

African Palliative Care Association

# Palliative Care Core Curriculum



Introductory Course  
In Palliative Care



ISBN 978 9970 204 08 3

© African Palliative Care Association (APCA) 2012

All rights are reserved, whether referring to the whole or a part of the material, particularly the rights to reproduce images or text or to translate or reprint. Requests for permission to reproduce text or images, or to translate APCA publications, or any other inquiries, should be directed to APCA, PO Box 72518, Kampala, Uganda.

Tel: +256 414 266 251, Fax: +256 414 266 217, email: [info@africanpalliativecare.org](mailto:info@africanpalliativecare.org)

This curriculum was made possible by the support of the American people through the United States Agency for International Development (USAID) and the AIDSTAR-One project. The African Palliative Care Association takes sole responsibility for the contents of this report, which do not necessarily reflect the views of the donors cited. APCA does not warrant that the information contained in this publication is complete and correct and shall not be liable for any damages incurred because of its use. This curriculum contains generic guidance relating to introducing palliative care within Africa; however, adaptation to the context of each individual country is recommended.

# CONTENTS

<b>Acknowledgements</b> .....	<b>4</b>
<b>Foreword</b> .....	<b>5</b>
<b>1. Introduction and background to the Development OfThe Palliative Care Core Curriculum For Africa</b> .....	<b>6</b>
1.1 Introduction .....	7
1.2 Assessing the need for education and training programmes in Africa .....	7
1.3 A review of existing palliative care curricula and training materials .....	8
1.4 Addressing the gaps in palliative care education and training.....	10
1.5 The curriculum development process .....	10
<b>2. Rationale for a Palliative Care Core Curriculum in Africa</b> .....	<b>11</b>
<b>3. Core Curriculum for an introductory course in Palliative Care for Africa</b> .....	<b>13</b>
3.1 Target group .....	14
3.2 Trainers' credentials.....	14
3.3 Task profile of trainees .....	14
3.4 Competencies .....	14
3.5 Aim of the programme .....	15
3.6 Learning outcomes .....	15
3.7 Structure .....	15
3.8 Learning experiences .....	17
3.9 Assessment and evaluation.....	17
3.10 Resources.....	18
3.11 Follow-up, support supervision and mentorship .....	18
<b>4. Modules</b> .....	<b>19</b>
4.1 Module 1: Introduction to palliative care.....	20
4.2 Module 2: Effective communication in palliative care.....	20
4.3 Module 3: Assessment and management of common symptoms .....	21
4.4 Module 4: Pain assessment and management.....	22
4.5 Module 5: Emotional/psychological and social support in palliative care .....	25
4.6 Module 6: Legal and ethical issues.....	25
4.7 Module 7: Developing and sustaining palliative care services .....	26
4.8 Module 8: Practicum .....	27
<b>5. Recommended books and reference material</b> .....	<b>29</b>
<b>6. Definition of Terms</b> .....	<b>32</b>
<b>About APCA</b> .....	<b>35</b>
<b>About AIDSTAR-One</b> .....	<b>36</b>

## ACKNOWLEDGEMENTS

The African Palliative Care Association would like to acknowledge various organisations and individuals for their contribution to the development of this core curriculum. These include:

- The Diana, Princess of Wales Memorial Fund, UK; USAID through JSI/AIDSTAR-One, and Friends in Global Health, who provided funding support at various stages of the development of the core curriculum for palliative care training for Africa
- The staff at the African Palliative Care Association, who contributed to the curriculum
- Expert reviewers who reviewed the curriculum and provided their input:
  - Eunice Garanganga: Palliative care technical adviser, Hospice and Palliative Care Association of Zimbabwe, Harare, Zimbabwe
  - George Ndikintum: National coordinator, Hospice and Palliative Care Association of Cameroon
  - Joan Marston: Chief executive officer, International Children's Palliative Care Network
  - Lameck Thambo: National coordinator, Palliative Care Association of Malawi
  - Professor Flora Fabian: Dean of the Faculty of Medicine, International Medical and Technological University, Tanzania
  - Professor Dr. Lukas Radbruch, Chair of Palliative Medicine, University of Bonn, Germany
  - Rose Kiwanuka: National coordinator, Palliative Care Association of Uganda
- Mrs Gillian Kasirye of Makerere University, Kampala, who brought in her expert knowledge, experience and guidance on the development of a competence-based curriculum
- Carola Meyer, who edited the document.

## FOREWORD

Palliative care education is one of the four components of the World Health Organization (WHO) public health strategy for palliative care, and its provision is crucial for the effective integration or establishment of palliative care in society and to change the experience of patients and their families<sup>1</sup>. In order to scale up palliative care provision in Africa, there is a need to make palliative care knowledge accessible to all service providers, as well as to educators. Palliative care education and training should be looked at as an ongoing process that begins at undergraduate level and continues through specialist training and into continuing education.

Education and training should aim at developing not just knowledge and skills but also attitudes, beliefs and values. Training needs to be competency-based to ensure that the knowledge is applied at the various levels of service delivery, from primary to specialist services. This is critical for ensuring appropriate knowledge, skills and attitudes for all service providers, including care providers, patients, families and the general public<sup>2</sup>.

To contribute to the availability of basic knowledge and skills for the provision of palliative care in the African region, the African Palliative Care Association (APCA) has developed a competency-based core curriculum framework for use in introductory training on palliative care. The curriculum is based on the *APCA Standards for Providing Quality Palliative Care Across Africa* to ensure that care providers are trained to the appropriate competence for their cadre and level of skill. This curriculum therefore aims to facilitate the development of the best basic skills and attitudes required for the delivery of palliative care services that meet the desired standards of palliative care. The curriculum incorporates theoretical, practical, mentorship and supervision components that are critical to the effective application of knowledge in practice.

APCA hopes that this core curriculum will contribute to the development of positive initial experiences in palliative care and raise enthusiasm and excitement for further development of the discipline across Africa. It is also anticipated that the core curriculum will be used by care providers and educators in the development and implementation of suitable country-based, as well as regional training programmes in palliative care. APCA recommends the adoption of the curriculum, adapted where appropriate, and remains committed to providing technical support through these processes.

### **Dr Faith Mwangi-Powell**

*Executive director*

*African Palliative Care Association (APCA)*

<sup>1</sup>Stjernswärd J, Foley KM and Ferris FD. (2007). *The public health strategy for palliative care. Journal of Pain and Symptom Management*, 33(5): 486-93.

<sup>2</sup>Hospice Casa Sperantei. (2002). *National Standards in Palliative Care. Romania.*

# **CHAPTER I:**

## **INTRODUCTION AND BACKGROUND TO THE DEVELOPMENT OF THE PALLIATIVE CARE CORE CURRICULUM FOR AFRICA**

---

# I. Introduction and background to the development of the Palliative Care Core Curriculum for Africa

## I.1 Introduction

The WHO estimates that the need for palliative care is equivalent to one per cent of a country's total population<sup>1</sup>. This means that approximately 9.7 million people are in need of palliative care across Africa. Despite this, access to culturally appropriate, holistic palliative care is at best limited, and at worst non-existent, for the overwhelming majority of Africans with progressive and life-limiting illnesses<sup>2</sup>. Palliative care is increasingly being developed in Africa, though national scale-up is hampered by the failure to integrate it into health systems. The limited or complete lack of knowledge and skills for the provision of palliative care has been consistently identified as a major barrier to wider access to palliative care services in Africa. Yet according to WHO, the quality of life of at least 100 million people would be improved if today's knowledge of palliative care were accessible to everyone<sup>3</sup>.

Since its establishment in 2005, and through its first strategic plan (i.e. 2007-2010), the African Palliative Care Association (APCA) has made deliberate efforts to support the development of palliative care knowledge and skills across the region. These efforts include: facilitating the delivery of palliative care training programmes through technical assistance to partners; support for the development of training programmes; development of regional standards for palliative care; and the identification of gaps in palliative care education to inform future developments.

## I.2 Assessing the need for education and training programmes in Africa

In 2008, APCA undertook a needs assessment of palliative care education and training programmes across Africa. The assessment was aimed at determining the effectiveness of existing training programmes and identifying any unmet needs. Results would also guide APCA, its partners and member organisations in developing appropriate education and training programmes that address the needs identified.

The needs assessment found numerous training programmes on the continent offering very similar content at similar levels of training, some using highly structured methods of teaching, others very informal. Lecturing was found to be the dominant teaching method. The assessment identified a need to change from this traditional classroom approach to reflective methodologies in teaching palliative care.

The following are some more general findings of the assessment:

- Country-specific training programmes were lacking, though several countries have started to address this gap.
- The curricula were not standardised across institutions.
- A lack of trainers was found to be a central problem and challenge to existing education and training programmes. Although some participating countries reported having palliative care trainers available, especially for short courses, the supply was sometimes inadequate, especially on long courses. A general observation from various countries was that the shortage of trainers had become more acute as the need for care increased.

<sup>1</sup>Harding R, Higginson IJ. Palliative care in sub-Saharan Africa: An appraisal. *Lancet* 2005; 365: 1971-7.

<sup>2</sup>Mwangi-Powell F, Dix O. Palliative care in Africa: An overview. *Africa Health* 2011; 33(5): 19-21.

<sup>3</sup>Stjernswärd J, Foley KM and Ferris FD. (2007). *The public health strategy for palliative care. Journal of Pain and Symptom Management*, 33(5): 486-93.

- Training materials and resources were insufficient. Although some countries reported having various training materials and resources available, other countries reported gaps in this area. More specifically, there was evidence of a shortage of materials relating to regional palliative care practice and needs. While there were many books and other materials globally, these were expensive, and there were few textbooks on palliative care in Africa. Gaps in textbook and journal provision suggested limitations in the breadth and depth of authority that trainers could refer to for content delivery.
- With regard to the assessment and evaluation of the impact of existing palliative care education, a variety of assessment practices was found across the training programmes. Some programmes had highly structured assessment systems; others had no structure at all. Evaluation practices also varied greatly. Some courses were evaluated; others were not. Overall, there was a need for guidelines on assessment and evaluation procedures to be provided to all trainers.

The above findings gave rise to a recommendation that education and training be formalised in order to ensure that the same programmes can be delivered across the continent. This vision can be achieved through the development and implementation of core curricula for different levels of service delivery and different cadres.

### 1.3 A review of existing palliative care curricula and training materials

In 2010, the first edition of the *APCA Standards for Providing Quality Palliative Care Across Africa* was published. This created a need to review existing palliative care curricula and training materials to answer the following key questions:

- Are there curricula that can be adapted or adopted as a core curriculum for the region?
- Is the content of the curricula aligned to the APCA standards?
- Which cadres are taken care of, and where are the gaps?
- What recommendations can be made for the development of a core curriculum that will inform the development of education and training standards for the region? Areas to consider include the need, content by cadre and duration of the training.

The review found varying degrees of alignment between existing curricula and the APCA palliative care standards. Some of the reviewed curricula were found to address large parts of the regional palliative care standards and competencies and could therefore be used as the basis for a core curriculum for the region. Of the eight African curricula reviewed, four were identified as having useful foundation material for the development of a standard core curriculum for introductory training in palliative care in Africa. Table 1 below gives an overview of the curricula that were reviewed.

The Help the Hospices (HtH) curriculum was the only one reviewed that addresses all three service levels (i.e. basic, intermediate and specialised). It covers some of the gaps identified in the assessment and could therefore make a useful contribution to the development of the integrated APCA core curriculum. The curricula of Hospice Africa Uganda (HAU) and of the Hospice Palliative Care Association of South Africa (HPCA) address a wide range of standards and competencies in their longer courses and were both found to achieve good quality palliative care training. However, it was noted that shorter courses were in greater demand, especially for health workers who had limited time to attend longer courses.



The challenge was to develop a comprehensive curriculum for a shorter course that would address the gaps identified in the needs assessment. From the review above, APCA decided to develop a 15-day core curriculum using aspects of all three curricula (HAU, HPCA and HtH), but to model it on the format of the male care-givers' curriculum developed by APCA. The new core curriculum would offer 10 days' theory and five days' clinical experience provided within a framework of mentorship and supervision. The clinical modelling would be integrated with theoretical instructions so as to give trainees the opportunity to acquire clinical skills.

**Table 1: Reviewed curricula**

Organisation and name	Time	Cadres	Can be used to support the core curriculum
Help the Hospices: Palliative Care Toolkit and Trainer's Manual	5 days full time	Health workers, family care-givers, community care-givers	Yes
Hospice Africa Uganda: Clinical Palliative Care Course	9 months part time	Nurses, clinical officers	Yes
WHO Integrated Management of Adult Illness: Palliative care: symptom management and end-of-life care	5 days full time	Health workers	No
Palliative Care Association of Malawi: Introduction to Palliative Care	5 days full time	Health workers	No
APCA male care-givers: Palliative Care Trainer's Guide	15 days full time	Male community care-givers	Yes
The Hospice Palliative Care Association of South Africa: Introduction to Palliative Care	6 months part time	Multi-disciplinary groups: doctors, nurses, social workers	Yes
Hospice and Palliative Care Association of Zimbabwe / Ministry of Health: National home-based care training manual	10.5 days full time	Community care-givers	No
Hospice Africa Uganda: Certificate in Children's Palliative Care Curriculum	12 weeks over 26 weeks part time	Health workers and allied health workers	Yes

## 1.4 Addressing the gaps in palliative care education and training

After the 2008 needs assessment, APCA took on the task of closing the gaps identified in existing palliative care education and training programmes. A series of palliative care materials and resources have since been developed and published for the African region. They can be accessed through the Resource Centre section of the APCA website, [www.africanpalliativecare.org](http://www.africanpalliativecare.org). APCA's scholarship and small grants programmes are also supporting the development of more qualified care providers and educators in palliative care. The development of a core curriculum aims to harmonise these efforts by:

- Ensuring consistency in training content and approaches
- Guiding the development of appropriate generic training materials and resources for trainees and trainers
- Creating a more formalised system for monitoring and evaluation of the impact of palliative care training
- Ensuring that palliative care education and training is aligned with the regional palliative care standards and core competencies in order to maximise its impact both on service providers and on patients and their families.

### The format of the curriculum

The curriculum incorporates both theoretical and practical components and includes mentorship and supervision, all which are critical to the effective application of knowledge in practice. It outlines the aim, key competencies, task profiles, learning outcomes and the most suitable content for an introductory palliative care-training programme.

## 1.5 The curriculum development process

In 2011, APCA's palliative care technical team drafted a core curriculum based on recommendations from the assessment of education programmes in Africa (2008) and the review of existing curricula and training materials (2010). In 2012, the draft curriculum was further reviewed and developed with support from an expert curriculum specialist, after which a second draft was developed. This draft was then further reviewed by a palliative care expert team made up of individuals who are serving on APCA's Palliative Care Advisory Board and have a wealth of experience in palliative care. Comments and feedback were incorporated and final editing undertaken to produce a final curriculum document.

# **CHAPTER 2:**

## **RATIONALE FOR A PALLIATIVE CARE CORE CURRICULUM IN AFRICA**

---

## 2. Rationale for a Palliative Care Core Curriculum in Africa

This core curriculum is competence-based and attempts to define training standards and a framework of educational concepts and the principles of palliative care as well as principles of teaching and learning that should guide training throughout the region. It provides a framework that will guide the adoption and/or adaptation of content as well as the alignment of the general curriculum to specific country contexts. The curriculum is competence-based to support a shift from the dominant traditional classroom approaches of teaching palliative care to more reflective methodologies, as these enhance the application of knowledge in care settings. This design seeks to ensure that palliative care training programmes produce care providers who are able to apply knowledge in solving the problems of patients with progressive and life-limiting illnesses and their families through inter-disciplinary teams.

The curriculum is intended not only to guide the process of implementing education and training programmes but also to facilitate the monitoring of training by means of standardised tools to ensure ongoing improvement. This is in response to the assessment of training programmes in Africa, which identified the lack of formalised and standardised monitoring and evaluation as a major gap across the programmes.

The publication of the core curriculum is expected to lead to the development of a set of generic training materials for different levels of service provision and various cadres. These materials will be used to implement training programmes that are specific to the continent and will be available and appropriate for any country in Africa to adopt or adapt.

# **CHAPTER 3:**

## **CORE CURRICULUM FOR AN INTRODUCTORY COURSE IN PALLIATIVE CARE FOR AFRICA**

---

## 3. Core Curriculum For An Introductory Course In Palliative Care For Africa

### 3.1 Target group

Trainees should demonstrate an interest and enthusiasm to learn more about palliative care and have the ability to integrate and develop palliative care services in their own places of work. The curriculum can be delivered to a multi-disciplinary team of health care providers operating at all levels (primary, secondary and tertiary) and settings of care (e.g. hospitals, home-based care, health centres and dispensaries). It can be adapted to suit trainees with a range of educational backgrounds. However, to aid in the delivery, APCA recommends that trainees in any one course be of a similar educational background.

The curriculum is suitable for:

- Health and allied professionals
  - Doctors/medical officers
  - Registered nurses/comprehensive nurses
  - Clinical officers/assistant medical officers
  - Pharmacists, pharmacy dispensers and/or pharmacy technicians
  - Occupational therapists, physiotherapists
  
- Social care professionals – those who have completed tertiary-level education
  - Social workers
  - Spiritual care providers
  - Legal professionals
  - Counsellors, psychologists
  
- Community care-givers/volunteers – those who are literate and operating at community level.

### 3.2 Trainers' credentials

It is desirable that the trainers of this course should be experienced trainers/lecturers with a palliative care qualification (diploma or degree) with at least two years' practical experience in a palliative care setting.

### 3.3 Task profile of trainees

The task profile for each of the target group for this program is implied in the APCA core competencies.

### 3.4 Competencies

This course is designed to develop the following 10 competencies:

1. Application of the concepts and principles of palliative care
2. Taking and documenting a holistic patient history
3. Assessing and managing pain and other physical symptoms appropriately
4. Communicating with patients and their families with sensitivity and respect

5. Providing ethical, patient-centred care
6. Assessing and managing psycho-social and spiritual needs appropriately with respect and sensitivity
7. Appreciating and working in a multi-disciplinary team
8. Addressing end-of-life issues
9. Appreciating the role of evidence and advocacy for the sustainability of palliative care
10. Recognising the importance of effective management of palliative care services.

### 3.5 Aim of the programme

The aim of the programme is to introduce trainees to the concepts and principles of palliative care to enable them to deliver improved/quality services to patients and their families.

### 3.6 Learning outcomes

At the end of this training, trainees should demonstrate ability to:

1. Undertake holistic assessment and management of needs of adults and children with life-threatening illnesses and their families
2. Initiate the integration of palliative care within their own care setting
3. Advocate for palliative care at different levels of service delivery
4. Use a sensitive and respectful approach to patients and their families.

### 3.7 Structure

This is a 15-day introductory course in palliative care. It is designed to have a 10-day theoretical component and then a practicum of at least three days, during which trainees will be attached to a service provider to enable them to gain practical experience.

The curriculum is structured into eight modules. These are summarised here and will be discussed in more detail in Section 4 of this document.

#### Module 1: Introduction to palliative care

This module introduces trainees to the discipline of palliative care with a focus on its fundamental principles and frameworks. The module is divided into three sessions:

1. An introduction to the definition, concepts and principles of palliative care
2. The need for and status of palliative care across Africa and in the respective country
3. Models of palliative care delivery; multi-disciplinary teamwork.

#### Module 2: Effective communication in palliative care

This module equips the trainees with the knowledge and skills needed for effective communication in palliative care service delivery. It is divided into three sessions:

1. Self-awareness and its impact on palliative care delivery
2. Review of basic communication skills
3. Communicating bad news in palliative care.

### **Module 3: Assessment and management of common symptoms**

This module equips trainees with the knowledge and skills needed to appropriately assess and manage common symptoms in palliative care. It is divided into five sessions:

1. Principles of symptom assessment, control and management
2. Assessment and management of common symptoms
3. Palliative care emergencies
4. Nutrition and hydration
5. Managing symptoms at the end of life.

### **Module 4: Pain assessment and management**

This module equips trainees with the knowledge and skills needed to confidently conduct a holistic assessment of pain and to manage pain effectively. It is divided into five sessions:

1. The concept of total pain
2. Holistic history-taking
3. Assessment of physical pain
4. Pain management using the WHO ladder
5. The use of opioids in pain management.

### **Module 5: Psycho-social and spiritual issues in palliative care**

This module introduces trainees to the common psycho-social and spiritual issues that confront people with life-threatening illnesses and how these can impact on their quality of life. It explores the range of interventions that are required to support patients and families in meeting psycho-social and spiritual needs. The module is divided into nine sessions:

1. Overview of psycho-social care
2. Basic counselling
3. Grief, loss and bereavement care
4. Grief, loss and bereavement care in children
5. Working with families and communities
6. Sexuality and gender issues
7. Assessment and management of spiritual and cultural needs
8. Psycho-social and spiritual assessment tools
9. Care for carers.

### **Module 6: Legal and ethical issues**

This module addresses common legal, human rights, ethical issues, and their impact on palliative care provision. It is divided into three sessions:

1. Palliative care as a legal and human rights issue
2. Ethical principles in palliative care
3. Integration of legal and human rights support into palliative care services.



## **Module 7: Developing and sustaining palliative care services**

This module introduces trainees to the elements that reinforce sustainability in palliative care services. It is divided into four sessions:

1. Introduction to research, monitoring and evaluation in palliative care
2. Introduction to palliative care standards
3. Advocacy in palliative care
4. Developing and sustaining palliative care services.

## **Module 8: Practicum**

This module exposes trainees to the delivery of a holistic package of palliative care in practice. It involves placing trainees in established palliative care settings to gain work experience. The module is divided into three sessions:

1. Preparation for the practicum
2. Practicum
3. Feedback sessions.

### **3.8 Learning experiences**

The 10 days of formal teaching will consist of a variety of teaching methods, including group discussion, role-play, plenary sessions, brainstorming and video demonstrations. As the trainees are experienced adult learners, personal experience and the use of reflective diaries will play a significant part in the learning process. The sessions should encourage interactive participation and give trainees many opportunities to develop their competencies. In order to enhance the learning experiences, it is recommended that patients and practitioners be invited to deliver some of the sessions and give testimonials.

Trainees will be expected to identify their own personal learning needs and set out strategies to meet them. Starting in module 1, and throughout the course, trainees will write an action plan that will help them identify how they will further develop their competencies in palliative care and how they will integrate palliative care in their own work settings.

### **3.9 Assessment and evaluation**

The focus of the assessment should be on how well trainees are able to demonstrate the 10 competencies that this curriculum aims to develop. As these competencies include knowledge, skills and abilities, the assessment methods used will include:

1. A pre- and post-assessment of knowledge of palliative care and of pain and symptom management
2. The development of a personal action plan to be presented by each participant at the end of the course
3. Peer reviews and facilitator reviews
4. Report of the practicum supervisor
5. Reflective paper at the end of practicum.

### 3.10 Resources

The following resources are required:

#### Human resources:

1. Experienced trainers or lecturers with a palliative care qualification (diploma or degree) with at least two years' clinical experience in a palliative care setting
2. Patients who are willing to speak about their experiences (for some of the modules)
3. Up to 30 trainees. Health professionals and allied health professionals can attend the same course. Community volunteers should be taught as a specific group, as the curriculum would need to be adapted for them.

#### Physical resources:

1. A setting that will comfortably hold all trainees (recommended maximum is 30) and allow space for small group work
2. Food preparation utensils and space (for module 5)
3. Sufficient palliative care service provider settings that can absorb all the trainees to complete their practicum.

#### Materials and manuals:

1. Trainees' manual
2. Trainer's manual
3. CDs/DVDs
4. Food utensils and ingredients for Module 5
5. Journal template
6. Action plan template
7. Access to palliative care resource textbooks (a list of suggested texts can be found at the end of this curriculum)
8. Didactic materials as outlined in the trainer's manual.

### 3.11 Follow-up, support supervision and mentorship

Since this course is designed for practitioners, and focused on developing competencies, it is recommended that arrangements be made to ensure that all trainees receive follow-up support supervision. This can often be arranged via the national palliative care association, where such an organisation exists, or through other palliative care service providers.

# CHAPTER 4:

## MODULES

---

## 4. Modules

### 4.1 Module 1: Introduction to palliative care

#### Overview

This module introduces trainees to the discipline of palliative care with a focus on its fundamental principles and frameworks. The module is divided into three sessions:

1. An introduction to the definition, concepts and principles of palliative care
2. The need for and status of palliative care across Africa and in the respective country
3. Models of palliative care delivery; multi-disciplinary teamwork.

#### Learning outcomes

At the end of the module, trainees should be able to:

- Demonstrate an understanding of palliative care, its relevance and application
- Select the most appropriate model of palliative care service for their own context, and justify their choice

**Duration:** 5 hours

#### Sessions

1. **Introduction to the concepts and principles of palliative care** (definition and clarifications, e.g. home-based care, end-of-life care; history, continuum of care, relevant frameworks for palliative care – public health approach, declarations, holistic approach, importance of palliative care). 2 hours
2. **The need for and status of palliative care** (who needs it – cancer, HIV and AIDS, non-communicable diseases; status in Africa and in respective country – policy, education, services, medicines). 1 hour
3. **Models of palliative care delivery and multi-disciplinary teamwork.** 2 hours

#### Mode of delivery

Interactive lecture, brainstorming, case studies

#### Learner activities

- Sharing of experience
- Discussion in buzz groups.

#### Teaching materials

Flip charts, markers, laptop, LCD projector, action plan template

#### Assessment

- Written pre- and post-testing
- Review of action plan.

### 4.2 Module 2: Effective communication in palliative care

#### Overview

This module equips the trainees with knowledge and skills needed for effective communication in palliative care service delivery. It is divided into three sessions:

1. Self-awareness and its impact on palliative care delivery
2. Review of basic communication skills
3. Communicating bad news in palliative care.

## Learning outcomes

At the end of the module, trainees should be able to:

- Appreciate the impact of self-awareness to the provision of palliative care
- Deliver bad news competently.

**Duration:** 7 hours

## Sessions

1. **Self-awareness and its impact on palliative care delivery** (definition, Johari window, impact on communication with patient and team, cultural and gender sensitivity, reflective diary). 2 hours
2. Review of basic communication skills (effective listening, communication process, types of communication, importance of communication, levels of communication, communicating with diverse groups, barriers in communication, principles of communication (6C)). 2 hours
3. **Communicating bad news** (why, when, what, dos and don'ts, expectations, impact, stages of grief, communication in end-of-life and other difficult situations). 3 hours

## Mode of delivery

Interactive lecture, brainstorming, role-play, patient testimonials

## Learner activities

- Sharing of experience
- Reflective journaling
- Role play.

## Teaching materials

Flip charts, markers, masking tape, laptop and LCD, video clips, activity cards, case scenarios, journal template

## Assessment

- Demonstration
- Role play with facilitator and peer feedback.

## 4.3 Module 3: Assessment and management of common symptoms

### Overview

This module equips trainees with the knowledge and skills needed to appropriately assess and manage common symptoms in palliative care. It is divided into five sessions:

1. Principles of symptom assessment, control and management
2. Assessment and management of common symptoms
3. Palliative care emergencies
4. Nutrition and hydration
5. Managing symptoms at the end of life.

## Learning outcomes

At the end of this module, trainees should be able to:

- Assess symptoms appropriately using the holistic approach
- Manage symptoms appropriately using pharmacological and non-pharmacological methods
- Support the patient and family members to deal with the symptoms at the end of life with sensitivity and respect.

**Duration:** 7 hours (health professionals); 9 hours (community volunteers).

## Sessions

1. **Principles of symptom control** (definition of symptoms, outline common symptoms including pain, outline common principles (assess, re-assess, holistic, manage the causes, treat the treatable); implications of inaccurate symptom assessment). 1 hour
2. **Assessment and management of common symptoms** (common symptoms according to five body systems and their causes, including treatment-related; assessment of symptoms – history-taking, listening and physical examination, pharmacological and non-pharmacological management). 3 hours
3. **Palliative care emergencies** (list of common palliative care emergencies, their causes, presentation, assessment and management). 1 hour
4. **Nutrition and hydration** (in end-of-life care, in ARV treatment, in cancer). 1 hour (2 hours for community volunteers, to include demonstrations of food preparation)
5. **Managing symptoms at the end of life** (the signs of a patient approaching death, and appropriate management of the dying patient; fears and concerns experienced by patients and their families regarding imminent death; the two roads to death; last offices). 1 hour (2 hours for community volunteers).

## Mode of delivery

Interactive lecture with photos, case studies, brainstorming, group discussions, demonstration, reflective exercises, video clips on end-of-life care.

## Learner activities

- Case study discussions and plenary presentations
- Sharing of experience.

## Teaching materials

Laptop, LCD, flip charts, markers, case scenarios, video clips on end-of-life care; nutritional charts, food combination and charts if available, cooking utensils and a space for food preparation (for demonstration to community volunteers)

## Assessment

- Demonstration during practicum evaluation and practicum supervisor's observation
- Case study presentation
- Role play with facilitator and peer feedback.

## 4.4 Module 4: Pain assessment and management

**NB:** Module content to be adapted according to cadre: see trainer's guide.

### Overview

This module equips trainees with the knowledge and skills needed to confidently conduct a holistic assessment of pain and to manage pain effectively. It is divided into five sessions:

1. The concept of total pain
2. Holistic history-taking
3. Physical pain assessment
4. Pain management
5. The use of opioids in pain management.

## Learning outcomes

At the end of this module, trainees should be able to:

- Assess pain correctly using appropriate tools
- Take and document holistic history (using holistic assessment tool)
- Manage pain effectively using pharmacological and non-pharmacological methods
- Support the use of opioids in pain management.

**Duration:** 7 hours

## Sessions

1. **The concept of total pain** (definition, classification, dimensions, pathophysiology). 1 hour
2. **Holistic history-taking** (why take holistic history, what to use, what to ask and why, when to use the tool, overview and practical session). 2 hours
3. **Physical pain assessment** (overview of assessment, pain assessment tools, physical examination). 1 hour
4. **Pain management** (the WHO analgesic ladder, non-pharmacological methods). 2 hours
5. **The use of opioids in pain management** (myths and fears – contexts, policies and guidelines, supply chain, task shifting, prescriptions). 3 hours

## Mode of delivery

Interactive lecture, brainstorming, group discussions, role plays, plenary presentations, demonstration, reflective exercises, video clips, photos/pictures case studies

## Learner activities

- Role play
- Reflection
- Holistic history-taking exercise.

## Teaching materials

Flip charts, markers, masking tape, laptop and LCD, activity cards, DVD, role-play scenarios, pain charts, pain assessment tools, holistic history questionnaires, WHO analgesic ladder

## Assessment

- Demonstration during practicum evaluation and in-class practice session
- Practicum evaluation in holistic history-taking.

## 4.5 Module 5: Emotional/psychological and social support in palliative care

### Overview

This module introduces trainees to the common psycho-social and spiritual issues that confront people with life-threatening illnesses and how these can impact on their quality of life. It explores the range of interventions that are required to support patients and families in meeting psycho-social and spiritual needs. The module is divided into nine sessions:

1. Overview of psycho-social care
2. Basic counselling
3. Grief, loss and bereavement care
4. Grief, loss and bereavement care in children
5. Working with families and communities

6. Sexuality and gender issues
7. Assessment and management of spiritual and cultural needs
8. Psycho-social and spiritual assessment tools
9. Care for carers.

### Learning outcomes

At the end of the module, trainees should be able to:

- Appreciate the role of psycho-social and spiritual care in improving the quality of life of patients and their families
- Assess psycho-social and spiritual needs of patients and their families appropriately
- Manage psycho-social and spiritual needs within their capability
- Support referrals of more complex/advanced psycho-social and spiritual needs
- Support stress management interventions within a multi-disciplinary team.

**Duration:** 14 hours

### Sessions

1. **Overview and role of psycho-social care in palliative care** (definition of psycho-social care, common psycho-social problems, common interventions). 1 hour
2. **Basic counselling in palliative care** (principles of effective counselling, skills, models, using counselling to assess psycho-social needs, distress management). 2 hours
3. **Grief, loss and bereavement care** (definitions, factors that affect grief, loss, bereavement, manifestation, stages of grief, common interventions, end-of-life support). 2 hours
4. **Grief, loss and bereavement care in children** (specifics of dealing with children's grief, loss and bereavement; myths, special needs, using memory books, age-specific manifestation and management). 1 hour
5. **Working with families and communities** (the role of family and community in patient support, how to conduct family meetings, family meeting guide, networking and referral for social support). 2 hours
6. **Sexuality and gender issues in palliative care** (definition, needs, problems and causes, barriers, interventions). 1 hour
7. **Assessment and management of spiritual and cultural needs** (definitions, beliefs and practices around life-threatening illnesses, death and dying; common spiritual and cultural needs; support and interventions). 2 hours
8. **Psycho-social and spiritual assessment tools** (overview of psycho-social tools (e.g. family tree, social status, meaningful communication, distress thermometer, FICA tool for spiritual assessment)). 2 hours
9. **Care for carers** (description – stress management and emotional survival; importance, causes of stress, how to minimise stress). 1 hour

### Mode of delivery

Interactive lectures, brainstorming, role plays, demonstrations, patient testimonies and/or case studies, group discussions

### Learner activities

- Sharing of experience
- Self-reflection
- Role play.



## Teaching materials

Flip charts, markers, masking tape, laptop and LCD, video clips, activity cards, case scenarios, journal template, psycho-social and spiritual assessment tools

## Assessment

- Role play covering all major points of needs assessment
- Practicum demonstration
- Referrals made during practicum
- Case study presentation with signs of stress accurately identified.

## 4.6 Module 6: Legal and ethical issues

### Overview

This module addresses common legal, human rights, ethical issues, and their impact on palliative care provision. It is divided into three sessions:

1. Palliative care as a legal and human rights issue
2. Ethical principles in palliative care
3. Integration of legal and human rights support into palliative care services.

### Learning outcomes

At the end of this module, trainees should be able to:

- Understand why palliative care is a legal and human rights issue
- Understand the different legal frameworks that underpin the legal and human rights debate for palliative care
- Address common legal, human rights and ethical issues that arise in palliative care with sensitivity and respect
- Support referrals of complex legal, ethical and human rights issues.

**Duration:** 5 hours

### Sessions

1. **Palliative care as a legal and human rights issue** (definitions, international, regional, and national frameworks: WHO guidelines, UN statements on palliative care, declarations, national policies and guidelines, access to treatment, stigma and discrimination). 1 hour
2. **Ethical principles in palliative care** (ethical principles, ethical dilemmas – euthanasia, disclosure, confidentiality; implications for legal and human rights, stigma and discrimination). 2 hours
3. **Integration of legal and human rights support into palliative care services** (advance care planning; succession planning; referrals with legal organisations, integrating legal support into palliative care, child protection, addressing violations of human rights, will writing). 2 hours

### Mode of delivery

Interactive lecture, brainstorming, debates, group discussions, patients' experiences, demonstration

### Learner activities

- Sharing of experience
- Role play
- Debating
- Reflection
- Will-making exercise
- Sculpting.

### Teaching–learning resources

Flip charts, markers, laptop, LCD, case studies/scenarios, videos, will template, journal template, patient with relevant experience

### Assessment

- Demonstration
- Action plan review.

## 4.7 Module 7: Developing and sustaining palliative care services

### Overview

This module introduces trainees to the elements that reinforce sustainability in palliative care services. The module is divided into five sessions:

1. Introduction to research, monitoring and evaluation in palliative care
2. Introduction to palliative care standards
3. Advocacy in palliative care
4. Developing and sustaining palliative care services.

### Learning outcomes

At the end of this module, trainees should be able to:

- Appreciate the role of research, monitoring and evaluation in sustaining palliative care services
- Identify specific areas in the current service that require quality improvement
- Develop action plans for palliative care advocacy in their own setting
- Appreciate the role of networking, referral and stakeholder engagement in effective service delivery
- Understand how to mobilise resources effectively
- Understand the principles of organisational management.

**Duration:** 8 hours

### Sessions

1. **Introduction to research, monitoring and evaluation in palliative care** (Definitions; rationale for palliative care evidence; methods of collecting palliative care evidence – research, monitoring and evaluation, audits, clinical experience, publication, information management systems, reporting, evidence briefs). 2 hours
2. **Introduction to palliative care standards** (Overview – definitions; structure – principle, criteria, standard statement, importance; use of standards – audit, adaptation; levels of service delivery). 2 hours
3. **Advocacy in palliative care** (what is advocacy; why, when, how, who, where: national/district/organisation/community). 2 hours

- 4. Developing and sustaining palliative care services** (governance – importance of structure, policies, role of governance; leadership and management, human and material resources, competency-based performance management, risk management, networking and stakeholder engagement, organisational development and resource mobilisation). 2 hours

### Mode of delivery

Interactive lecture, brainstorming, group discussion, advocacy role plays

### Learner activities

- Sharing of experience
- Plenary
- Reflection
- Case studies in action planning.

### Teaching materials

Flip charts, markers, masking tape, laptop, LCD projector, activity cards, action plan template, relevant handouts, e.g. APCA Standards and Audit tool, advocacy toolkit, APCA grant management and resource mobilisation materials

### Assessment

- Written pre- and post-testing
- Review of action plan.

## 4.8 Module 8: Practicum

### Overview

This module exposes trainees to the delivery of a holistic package of palliative care in practice. It involves placing trainees in established palliative care settings to gain work experience. The module is divided into three sessions:

1. Preparation for the practicum
2. Practicum
3. Feedback sessions.

### Learning outcomes

At the end of this module, trainees should be able to:

- Perform appropriate assessment and management of pain and other symptoms in patients with palliative care needs
- Work in a multi-disciplinary team
- Feel confident to apply the competencies in their settings.

**Duration:** Lecture 7 hours; placement 3-10 days

### Sessions

1. **Preparation for the practicum** (introduction, description of sites and specific requirements; setting objectives for the practicum; general guidelines – issues before, during and after placement; competencies that should be developed with practicum; tools, e.g. journaling, evaluation). 3 hours
2. **Practicum** (guidelines for sites, support supervision and mentorship) 3-10 days
3. **Feedback sessions** (after practicum and later follow-up, support supervision) 4 hours

## **Mode of delivery**

Interactive lecture, brainstorming, placement at a palliative care delivery site, including home visits

## **Learner activities**

- Writing of reflective learning journal
- Client history-taking
- Review of patients – physical examinations, home visits.

## **Teaching and learning resources**

Flip charts, markers, masking tape, journal template, evaluation forms, notebooks, patients at the palliative care sites

## **Assessment**

- Practicum demonstration
- Review of reflective paper
- Practicum evaluation.

# **CHAPTER 5:**

## **RECOMMENDED BOOKS AND REFERENCE MATERIAL**

---

## 5. Recommended books and reference material

### Module 1: Introduction to palliative care

- *National cancer control programmes: Policies and managerial guidelines.* (2002). Retrieved 21 March 2012. From [www.who.int/cancer/palliative/definition/en/](http://www.who.int/cancer/palliative/definition/en/).
- *Palliative care: A handbook of palliative care in Africa.* (2010). Uganda: African Palliative Care Association.

### Module 2: Effective communication in palliative care

- Davis H & Fallowfield L. (1991). *Counselling and communication in healthcare.* Chichester: John Wiley and Sons.
- Kissane D et al. (2010). *Handbook of communication in oncology and palliative care.* Oxford: Oxford University Press.
- Lancaster J & Lancaster W. (1982). *Concepts for advanced nursing practice: The nurse as change agent.* St Louis: Mosby.
- O'Neill J et al. (2003). *A clinical guide to supportive and palliative care for HIV/AIDS.* US Department for Health and Human Resources. Health Resources and Services Administration HIV/AIDS Bureau.
- Tschudin V. (1995). *Counselling skills for nurses.* 4th edition. London: Bailliere Tindall.

### Module 3: Symptom assessment and management

- *Beating pain: A pocket guide for pain management in Africa.* (2012). 2nd edition. Kampala: African Palliative Care Association.
- Twycross R, Vilcock A & Toller C. (2000). *Symptom management in advanced cancer.* 4th edition. Nottingham: Palliativedrugs.com
- Watson M, Lucas C, Hoy A & Back I. (2005). *Oxford handbook of palliative care.* Oxford: Oxford University Press.

#### Nutrition

- Hallenbeck J. (2003). *Palliative care perspectives.* Oxford: Oxford University Press.
- *HIV/AIDS: A guide for nutrition care and support.* (2004). Washington D.C.: Food and Nutrition Technical Assistance Project. Academy for Educational Development.
- *Living well with HIV/AIDS: A manual on nutritional care and support for people living with HIV/AIDS.* (2002). Rome: Food and Agriculture Organisation.
- *Nutrition for PLWHA – Counselling Cards.* (2005). Kampala, Uganda: Regional Centre for Quality of Health Care.

#### End-of-life care

- Kübler-Ross E. (1969). *On death and dying.* New York: Macmillan.
- Oliviere D & Monroe B. (2004). *Death, dying and social differences.* Oxford: Oxford University Press.

### **Module 4: Pain assessment and management**

- *Cancer pain and relief*. (1996). 2nd edition. Geneva:WHO.
- Dickman A. (2008). *Pain in palliative care:A review*. *South African Pharmaceutical Journal*. 75(5), 45-50.
- Doyle D, Merriman A & Benson T. (2006) *Pain and Symptom control in the cancer and/or HIV/AIDS patient in Uganda and other African countries*. 4th edition. Kampala: Hospice Africa Uganda.
- Fallon M & Hanks G. (2006). *ABC of palliative care*. Malden, Mass: BMJ Books/Blackwell Publisher.
- McCaffery M. (1968). *Nursing practice theories related to cognition, bodily pain, and man-environment interaction*. Los Angeles: UCLA Students' Store.
- O'Neill J, Selwyn P & Schietinger H. (2003) *A clinical guide to supportive and palliative care for HIV/AIDS*. Rockville, MD: Health Resources and Services Administration.
- Twycross R, Wilcock A & Toller C. (2009). *Symptom management in advanced cancer*. 4th edition. Nottingham: Palliativedrugs.com.
- Uganda Ministry of Health. (2001). *Regulations for class A drugs*. Kampala: Ministry of Health, Ugandan Government.
- Watson M et al (2009). *Oxford handbook of palliative care*. 2nd edition. Oxford: Oxford University Press.

### **Module 5: Psycho-social and spiritual issues in palliative care**

- Amenta M & Bohnet N. (1986). *Nursing care of the terminally ill*. Boston: Little, Brown.
- Atilio T & Otis-Green S. (2011). *Oxford textbook of palliative social work*. Oxford: Oxford University Press.
- Bond C, Lavy V & Woolridge R. (2008). *Palliative care toolkit: Improving care from the roots up in resource-limited settings*. World Palliative Care Alliance. London: Help the Hospices.
- Frankl V. (1984). *Man's search for meaning*. New York: Simon & Schuster.
- Kübler-Ross E. (1969). *On death and dying*. New York: Simon & Schuster.
- Schover L. (2004). *Sexuality and cancer: For the woman who has cancer and her partner*. New York: American Cancer Society.

### **Module 6: Legal and ethical issues**

- *Code of professional conduct*. (1992). 3rd edition. London: United Kingdom Central Council for Nursing, Midwifery and Health Visiting.
- Fish B & Kotzer L. (2006). *The family fight: planning to avoid it*. Toronto: Continental Atlantic Publications.
- Rumbold G. (1999). *Ethics in nursing practice*. 3rd edition. Edinburgh: Bailliere Tindall.
- Seedhouse D. (2000). *Practical nursing philosophy: The universal ethical code*. Chichester: John Wiley.
- Valles M. (2008). *The complete guide to leaving an inheritance for your children and others:What you need to know explained simply*. Ocala, Florida:Atlantic Publishing Group Inc.

## Module 7: Palliative care service development

- *APCA standards for providing quality palliative care across Africa.* (2010). Kampala: African Palliative Care Association.
- *Cancer control knowledge into action: WHO guide for effective programmes.* (2007). Geneva: WHO.

## Module 8: Practicum

- *Beating pain: A pocket guide for pain management in Africa.* (2012). 2nd edition. Kampala: African Palliative Care Association.

## Other general resources

### Books:

- Abraham J. (2005). *A physician's guide to pain and symptom management in cancer patients.* 2nd edition. Baltimore, MD: Johns Hopkins University Press.
- Bruera E et al. (2006). *Textbook of palliative medicine.* London: Hodder Arnold.
- Davis H & Fallowfield L. (1991). *Counselling and communication in healthcare.* Chichester: Wiley.
- Doyle D et al. (2011). *Oxford textbook of palliative medicine.* 4th edition. New York: Oxford University Press.
- Downie R. (1996). *Palliative care ethics: A good companion.* Oxford: Oxford University Press.
- Hutchinson R & Swash M. (1989). *Hutchinson's clinical methods.* London: Bailliere ELBS.

### Journals:

- *European Journal of Palliative Care.* [www.ejpc.eu.com/ejpc/home.asp](http://www.ejpc.eu.com/ejpc/home.asp)
- *International Journal of Palliative Nursing.* [www.ijpn.co.uk](http://www.ijpn.co.uk)
- *Journal of Hospice and Palliative Nursing.* <http://journals.lww.com/jhpn>
- *Journal of Pain and Symptom Management.* [www.jpmsjournal.com](http://www.jpmsjournal.com)
- *Journal of Palliative Care.* [www.criugm.qc.ca/journalofpalliativecare](http://www.criugm.qc.ca/journalofpalliativecare)
- *Journal of Palliative Medicine.* [www.liebertpub.com/jpm](http://www.liebertpub.com/jpm)
- *Journal of Social Work in End-of-life and Palliative Care.* [www.tandfonline.com/toc/wswe20/current](http://www.tandfonline.com/toc/wswe20/current)
- *Palliative Medicine.* <http://pmj.sagepub.com>



# **CHAPTER 6:**

## **DEFINITION OF TERMS**

---

## 6. Definition of terms

**Assessment:** The comprehensive evaluation of a patient's needs (physical, psychological, social and spiritual) and clinical history. It includes an evaluation of how the illness is affecting the whole family and their care needs.

**Bereavement:** The state of having suffered a loss. It incorporates the period of adjustment in which the bereaved person learns to live with the loss.

**Care provider:** Anyone who is involved in the care of the patient, whether they be professional care providers, community care providers or family members.

**Clinical supervision:** A formal process of professional support and learning that enables individual care providers to develop knowledge and skills, assume responsibility for their own practice and enhance patient protection and safety of care. Clinical supervision allows staff to continually improve their clinical practice, develop professional skills, and maintain and safeguard standards of practice.

**Community:** A group of people or organisations that are linked by social ties and interaction, share common perspectives and values, and engage in joint action in a geographical location or setting.

**Community care provider:** Someone who provides care for the patient and their family, with supervision from professional care providers, but who does not have a professional qualification recognised by the Ministry of Health. They will, however, have had some training to prepare them for their role. Examples include community health workers, community volunteers, lay care-givers and nursing aides.

**Competency:** A specified attribute that an individual is expected to have in order to perform a task or set of tasks effectively in a specified field or context. It is useful for describing that individual's quality in relation to the demands of the tasks that he or she is required to perform, including knowledge, attitudes and behaviours, and skills. A person who is described as having achieved a given competency needs to have demonstrated that he or she has learned a particular skill and is able to practise it to an acceptable standard.

**Data collection:** The process by which information is gathered using specified methods, such as questionnaires or recorded observation.

**Education:** A programme of instruction of a specified kind or level – it is an instructive or enlightening experience and should have a positive impact on knowledge, skills and attitudes. It is concerned with task-based problems and always has a value base.

**End-of-life stage:** The period of life when it has become obvious that death is inevitable and imminent (happening very soon). The primary aim of any treatment at this stage is to improve the patient's quality of life as opposed to extending length of life or curing the illness.

**Ethics:** A code of behaviour that is followed, especially by a particular group, profession or individual, e.g. medical ethics – it evaluates the moral value or correctness of a decision or a course of action.

**Evaluation:** A systematic process of collecting and analysing information to assess the effectiveness of an organisation in achieving its goals. Evaluation provides regular feedback that helps an organisation analyse the consequences, outcomes and results of its actions and draws conclusions that may inform future programmes.

**Grief:** The normal, dynamic process that occurs in response to any type of loss. It includes physical, emotional, cognitive, spiritual and social responses to loss.

**Holistic history:** A gathering of 'life facts' that encompasses the physical, psychological, social, spiritual and cultural needs of an individual, all of which should be considered when taking patient history for those seeking palliative care services.

**Holistic needs:** The total combination of the physical, psychological, social, spiritual and cultural needs of an individual, all of which should be taken into account when providing palliative care.

**Life-limiting illness:** An illness where the likelihood of potential fatal outcome is high unless the course of the disease is interrupted. This does not mean that the disease will result in early death, as there might be a chance of long-term survival.

**Multi-disciplinary team:** A team of professionals who consistently work closely together to care for a patient. Team membership varies, as teams are composed according to the identified expectations and needs of the target population. The team typically includes doctors, nurses, social workers, counsellors, pharmacists, personal support workers and volunteers. Other disciplines may also be included. The team works interdependently, sharing information and decisions, and members contribute their particular expertise. Teams meet on a regular basis to discuss patient care and develop a unified plan of management for each patient, and also to support other members of the team.

**Non-pharmacological methods:** Therapies that do not involve the use of medicines, e.g. massage.

**Opioids:** A group of narcotic drugs that are generally prescribed to manage pain.

**Outcomes:** Results relating to intermediate change and effects sought. Outcomes lead to longer-term impacts.

**Outputs:** Results relating to short-term or immediate change effects and results sought. Outputs lead to outcomes.

**Pain:** Pain is what the patient says hurts. It is an unpleasant sensory and emotional experience associated with actual or potential tissue damage. It is often treated inadequately, resulting in unnecessary suffering. People's experience of pain is affected by physical, emotional, social and spiritual factors: the 'total pain' experience of the individual is important.

**Palliative care:** 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, psycho-social and spiritual. (WHO, 2002)

**Palliative care for children:** Palliative care for children represents a special field, albeit closely related to adult palliative care. 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 definition).

**Patient:** A person or individual who is living with a life-threatening illness and is in contact with the health system to seek attention for a health condition. The term 'patient' (as opposed to 'client') is used in recognition of the individual's potential vulnerability at any time during the illness.

**Pharmacological methods:** Therapies that involve the use of medicines to treat symptoms and illnesses.

**Psychological:** Related to or arising from the mind or the emotions (as opposed to being physical in nature).

**Psycho-social care:** Care concerned with the psychological and emotional wellbeing of the patient, their family and carers. The psycho-social area includes issues of self-esteem, insight into adaptation to the illness and its consequences, communication, social function and relationships as well as practical aspects such as finance, housing and aids to daily living.

**Research:** Any process in which data is collected, processed and analysed in a systematic, rigorous manner, and used to improve the services offered. Research seeks new knowledge and what the 'ideal' might be, and may take the form of an audit.

**Service providers:** Organisations or programmes providing care.

**Special populations:** Disadvantaged or marginalised groups in the community; people who may have characteristics (medical, cultural, cognitive, racial, physical, or a combination) that set them apart from other individuals in terms of needs.

**Spirituality:** An existential construct that includes all the ways in which a person creates meaning and organises his or her sense of self around a personal set of beliefs, values and relationships. This is sometimes understood in terms of transcendence or inspiration. Involvement in a community of faith and practice may or may not be a part of an individual's spirituality. Spirituality is also described as a capacity and tendency that is innate and unique to all people. The spiritual tendency moves the individual towards knowledge, love, meaning, peace, hope, transcendence, connectedness, compassion, wellbeing and wholeness. It includes the capacity for creativity, growth and the development of a value system.

**Standard:** The desired achievable level of performance against which actual performance can be measured (in other words, a standard describes the level of performance to be achieved). It is a level of excellence required or specified. It serves as a basis for comparison and is a statement of expectations; an expected level of performance or quality.

**WHO analgesic ladder** (also called the pain ladder): Guidelines issued by the WHO to help clinicians manage pain using a three-step process (ladder). While originally developed with cancer pain in mind, the analgesic ladder has successfully been used for the management of other palliative care-related pain, such as that experienced by people with AIDS.

## ABOUT APCA



The African Palliative Care Association (APCA) is a non-profit-making pan-African membership-based organisation, which was provisionally established in November 2002 and formally established in Arusha, Tanzania, in June 2004. Acknowledging the genesis of modern palliative care within the United Kingdom, APCA strives to adapt it to African traditions, beliefs, cultures and settings, all of which vary between and within communities and countries on the continent. As such, APCA being a recognised regional voice for palliative care in Africa works in collaboration with its members and partners to seek African solutions to African problems.

APCA's vision is to ensure access to palliative care for all in need across Africa, while its mission is to ensure that palliative care is widely understood, underpinned by evidence, and integrated into all health systems, to reduce pain and suffering across Africa. APCA's broad objectives are to:

- Strengthen health systems through the development and implementation of an information strategy to enhance the understanding of palliative care among all stakeholders
- Provide leadership and coordination for the integration of palliative care into health policies, education programmes and health services in Africa
- Develop an evidence base for palliative care in Africa
- Ensure good governance, efficient management practices and competent human resources to provide for institutional sustainability
- Position palliative care in the wider global health debate in order to access a wider array of stakeholders and to develop strategic collaborative partnerships
- Diversify the financial resources base to meet APCA's current funding requirements and to ensure the organisation's future sustainability.

APCA works to build effective linkages between all our key stakeholders, including: patients, their families and communities; carers (both family and volunteers); health care providers and educators; African governments, policy makers and decision-makers; its constituent members (both individuals and organisations); national palliative care associations, hospices and palliative care organisations; academic institutions; the media; governmental and non-governmental donors (both within and outside the continent), and the general public, in a network of national, regional and international partnerships.

The development of a core curriculum for palliative care is one of the strategies through which palliative care can be integrated in existing pre service and post service health education programmes. This is instrumental in ensuring that palliative care is integrated into the wider health systems across the African continent.

**[www.africanpalliativecare.org](http://www.africanpalliativecare.org)**

## ABOUT AIDSTAR-ONE



The AIDS Support and Technical Resources (AIDSTAR) mechanism is an indefinite quantity contract (IQC) managed out of the Office of HIV and AIDS in USAID's Bureau for Global Health. AIDSTAR-One is a flexible mechanism available to US Government (USG) country teams, USAID/Washington operating units, missions and other USG agencies to access technical expertise and implementation support across a broad range of HIV- and AIDS-related technical areas. AIDSTAR-One may be used for:

- Long- or short-term technical assistance and programme implementation support in specialised HIV and AIDS technical areas, including behaviour change, clinical and community-based HIV and AIDS services, care for orphaned and other vulnerable children, monitoring and evaluation, and health systems strengthening specific to HIV and AIDS services
- Long- or short-term in-country support for coordination and scale-up for HIV and AIDS activities in support of US Government country strategies
- Documenting and disseminating successful innovative approaches and sustainable models; evidence-based best practices and lessons learned; and new approaches, tools and methodologies in HIV and AIDS programming.

African Palliative Care Association  
PO Box 72518  
Plot 850, Dr Gibbons Road  
Kampala, Uganda  
Tel: +256 414 266 251  
Fax: +256 414 266 217  
E: [info@africanpalliativecare.org](mailto:info@africanpalliativecare.org)  
W: [www.africanpalliativecare.org](http://www.africanpalliativecare.org)



**USAID**  
FROM THE AMERICAN PEOPLE

**AIDSTAR-One**  
AIDS SUPPORT AND TECHNICAL ASSISTANCE RESOURCES



---

All rights are reserved, whether referring to the whole or a part of the material, particularly the rights to reproduce images or text or to translate or reprint. Requests for permission to reproduce text or images, or to translate APCA publications, or any other inquiries, should be directed to APCA, PO Box 72518, Kampala, Uganda. Tel: +256 414 266 251, Fax: +256 414 266 217, email: [info@africanpalliativecare.org](mailto:info@africanpalliativecare.org), website: [www.africanpalliativecare.org](http://www.africanpalliativecare.org).