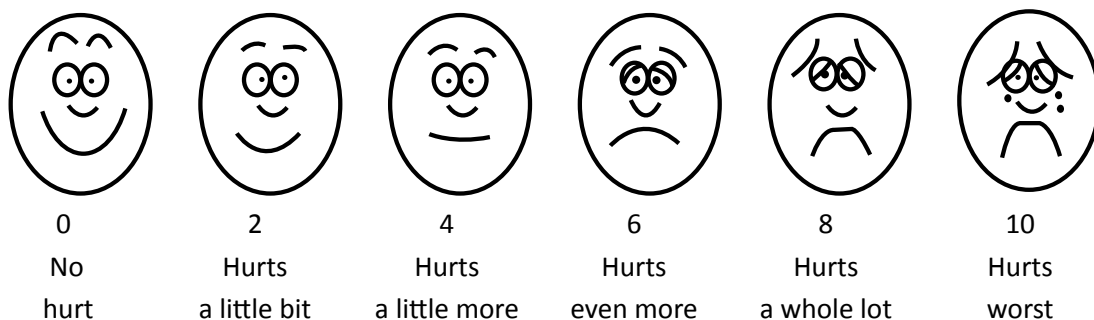
### Visual Analogue Scale (VAS)<sup>2</sup>



<sup>1</sup> If used as a Graphic rating, a 10-cm baseline is recommended.

<sup>2</sup> A 10-cm baseline is recommended for VAS scales.

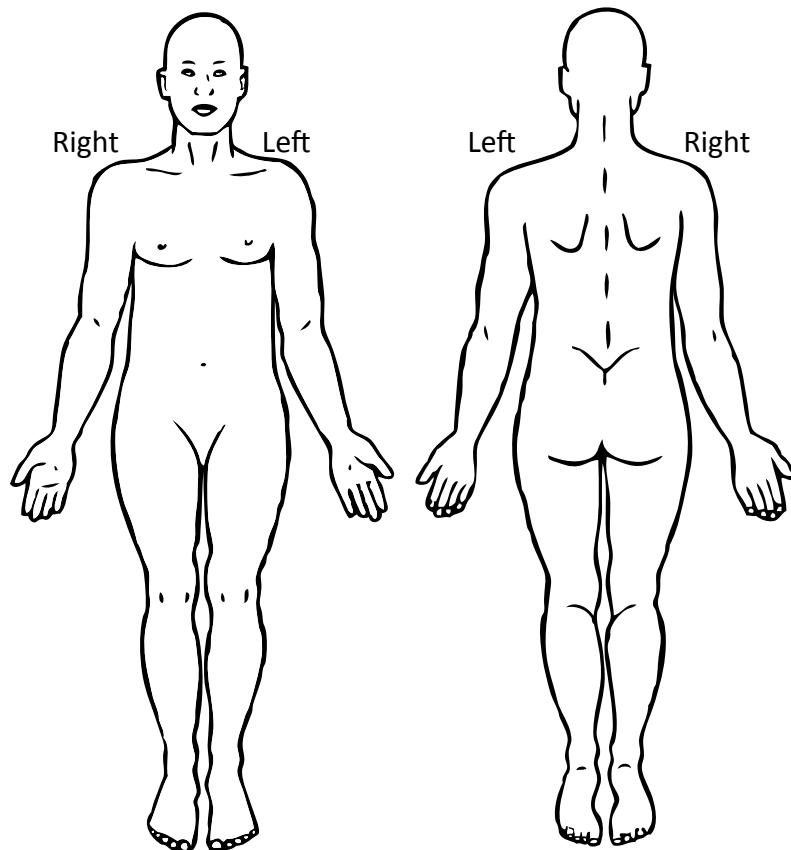
Source: AHCP, 1992.



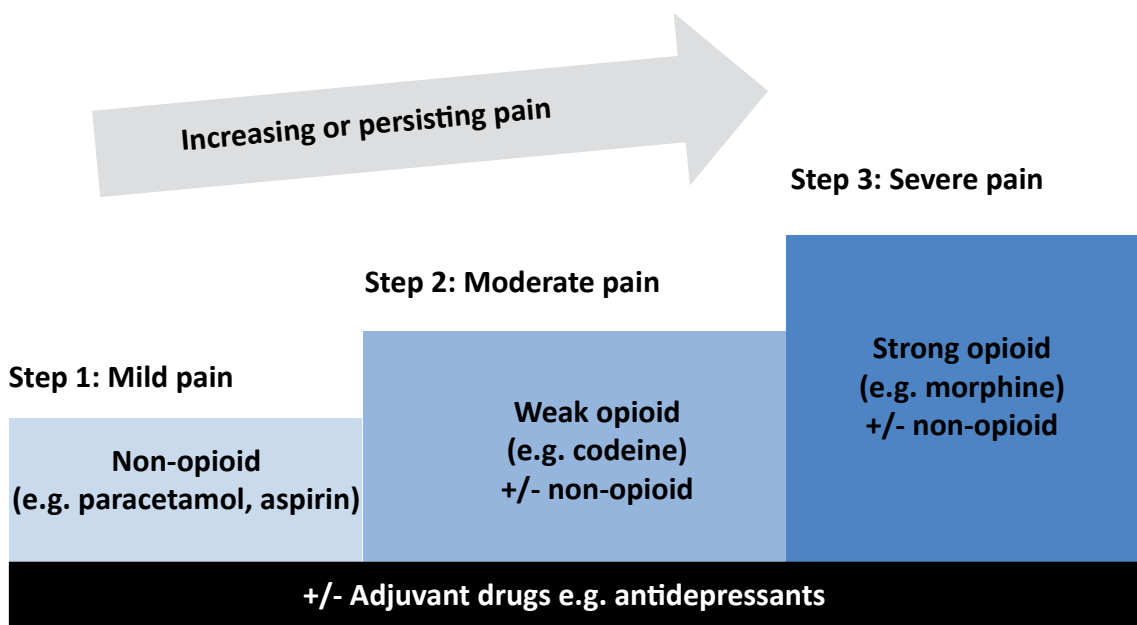
Explain to the person each face is for a person who feels happy because he has no pain (hurt) or sad because he has a lot of pain. Face 0 is very happy because he doesn't hurt at all. Face 2 hurts just a little bit. Face 4 hurts a little more. Face 6 hurts even more. Face 10 hurts as much as you can imagine, although you don't have to be crying to feel this bad. As the rating scale recommended for persons age 3 and older.

Source: Wong DL, Hockenberry-Eaton M, Wilson D, Wilkenstain ML, Schwartz P. Wong's Essentials of Paediatric Nursing, 6th ed St. Louis: Mosby, Inc, 2001. Copyrighted by Mosby, Inc. Reprinted by permission.

**Annex 3: Body Chart (pictogram)**



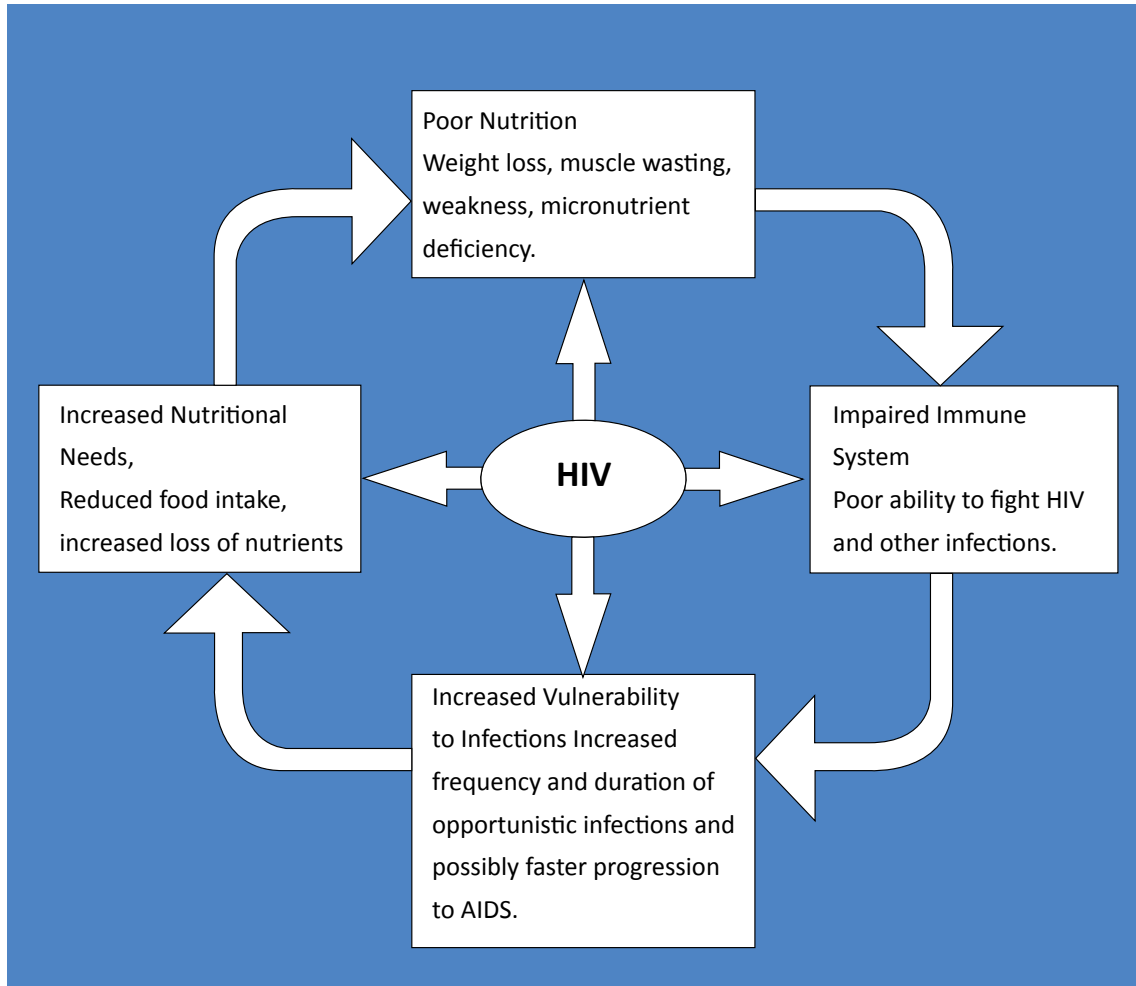
**Annex 4: The WHO analgesic ladder**



**Annex 5: Care of the skin**

<b>Intervention</b>	<b>Rationale</b>
Minimise shower or both time, and do not bathe or shower more than once a day. Apply moisturizer such as vaseline emulsifying ointment after bathing. Humidify the air by boiling water.	Prevent drying of skin.
Avoid hot water and sitting next to heater.	Prevent vasodilation, which exacerbates itching.
Use soap sparingly if at all. For soap, use gentle cleaners (plain white toilet soap or aqueous cream); avoid deodorant soap. Add soluble bath oil or aqueous crème 1 tbs to bath water.	Prevent removal of skin's natural moisture; deodorant soap dehydrates and may irritate the skin.
Use soft, non abrasive sponge, wash-cloth and towels. Minimise friction during cleansing and drying (pat skin dry).	Prevent mechanical irritation.
Moisturize frequently with water-soluble lotion or emollient. Apply two to threetimes a day, including after bath while the skin is still damp and at bedtime. (Products include Vaseline and emulsifying ointment.)	Adds or helps to retain moisture.
If the above lotions are ineffective, use lactic acid, urea (10% urea cream), or sodium lactate moisturisers, or 20% salicylic acid.	Adds or helps to retain moisture.
Keep typical cream and ointments cool or refrigerate	The cooling sensation has an antipruritic effect.
Encourage fluids intake, but avoid or discourage drinking alcohol.	Maintains hydration of skin.
Avoid restrictive or non-absorbent clothing.	Guards against mechanical irritation.
Keep fingernails short and smooth.	Guards against breaking the skin while scratching.
Wash hands frequently.	Prevents contamination of open areas.
Use fragrance-free products rather than unscented products.	Unscented products may contain fragrance masking which elicit allergic responses in some patients.
Avoid lanolin-based creams.	Produces high rate of allergic response.

**Annex 6: Nutrition and HIV & AIDS vicious cycle**



*Source: Nutrition Management in Comprehensive Care Centres in Kenya (Trainer's Manual, 2007)*

## Annex 7: “Power packing” foods

Add these extras to foods you already eat to make every bite count for more.

- Margarine, butter, oil
- Nuts
- Gravies, sauces
- Sugar, honey, jams, jellies
- Dried fruit
- Mayonnaise, salad dressing, sour cream
- Cream cheese
- Granola
- Avocado
- Cream, half and half or whole milk

### “Power Packing” Foods

Power Pack the foods you already eat to make them even higher in protein and calories!

#### Here’s how:

- Baked beans + cheese on top = Power Pack
- Scrambled eggs + milk + cheese + margarine = Power Pack
- Bread + peanut butter + jelly = Power Pack

#### Ways to Add Snacks

- Eat on a schedule every two hours, even if only a couple of bites
- Ask for help from your family and friends to help with grocery shopping and food preparation
- Prepare ahead
- Pack a snack or supplement if you know you are going to be in one place for long (such as waiting rooms, planes, cars, etc.)

#### Protein requirements

Protein requirements increase with age from early childhood to adolescence. An optimum protein intake should be about 1g per kg body weight. However this can reduce or increase depending on the severity and the stage of the disease

Main source of proteins in Kenya are;

Animal sources: Milk and milk products, eggs, beef, pork, mutton, fish and poultry.

Plant sources: pulses and legume which includes beans, peas, lentil, soya beans, and groundnuts.

**Strategies to meet protein requirements**

Protein builds and repairs tissues. Include these foods with each snack and meal.

- Milk, yogurt, cream, half and half
- Nonfat dry milk powder
- Yogurt
- Meat, fish, chicken
- Beans and peas (kidney, pinto, etc.)
- Cheese or cottage cheese
- Eggs or egg substitute
- Nuts or peanut butter
- Soy foods (tofu, soy milk, soybeans, soynuts)

**Annex 8: APCA AFRICAN POS**

ASK THE PATIENT	POSSIBLE RESPONSES
Q1. Please rate your pain (from 0 = no pain to 5 = worst/overwhelming pain) during the last 7 days	0 (no pain) - 5 (worst/overwhelming pain)
Q2. Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 7 days?	
Q3. Have you been feeling worried about your illness in the past 7 days?	
Q4. Over the past 7 days, have you been able to share how you are feeling with your family or friends?	
Q5. Over the past 7 days have you felt that life was worthwhile?	
Q6. Over the past 7 days, have you felt at peace?	
Q7. Have you had enough help and advice for your family to plan for the future?	
ASK THE FAMILY CARER	FAMILY CARER
Present	Absent  <i>(Tick as appropriate)</i>
Q8. How much information have you and your family been given?	0 (none) - 5 (as much as wanted) N/A
Q9. How confident does the family feel caring for you (Client) ____?	0 (not at all) - 5 (very confident) N/A
Q10. Has the family been feeling worried about you (the Client) over the last 7 days?	0 (not at all) - 5 (severe worry) N/A

