

Planning and implementing palliative care services: a guide for programme managers



World Health
Organization

Planning and implementing palliative care services:

a guide for programme managers



WHO Library Cataloguing-in-Publication Data

Planning and implementing palliative care services: a guide for programme managers.

1. Palliative care – organization and administration. 2. Palliative care – utilization. 3. Hospice care – organization and administration. 4. Health planning. 5. National health programs – organization and administration. I. World Health Organization.

ISBN 978 92 4 156541 7

(NLM classification: QV 250)

© World Health Organization 2016

All rights reserved. Publications of the World Health Organization are available on the WHO website (<http://www.who.int>) or can be purchased from WHO Press, World Health Organization, 20 Avenue Appia, 1211 Geneva 27, Switzerland (tel.: +41 22 791 3264; fax: +41 22 791 4857; email: bookorders@who.int).

Requests for permission to reproduce or translate WHO publications – whether for sale or for non-commercial distribution – should be addressed to WHO Press through the WHO website (http://www.who.int/about/licensing/copyright_form/en/index.html).

The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted and dashed lines on maps represent approximate border lines for which there may not yet be full agreement.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by the World Health Organization in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

All reasonable precautions have been taken by the World Health Organization to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either expressed or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall the World Health Organization be liable for damages arising from its use.

Design and layout: Jean-Claude Fattier

Printed in Switzerland

Contents

| | |
|---|-----------|
| List of tables ----- | v |
| List of figures ----- | v |
| List of acronyms and abbreviations ----- | vi |
| Foreword ----- | 1 |
| Acknowledgements----- | 2 |
| 1: Introduction – the need for palliative care----- | 5 |
| 1.1 What is palliative care? ----- | 5 |
| Who needs palliative care? ----- | 5 |
| 1.2 Government commitments to provide palliative care ----- | 6 |
| 1.3 Purpose and scope of this guide----- | 7 |
| 2: Palliative care services – overview ----- | 9 |
| 2.1 Identifying who can benefit from palliative care ----- | 9 |
| Assessing the needs of patients and their families ----- | 9 |
| 2.2 Relief of pain and other symptoms----- | 10 |
| Common symptoms----- | 10 |
| General principles----- | 10 |
| 2.3 Addressing psychosocial and spiritual needs ----- | 12 |
| 2.4 Caring for families and caregivers----- | 13 |
| 3: Establishing palliative care services ----- | 17 |
| 3.1 Deciding where to start ----- | 17 |
| 3.2 Setting up a home-based palliative care service ----- | 18 |
| What is home-based palliative care? ----- | 18 |
| Essential requirements for a home-based palliative care service ----- | 18 |
| How to set up a home-based palliative care service ----- | 20 |
| 3.3 Setting up a community-based palliative care service----- | 21 |
| What is community-based palliative care?----- | 21 |
| How to set up a community-based palliative care service----- | 22 |
| 3.4 Setting up a hospital-based palliative care service ----- | 26 |
| Options for a hospital-based palliative care service ----- | 26 |
| How to set up a hospital-based palliative care service----- | 27 |
| Staffing the hospital-based palliative care service----- | 28 |
| 3.5 Setting up a palliative care service for children----- | 29 |
| Minimum staffing requirements ----- | 30 |
| Requirements for a palliative care service for children ----- | 31 |
| Process for developing a palliative care service for children ----- | 32 |
| 3.6 Setting up a stand-alone palliative care centre or hospice ----- | 33 |
| Scope of services and support provided ----- | 33 |
| Target group of patients ----- | 35 |
| Human resources----- | 36 |

| | |
|--|-----------|
| Reliable availability of essential medications ----- | 37 |
| Funding ----- | 37 |
| 3.7 Establishing an integrated approach in a district ----- | 38 |
| What makes for successful integration? ----- | 39 |
| Stages of integration ----- | 39 |
| 4: Components of a comprehensive approach to palliative care ----- | 47 |
| 4.1 What is a comprehensive approach? ----- | 47 |
| 4.2 Developing a palliative care policy ----- | 47 |
| Situation assessment ----- | 49 |
| 4.2 Scaling up and integrating palliative care into the health-care system ----- | 50 |
| 4.3 Improving access to medicines for pain relief and palliative care ----- | 53 |
| Barriers to pain management in palliative care ----- | 53 |
| Strategies to improve access to medicines for palliative care ----- | 54 |
| 4.4 Strengthening human resources for palliative care ----- | 59 |
| Who are palliative care providers? ----- | 59 |
| Defining core tasks and skills ----- | 60 |
| Task-shifting ----- | 62 |
| Strengthening palliative care in the primary care workforce ----- | 63 |
| Developing skills and training ----- | 63 |
| 4.5 Setting standards and evaluating palliative care services ----- | 65 |
| Evaluating overall progress in palliative care development ----- | 65 |
| Measuring palliative care quality ----- | 66 |
| Other dimensions to consider ----- | 67 |
| Setting standards for palliative care ----- | 67 |
| 4.6 Costing palliative care services ----- | 69 |
| Cost impact of palliative care ----- | 69 |
| Costing palliative care ----- | 69 |
| 5: Other WHO tools and resources ----- | 73 |
| Clinical management in palliative care ----- | 73 |
| Policy and programme design ----- | 73 |
| Monitoring palliative care ----- | 73 |
| Advocacy and communications ----- | 74 |
| References ----- | 75 |
| Annex 1: WHO Model List of Essential Medicines for palliative care ----- | 79 |
| Annex 2: WHO Model List of Essential Palliative Care Medicines for Children ----- | 81 |
| Annex 3: Sample basic equipment and medicines for a palliative care home-care kit ----- | 83 |
| Annex 4: Sample curriculum for a 16-hour training programme in palliative care for community volunteers ----- | 85 |
| Annex 5: Sample curriculum in basic palliative care for doctors and clinical officers ----- | 86 |
| Annex 6: World Health Assembly resolution WHA67.19 “Strengthening of palliative care as a component of comprehensive care throughout the life course” ----- | 89 |

List of tables

| | | |
|-----------|---|----|
| Table 1. | Essential practices for primary palliative care ----- | 9 |
| Table 2. | Categories of palliative care services ----- | 17 |
| Table 3. | Suggested minimum training standards for the home-care team ----- | 20 |
| Table 4. | Key human resources required for a community-based palliative care service ----- | 22 |
| Table 5. | Minimum staffing required for a hospital-based palliative care service ----- | 29 |
| Table 6. | Ideal health workforce for a paediatric palliative care service ----- | 30 |
| Table 7. | Different roles and functions of a stand-alone palliative care centre or hospice ----- | 34 |
| Table 8. | Example of a step-wise approach to introducing a palliative care programme ----- | 51 |
| Table 9. | Key factors for successful implementation of an essential medicines list ----- | 55 |
| Table 10. | Trained health workers able to perform palliative care tasks safely and effectively ----- | 62 |
| Table 11. | Sample indicators for assessing overall palliative care development ----- | 66 |

List of figures

| | | |
|------------|---|----|
| Figure 1. | Examples of scenarios with different levels of care to meet palliative care needs ----- | 18 |
| Figure 2. | Minimum requirements for a home-based palliative care service ----- | 19 |
| Figure 3. | Steps for establishing a home-based palliative care service ----- | 20 |
| Figure 4. | Process for starting a new community palliative care service ----- | 25 |
| Figure 5. | Steps for establishing a hospital-based palliative care service ----- | 28 |
| Figure 6. | Children in need of palliative care by disease group ----- | 30 |
| Figure 7. | Steps for establishing a pediatric palliative care service ----- | 32 |
| Figure 8. | An example of integration between different levels of palliative care services ----- | 39 |
| Figure 9. | Steps required in integration of palliative care ----- | 40 |
| Figure 10. | Integrating palliative care into district health services ----- | 41 |
| Figure 11. | Identifying gaps in palliative care in district health services ----- | 41 |
| Figure 12. | The 11 Ps of successful palliative care integration ----- | 42 |
| Figure 13. | Example of a stepwise process for developing palliative care ----- | 48 |
| Figure 14. | Where palliative care is provided ----- | 59 |



List of acronyms and abbreviations

| | |
|-----------------|--|
| APCA | African Palliative Care Association |
| CHC | Community health centre |
| CHEW | Community health extension workers |
| CNPC | Community Network in Palliative Care (Jakarta) |
| CoHSASA | Council for Health Services Accreditation of Southern Africa |
| CVW | Community volunteer workers |
| EAPC | European Association of Palliative Care |
| ESAS | Edmonton Symptom Assessment Scale |
| HIV/AIDS | Human immunodeficiency virus infection and acquired immune deficiency syndrome |
| HPCA | Hospice Palliative Care Association (HPCA) of South Africa |
| IAHPC | International Association for Hospice and Palliative Care |
| ICHC | Integrated community-based home care |
| INCB | International Narcotics Control Board |
| IPPF | International Pain Policy Fellowship |
| MTRH | Moi Teaching and Referral Hospital |
| NCDs | Noncommunicable diseases |
| NGOs | Non-governmental Organizations |
| NNPC | Neighbourhood Network in Palliative Care (Kerala) |
| NSAIDs | Non-steroidal anti-inflammatory medicines |
| PHO | Public Health Officer |
| POS | Palliative Outcome Score |
| PPSG | Pain and Policy Studies Group, University of Wisconsin, WHO Collaborating Centre for Pain Policy and Palliative Care |
| THET | Tropical Health and Education Trust |
| WHO | World Health Organization |

Foreword

In 2014, the first ever global resolution on palliative care, WHA 67.19, called upon WHO and Member States to improve access to palliative care as a core component of health systems, with an emphasis on primary health care and community/home-based care. In the WHO Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013-2020, palliative care is explicitly recognized as part of the comprehensive services required for the noncommunicable diseases. Member States have requested WHO to develop evidence-based tools on integrating palliative care into national health systems, across disease groups and levels of care. High-quality palliative care is an explicit element of the WHO Framework on integrated people-centred services, approved at the 69th World Health Assembly in 2016.

This is a practical manual on how to plan and implement palliative care services, integrated into existing health-care services, at national or subnational level. It has been designed primarily for health programme managers at national, provincial, or district level, whether they are responsible for noncommunicable diseases, infectious disease programmes, health services, or other technical areas where palliative care is important.

It aims to describe a range of options and starting points for building and strengthening palliative care services. A step-wise approach is outlined in each section as much as possible, with an emphasis on approaches that are feasible for low- and middle-income settings. This manual should contribute to providing equitable access to good palliative care in the context of Universal Health Coverage; it should help countries to strengthen palliative care programmes especially at primary health care level and across disease groups. The approach is based on people-centredness with an aim to address the patients' needs and expectations. To do so, health services need to involve health-care workers as well as the patients and their communities in a proactive way, taking into account the social and cultural specificities.

This manual does not cover clinical guidelines or protocols for patient care – existing WHO guidance for pain and symptom management and a range of further tools and resources that users may find helpful are listed at the end. In the future this manual should be complemented with a series of publications addressing more specific aspects of palliative care and additional measurement tools to monitor the quality of palliative care at country level.

Access to palliative care has been identified as a fundamental right. With this manual WHO reaffirms its commitment to work with Member States in order to ensure that this becomes a reality for everyone: adults, older people and children.

Oleg Chestnov

Assistant Director-General
Noncommunicable diseases and mental health

Marie-Paule Kieny

Assistant Director-General
Health systems and innovation

Acknowledgements

This manual was prepared under the leadership and guidance of Etienne Krug and Edward Kelley, with overall coordination and technical input from Belinda Loring, Marie-Charlotte Bouësseau, and Cherian Varghese.

The following people contributed technical content and provided expert review:

Carlos Acuña, Nayaz Ahmed, Zahir Al Mandhari, Samy Alsirafy, David Bramley, Clarito Cairo Jr, Alexis Chavarría, Jim Cleary, Stephen Connor, Massimo Costantini, Marilys Corbex, Liliana de Lima, Luc Deliens, Ibtihal Fadhil, Frank Ferris, Kathy Foley, Gilles Forte, Eduardo Garcia Yaneo, Elizabeth Grant, Cynthia Goh, Xavier Gomez-Batiste, Liz Gwyther, Richard Harding, Eric Krakauer, Suresh Kumar, Phil Larkin, Martha León, Richard Lim, Diederik Lohman, Emmanuel Luyirika, Joan Marston, Diane Meier, Geoff Mitchell, Scott Murray, Tania Pastrana, Sheila Payne, Gabriela Píriz Alvarez, Christina Puchalski, Lisbeth Quesada, Farrukh Qureshi, Lukas Radbruch, M.R. Rajagopal, Javier Rojas Elizondo, Elena Tsoyi, Allan Varela, Rosibel Vargas, Bee Wee, Chandrika Wijeyaratne, Juliana Yong.

Special acknowledgements to Xavier Gomez-Batiste and Stephen Connor for collating inputs to an earlier draft of this document.

Photograph credits (cover images starting from top-right, in anti-clockwise direction):

1. © WHO/Chris de Bode
2. © Luikov
3. © WHO/SEARO/Nursila Dewi
4. © Pentium5
5. © Yongtick
6. © XiXinXing



1

Introduction – the need for palliative care

What is palliative care?

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems. Palliative care is the prevention and relief of suffering of any kind – physical, psychological, social, or spiritual – experienced by adults and children living with life-limiting health problems. It promotes dignity, quality of life and adjustment to progressive illnesses, using best available evidence.

Palliative care for children represents a special field in relation 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. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.

All people, irrespective of income, disease type, or age, should have access to a nationally determined set of basic health services, including palliative care. Financial and social protection systems need to take into account the human right to palliative care for poor and marginalized population groups.

Who needs palliative care?

Globally, it is estimated that palliative care is needed in 40-60% of all deaths (1). Palliative care is required for patients with a wide range of life-limiting health problems. The majority of adults in need of palliative care have chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%). Patients with many other conditions may require palliative care, including kidney failure, chronic liver disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis. Children may have a high incidence of congenital anomalies and genetic conditions and mortality is highest in the neonatal period.

Each year an estimated 20 million people are in need of palliative care in the last year of their life, with many more requiring palliative care prior to the last year of their life. Of these people in need, 78% live in low- and middle-income countries. For children, 98% of those needing palliative care live in low- and middle-income countries with almost half of them living in Africa. In 2014, it was estimated that only 14% of people needing palliative care at the end of life, actually receive it (1).

Pain is one of the most frequent and serious symptoms experienced by patients in need of palliative care. Opioid analgesics are essential for treating the pain and other common distressing physical symptoms associated with many advanced progressive conditions. For example, 80% of patients with AIDS or cancer, and 67% of patients with cardiovascular disease or chronic obstructive pulmonary disease will experience moderate-to-severe pain at the end of their lives (2). In 2011, 83% of the world's population lived in countries with low to non-existent access to opioid pain relief (3). Psychosocial support is another common need in palliative care. Patients with life-threatening or terminal illness and their caregivers go through great stress, and health professionals treating them need to be adequately trained or prepared to help them manage their stress. The health system and health facilities may need certain simple features to facilitate other end-of-life needs of a patient, such as spiritual needs, family support, legal support where needed, and a motivating physical environment.

1.2 Government commitments to provide palliative care

In 2014, the first ever global resolution on palliative care, WHA 67.19, called upon WHO and Member States to improve access to palliative care as a core component of health systems, with an emphasis on primary health care and community/home-based care.

In the WHO Global Action Plan for the Prevention and Control of Noncommunicable Diseases (NCDs) 2013-2020, palliative care is explicitly recognized as part of the comprehensive services required for the noncommunicable diseases. Governments acknowledged the need to improve access to palliative care in the Political Declaration of the High-Level Meeting of the UN General Assembly on the Prevention and Control of Noncommunicable Diseases in 2011, and access to opioid pain medicines is one of the 25 indicators in the global monitoring framework for NCDs.

Palliative care is included in the definition of universal health coverage. The WHO global strategy on people-centred and integrated health services offers a framework for the strengthening of palliative care programmes across diseases.

Palliative care medicines, including those for pain relief, are included in WHO's list of essential medicines for adults and children, and should be made accessible to all who need them. These lists include opioid and non-opioid medicines for pain relief, as well as medicines for the most common symptoms in palliative care.

Ensuring the accessibility of palliative care is not just an ethical obligation of health systems; it is also an obligation under international human rights law. The right to palliative care and pain relief is recognized under the human right to health.¹ Under international drug control conventions, countries have a dual obligation to ensure that controlled substances are accessible for medical purposes, at the same time as protecting their populations against dependence and misuse.² Unfortunately, countries have paid far more attention to their obligation to prevent abuse than to their obligation to ensure access for medical purposes.

“The reaction of some legislators and administrators to the fear of drug abuse developing or spreading has led to the enactment of laws and regulations that may in some cases unduly impede the availability of opiates.” International Narcotics Control Board, cited in (4) p16

1.3 Purpose and scope of this guide

This is an operational manual on how to set up palliative care services and integrate them into health systems intended for national, provincial, or district-level programme managers or health officials.

It covers the general principles and core components needed to strengthen palliative care. It also describes a range of possible starting points for establishing palliative care services. There is no single best starting point for all settings – the starting points in this manual are presented as options to consider and discuss in the national context. Some of the approaches are complementary and could also be started at the same time, depending on capacity and context.

This manual is not intended to cover the clinical guidance required to treat patients in need of palliative care. Separate WHO guidance on pain management and management of common palliative care symptoms should be consulted for this purpose.

¹ The right to health is guaranteed in a wide range of international and regional human rights treaties, including for example the International Covenant on Economic Social and Cultural Rights, (in Article 12) and the Convention on the Rights of the Child (in Article 24). The latter treaty has been ratified by every country in the world with the exception of Somalia and the United States of America. See <http://indicators.ohchr.org/>

² Single Convention on Narcotic Drugs 1961



2

Palliative care services – overview

Palliative care may often be seen simply as giving painkilling medicines. The rationale for palliative care certainly includes the need for relief from pain and other distressing symptoms, but it goes further to include efforts to enhance the quality of life, and even influence the course of illness in a positive way. Life is affirmed and dying is regarded as a normal process, with care integrating physical, psychological, social, cultural and spiritual aspects. Patients are helped to live as actively as possible until death, and a support system offers help to the family to cope both during the patient's illness and during bereavement.

Palliative care is not intended to hasten or postpone death, but uses ethical principles, shared decision-making and advanced care planning to identify patients' priorities and goals for their care at the end of life. A team approach is used and many kinds of health and social care providers, as well as volunteers, can be involved. It is important that palliative care should not be considered as something that only hospitals can do. It can be provided in any health-care setting and also in patients' homes and can be successfully implemented even if resources are limited.

Palliative care services should, therefore, at a minimum:

- identify patients who could benefit from palliative care;
- assess and reassess patients for physical, emotional, social and spiritual distress and (re)assess family members for emotional, social, or spiritual distress;
- relieve pain and other distressing physical symptoms;
- address spiritual, psychological and social needs;
- clarify the patient's values and determine culturally appropriate goals of care.

The essential practices in primary palliative care can be classified into four categories, namely: physical care, psychological/emotional/spiritual care, care planning and coordination, and communication (Table 1).

Table 1. Essential practices for primary palliative care

| Identify, evaluate, diagnose, treat, apply solution measures for: | Identify, evaluate, provide support, apply solution measures and refer when necessary for: |
|---|---|
| Physical care needs | |
| <ul style="list-style-type: none"> ■ Pain (all types) ■ Respiratory problems (dyspnoea, cough) ■ Gastrointestinal problems (constipation, nausea, vomiting, dry mouth, mucositis, diarrhoea) ■ Delirium ■ Wounds, ulcers, skin rash and skin lesions ■ Insomnia | <ul style="list-style-type: none"> ■ Fatigue ■ Anorexia ■ Anaemia ■ Drowsiness or sedation ■ Sweating |
| Psychological/emotional/spiritual care needs | |
| <ul style="list-style-type: none"> ■ Psychological distress ■ Anxiety ■ Suffering of family or caregivers | <ul style="list-style-type: none"> ■ Spiritual needs and existential distress ■ Depression ■ Bereavement support for family/caregivers |

Consider and manage:**Care planning and coordination**

- Identify support and resources available; develop and implement care plan based on patient's needs
- Provide care in the last weeks/days of life
- Facilitate the availability and access to medications (especially opioids)
- Identify the psychosocial/spiritual needs of professionals providing care (including self)

Communication issues

- Communicate with patient, family and caregivers about diagnosis, prognosis, treatment, symptoms and their management, and issues relating to care in the last days/weeks of life
- Identify and set priorities with patient and family/caregivers
- Provide information and guidance to patients and caregivers according to available resources

Source: Adapted from IAHPC (5).

2.1 Identifying who can benefit from palliative care

The majority of dying patients require palliative care, as well as a large proportion of patients living with chronic, complex, life-limiting health problems. It is important to start a palliative care approach as soon as the health problem is serious, complex or life-threatening, while disease-modifying care may continue. There are ways to make early identification a feature of all health-care settings. Pain that disrupts daily life activities, breathlessness at rest, or functional decline are clinical indicators that should result in palliative care assessment, or even prompt the question "Would I be surprised if this patient were to die in the next year?" If the answer is "no", it may be worth having a conversation with the patient and/or family, as culturally appropriate, to seek to maximize the quality of life.

Assessing the needs of patients and their families

Palliative care starts with a multidimensional assessment of physical, emotional, social, spiritual, and cultural needs, values and preferences of patients and families.

Short screening instruments, validated in both rich and poor settings, are available, such as the Edmonton Symptom Assessment Scale (ESAS) and the Palliative Outcome Score (POS) as adapted by the African Palliative Care Association (African POS).

Patients and/or their caregivers also have information and communication needs, and often they will need help with the organization of care. It is important to determine the patient's values and priorities as a prerequisite to formulating the best plan of care. Advance directives such as a living will or power of attorney may be useful instruments. However, in some situations, patients prefer that one or more family members receive medical information and make decisions about their care for them. Family members and caregivers may also need emotional and social support, and they will need bereavement support after the death of the patient.

Needs will change. Assessment of patient's needs is therefore something that should be repeated regularly throughout the course of the disease.

2.2 Relief of pain and other symptoms

Common symptoms

The most frequent and burdensome symptoms in patients with chronic, complex, life-limiting health problems tend to be the same across diseases. For example, in cancer patients the major physical problems are pain, depression and fatigue, and these are also predominant problems in patients with HIV/AIDS as well as in patients with cardiac or respiratory failure.

The most common symptoms occurring in the advanced stages of the most common life-limiting conditions include anxiety, appetite loss, breathlessness, constipation, delirium, depression, diarrhoea, fatigue, nausea, pain and respiratory tract secretions.

Pain is one of the most frequent and serious symptoms experienced by adults and children in need of palliative care. For example, 80% of patients with AIDS or cancer, and 67% of patients with cardiovascular disease or chronic obstructive pulmonary disease will experience moderate to severe pain at the end of their lives. Pain is multidimensional: Cicely Saunders introduced the concept of "total pain", where pain includes physical, emotional, psychosocial, and spiritual dimensions (6).

General principles

Treatment should aim to maintain or improve the quality of life and optimize physical and cognitive function of the patient throughout the course of illness. This requires:

- treatment of the underlying cause(s) of symptoms, if consistent with the goals of care;
- pharmacological and/or non-pharmacological treatment of any symptom;
- attention to each patient's values and needs.

Treating underlying causes

The underlying mechanism causing the symptom should be identified and treated, if possible. For example, this might include radiotherapy or chemotherapy even in advanced cancer, as reduction of tumour size can alleviate symptoms. This requires careful consideration of the balance between expected benefit and burden from the intervention.

Symptomatic pharmacological treatment

A number of medications for the treatment of pain and other common symptoms in palliative care are included in the WHO model lists of essential medicines for adults and children. Using these essential medicines, the vast majority of patients' burdensome symptoms can be alleviated adequately. Opioid analgesia is essential to the effective control of moderate-to-severe pain. The 2012 WHO guidelines on pain management in children recommend that strong opioid analgesia is essential for the relief of moderate to severe pain in children (7). Countries should review and if necessary revise national regulations and policies to ensure that health professionals can provide opioid analgesia including oral immediate-release morphine in accordance with WHO and INCB.

Symptomatic non-pharmacological treatment

Pharmacological treatment should be combined with non-pharmacological treatment. This may include mouth care with a wet sponge, swab or cloth; skin care with ointments or washing procedures; lymphatic drainage for oedema or a fan for breathlessness. Other forms of therapy that may provide relief include art therapy, hydrotherapy, pet therapy, music therapy, hypnosis, play therapy, physical therapy and occupational therapy.

Individualized, patient-centred care

Symptom relief in palliative care has to be adapted to the individual values and needs of the patient. Medicines, routes of administration, dosing intervals and dosages should be selected according to these values and needs. Treatment should be focused on symptoms that reduce the patients' quality of life. Otherwise side-effects from the interventions may cause more impairment than the pathology itself.

The patient and/or family caregivers, as appropriate, should be involved in decision-making about the treatment plan. If the patient does not wish or is not able to participate, surrogate decision makers (usually close family members or friends) can be involved.

The patient or surrogate(s) should be informed about available treatment options. Comprehensive information on the illness, the expected disease trajectory and treatment options should be delivered in an empathic way. This will reduce unknowns and hence reduce anxieties. The unknown may induce more anxiety than the reality. The person-centred approach also necessitates regular re-assessments of the patient's needs.

2.3 Addressing psychosocial and spiritual needs

Psychosocial care involves attention to the psychological, emotional, social and financial well-being of patients and family members. Psychological symptoms such as anxiety, depression, and delirium should be assessed and treated just as carefully as physical symptoms, and this can be done by primary care physicians.

Social suffering derives from many sources, including extreme poverty, lack of adequate food or clothing or housing, stigma and discrimination due to disease, sexism, racism, or religious prejudice. Many families face financial catastrophe due to serious illness of a family member. For those no longer able to support themselves and their families financially, palliative care workers can provide information on sources of funding. Palliative care must seek ways to address social suffering such as food packages, assistance in obtaining housing, and efforts to fight stigmatization and discrimination.

Spiritual distress and existential concerns should be treated with the same level of intensity and priority as psychosocial and physical distress or pain. Support may involve a spiritual carer. Where available, dignity-centred care, meaning-oriented therapy, legacy-building, guided-visualization, mindfulness meditation, yoga and other mind-body interventions, art therapy and journaling can be employed.

Bereavement support is a core component of palliative care. Patients and family members often need emotional support to face the losses associated with dying and bereavement, and some bereaved family members develop complicated grief, requiring treatment. Community support often can be mobilized to sustain bereaved family members and, where psychiatric referral is not easily accomplished, any physician can learn to diagnose and treat complicated grief.

Engaging in providing psychosocial care is demanding for health-care workers. Policies within organizations should encourage self-care and staff support strategies, such as regular sharing of difficult cases, memorial ceremonies for patients who have died, regular social activities for palliative care team members, regular exercise, and adequate free time.

2.4 Caring for families and caregivers

Support for family caregivers is a core aspect of palliative care provision. It is vital that family caregiver's needs are assessed and an appropriate care plan developed.

There are multiple reasons why family caregivers should have their needs assessed and are offered psychosocial support. Family caregivers typically have unmet needs and problems. For instance, they are prone to physical and psychological morbidity, with half of all caregivers below population norms for physical health and with rates of potential depression and anxiety between 30% and 50% being reported. Caregivers are responsible for numerous tasks, are often financially disadvantaged and frequently become socially isolated. Indeed, many caregivers have needs equal to, or even greater than, the needs of patients. Their difficult situation is often compounded by limited first-hand exposure to death and dying, and by exclusion from information and care planning so that they feel under-prepared for their role.

Nevertheless, caregivers have the potential (with appropriate support) for positive outcomes and gains from their role. Most people prefer to die at home, so family carers are pivotal to achieving successful home care. Family caregivers make a significant and under-recognized economic contribution to health care (8).

Some family caregivers take on the role not because they want to but because they feel obliged to do so. Patients' needs and expectations may not match those of their family caregiver(s). This makes it difficult for health and social care professionals to determine whose needs take priority. Cultural and spiritual aspects also need to be considered.

A one-size-fits-all approach to family caregiver support is not appropriate. However, common caregiver expectations include:

- They will be given information about what to expect as a caregiver (in written format as well as verbally).
- The patient's symptoms will be controlled.
- The patient's values will be respected.
- Help will be provided to prepare for the patient's death, if appropriate.
- Every effort will be made for the patient to receive care in the place of her/his choice. If the patient wishes to be at home, efforts will be made to assist family caregivers with home care, if needed.
- Decisions about goals of care will be shared between the health-care team and the patient and/or family caregiver(s), as appropriate.
- Bereavement support will be available.



3

Establishing palliative care services

3.1 Deciding where to start

Palliative care services can be established in a number of different ways. There is no single best starting point for all settings – the starting points in this manual are presented as options, to consider and discuss in the national context. Some of the approaches are complementary and could also be started at the same time, depending on capacity and context.

In all cases, it is important to assess which services are already providing palliative care, including in the nongovernmental sector, and to build on these existing resources. This section summarizes various models and strategies for establishing palliative care services, with the emphasis on integrating palliative care into existing health-care systems. The service delivery model must take into account the country's social and health system context. All examples described in this guide will require further adaptation to meet local needs.

Palliative care services can be established or expanded in a number of ways, depending on the local situation. For instance, a country may decide to begin by:

1. Setting up a palliative home-care service or integrating palliative home care into existing home-care services.
2. Establishing palliative care in a community setting.
3. Integrating palliative care services into a district or general hospital.
4. Establishing a palliative care service for children, including neonates.
5. Setting up a stand-alone palliative care centre or hospice.
6. Taking an integrated approach in a district.

It is important to note that palliative care services at different levels (Table 2) all ultimately serve an important function as part of a comprehensive system of palliative care.

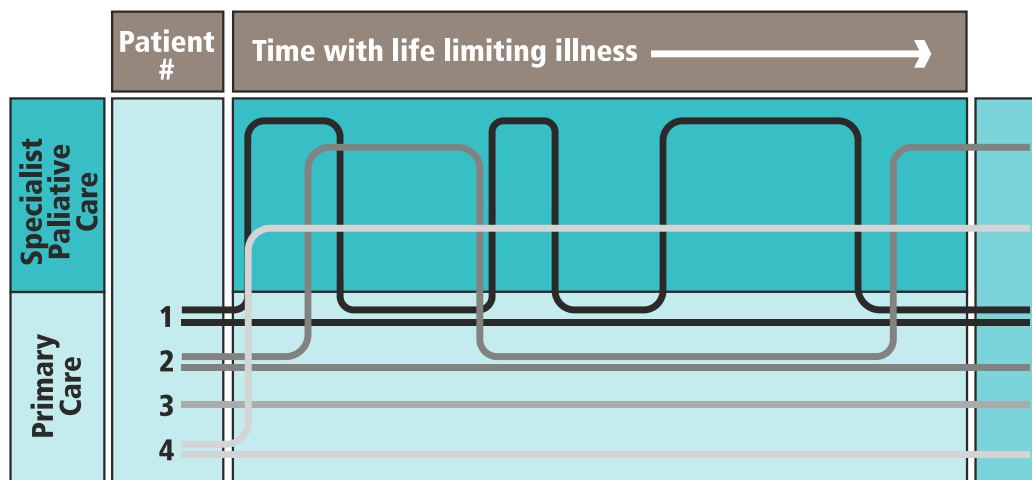
Table 2. Categories of palliative care services

| Palliative care | | | | |
|-----------------------|--|--|---------------------------------------|---|
| | Palliative care approach | Specialist support for general palliative care | | Specialist palliative care |
| Acute care | Hospital | Volunteer hospice service | Hospital palliative care support team | Palliative care unit |
| Long-term care | Nursing home, residential home | | Home palliative care teams | Inpatient hospice |
| Home care | General practitioners, community nursing teams | | | Home palliative care teams, day-care centre |

Source: EAPC (9) adapted from (10).

In a well-functioning system, there is also a need for interaction and integration between these different levels of care (Figure 1). Patients in need of palliative care may require support from different levels of palliative care services during the course of their care, and it is important that there are referral pathways in place to ensure a seamless transition for patients and their families.

Figure 1. Examples of scenarios with different levels of care to meet palliative care needs



Source: Palliative Care Australia (11).

3.2 Setting up a home-based palliative care service

What is home-based palliative care?

Home-based palliative care provides care to people with chronic, life-limiting health problems such as cancer, advanced cardiac, renal and respiratory diseases, HIV/AIDS and chronic neurological disorders, in the home in which the patient lives. It is best delivered by a multidisciplinary team trained in palliative care, including doctors, nurses, community health workers and volunteers.

There are a number of advantages to home-based palliative care in many situations. For instance, many patients feel more comfortable in their home than in a health-care setting. A home-based service means that family members are integrated into the process, which in turn means that the patient has easy access to care. A home-based approach provides advice and support to family members to help them as caregivers, and the home-care team is able to facilitate referral to additional services.

On the one hand, home-based care helps the patient and family maintain privacy and confidentiality, but on the other hand it helps to increase community awareness of palliative care. **Local resources and support networks can be mobilized and training can be provided by community health workers** to others in the local area.

Essential requirements for a home-based palliative care service

A basic home-based palliative care service can be set up quite simply. The minimum essential requirements for a home-care service are listed in Figure 2.

For disabled patients and those near the end of life, a family caregiver should take care of the patient as far as possible.

Home environments must be safe for the home-care team to visit, and there must be a safe and accessible place for the team to store medicines and equipment, as well as to discuss patients and plan visits. There is also a need for transport to enable the team to visit patients' homes, and team members also need mobile telephones so that they can stay in contact with patients and families around the clock. Patients and their caregivers should be able to contact the home-care team outside of visits.

A full-time nurse and a part-time doctor are the minimum requirements for a home-care team, although this depends on the regulatory and health system norms in the country. A multidisciplinary team of nurses,

doctors, psychologists/counsellors, social workers and trained volunteers or community health workers is ideal. The suggested minimum training for various members of the home-care team is provided in Table 3. Training of the team should include both theoretical and hands-on components. Training should also be offered to family caregivers, with simple printed information on managing care of the patient at home.

Standard forms should be used for documenting patient records, and ideally the patient/family should sign a consent form. A health record should be maintained for each patient. Records of utilization of all medicines (and especially morphine) should be maintained in compliance with local laws and regulations. A sample list, from India, of the basic medicines and medical equipment for the home-care kit is provided in Annex 3.

Figure 2. Minimum requirements for a home-based palliative care service

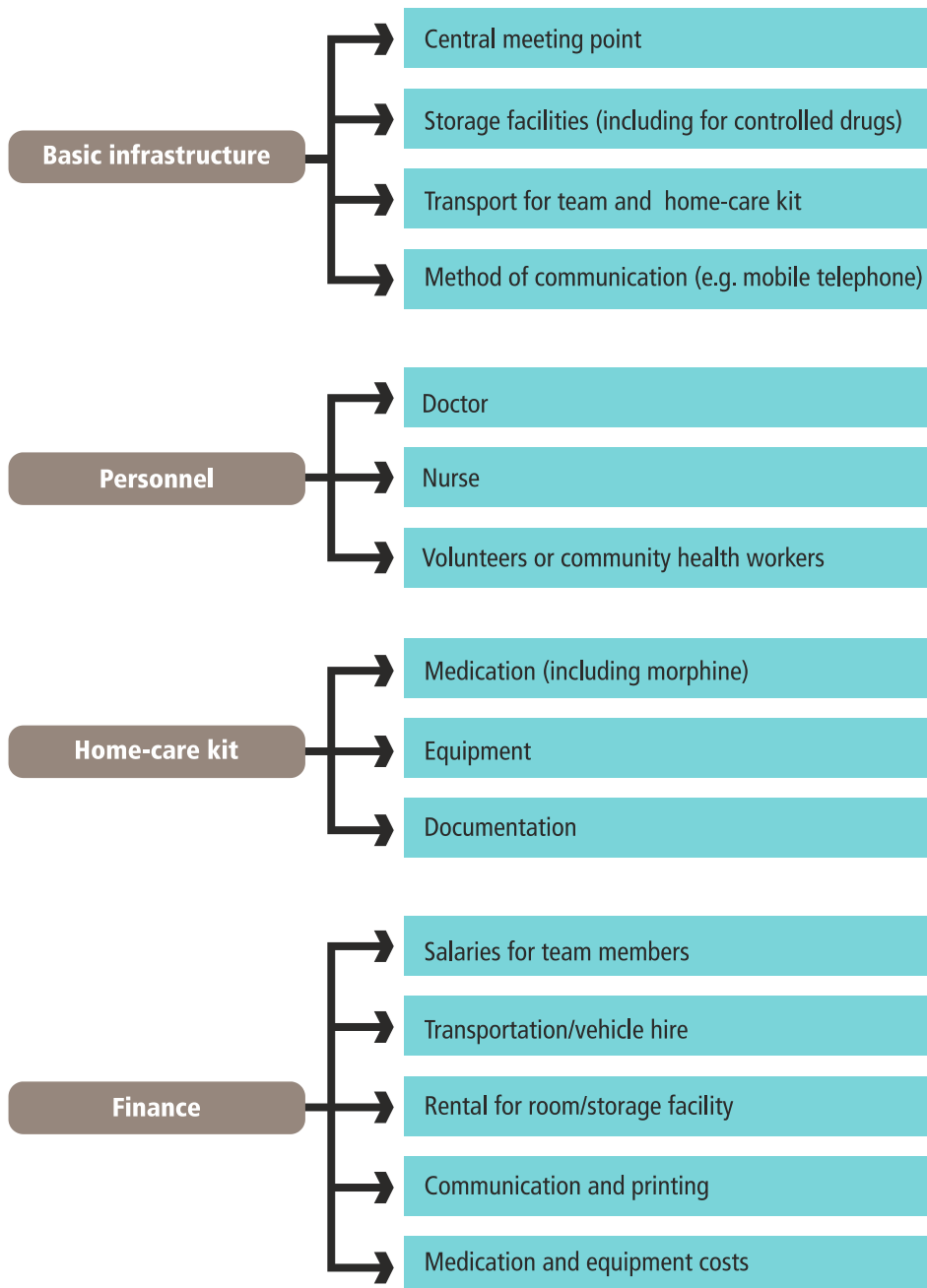


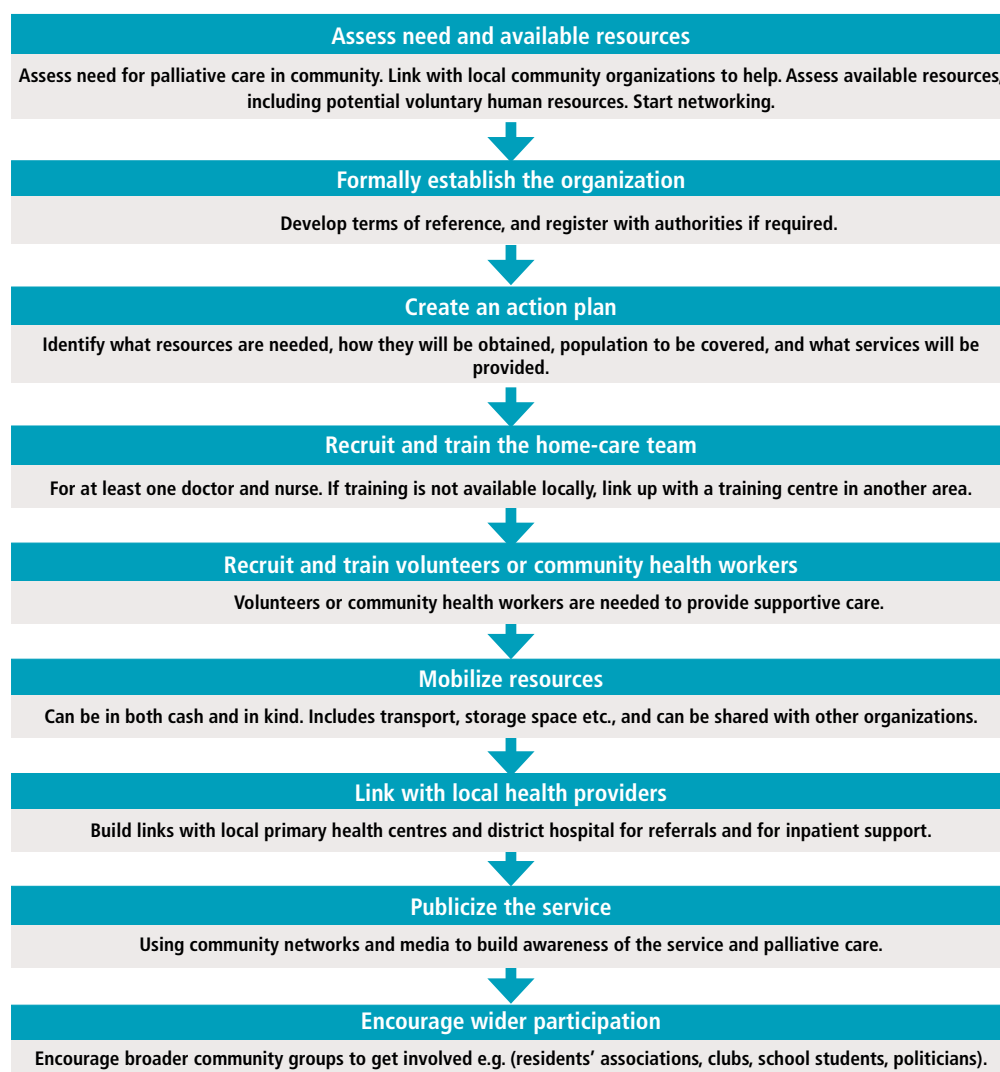
Table 3. Suggested minimum training standards for the home-care team¹

| | Basic | Mid-level | Advanced |
|--------------------------|--|--|--|
| Doctors | Foundation courses (3-10 days) | Residential course (6 weeks) | Fellowship/postgraduate qualification in palliative care (1-3 years) |
| Nurses | Foundation courses (3-10 days) | Residential course (6 weeks) | Certificate course (4 months), fellowship (1 year) |
| Community health workers | 3-6 hours to supplement prior training | Basic course (3 months/400 hours) | Advanced communication skills/lymphoedema management |
| Volunteers | Introductory course (3 hours) | 16 hours theory + 4 clinical sessions, | Advanced communication skills and train-the-trainer course |

¹ Note: Minimum requirements for home-care team depend greatly on the format of the health system. There are countries where nurses play a larger role, and others where home care is conducted more by doctors.

How to set up a home-based palliative care service

An example of steps for setting up a home-based palliative care service is outlined in Figure 3. Wherever possible, this should be initiated by the local health authorities and should follow the planning processes used in the local health system. This approach can also be used by nongovernmental organizations (NGOs) or other bodies to establish a home-care service which can later be integrated into the health system.

Figure 3. Steps for establishing a home-based palliative care service


Case example: Integrated community-based home care in South Africa

- The South African model of integrated community-based home care (IHC) (13) provides palliative care in a person's home through the use of trained community care workers supervised by a professional nurse, backed by a strong network of community organizations including the local clinic and district hospital. This model empowers family members and neighbours to cope in caring for patients at home, relieving the health system of the burden of care. The model was initially developed by South Coast Hospice in response to the AIDS epidemic and has been refined to cater for people with other diagnoses requiring palliative care.
- Identifying and training community caregivers is a key strength of this model of care. Family carers, volunteers and community health workers are the primary caregivers but are linked with primary health clinics and hospitals. Care, prevention and disease-oriented treatment are also linked. The IHC model promotes referral between all partners and ensures that community caregivers are trained, supervised and supported by a professional palliative care nurse and a team of professional palliative care workers. The patient and family are at the centre of the model, ensuring that the care providers focus on the patient's identified needs.
- The IHC model of care is applicable to all diagnoses and is cost-effective for a number of reasons: 1) care is provided in the person's home and supports family carers; 2) the primary care worker is a non-professional community caregiver trained in palliative care; 3) training, support and supervision are provided by a professional nurse who may also visit patients at home; 4) quality of care is assessed by audit on the basis of patient-reported outcomes; and 5) referral to and from health and welfare services is central to ensuring that care matches patient needs, including referral to a palliative care interdisciplinary team or inpatient hospice facility.
- The South African model of IHC for palliative care has two particular strengths: 1) trained community workers providing home care, supervised by a hospice, can reach more people, and 2) through collaboration between providers, including primary health clinics and hospitals, the IHC strengthens overall community health services.
- Funded by the National Department of Health, the model was rolled out to seven hospices in South Africa in different settings – urban, semi-urban and rural. The Hospice Palliative Care Association (HPCA) of South Africa established a formal organizational mentorship programme to guide organizations to achieve the standards of governance, management and palliative care required to mainstream the IHC model of care in South Africa's hospices.

3.3 Setting up a community-based palliative care service

What is community-based palliative care?

Community-based palliative care services are those offered at a community health centre (CHC) or that are run with community participation. Community participation is the involvement of people in a community to solve their own problems. This includes community involvement in the needs assessment, planning, implementation, resource mobilization, day-to-day management and evaluation of the programme. Settings that may be poor in financial resources can be rich in community resources. Community-based palliative care services can be a way to achieve significant coverage of services for patients with chronic,

life-limiting health problems. Wherever possible, this should be initiated in collaboration with the local health authorities and should follow the planning processes used in the health system. The community-based approach can also be used by community organizations that wish to establish a palliative care service for their community, and which can later be integrated into the health system.

Community-based palliative care services are typically provided by both health-care professionals and community health workers/volunteers. At a minimum, paid doctors and nurses are needed. They may work at the CHC and support the community health workers or volunteers who visit patients and families at home. Health-care professionals based at a CHC also can visit patients at home when needed and keep in touch with patients and family members via mobile telephone. The team may include other voluntary allied health professionals if available. Community health workers or volunteers, supported by health-care professionals, will provide the basic home care.

Table 4. Key human resources required for a community-based palliative care service

| | | Tasks | Suggested minimum training |
|--|---|-------|--|
| Community volunteers/health-workers | | | |
| Untrained sensitized volunteers | Provide support to the palliative care service (e.g. transport, food for patients, fund-raising). | | Sensitization course (approx. 2 hours) covering basics of palliative care, home care, communication. |
| Trained volunteers | Contribute to patient home care, offering: <ul style="list-style-type: none"> ■ emotional support ■ basic nursing tasks ■ help with mobility ■ reporting of uncontrolled distress to higher level. | | Basic palliative care course for volunteers (approx. 16 hours theory plus 4 home visit days) covering communication skills, emotional support, patient assessment, nursing care, home care, basics of symptom management, reporting to higher level. |
| Community health workers | Contribute to patient home care, offering: <ul style="list-style-type: none"> ■ emotional support ■ basic nursing chores ■ help with mobility ■ reporting of uncontrolled distress to higher level. | | Basic palliative care course for community health workers (approx. 3–6 hours) covering communication skills, emotional support, patient assessment, reporting to higher level. |
| Health care professionals | | | |
| Nurses | Key professionals in the team, providing nurse-led home care and/or care at CHCs. | | Staff nurses with mid-level training in palliative care (see Table 3) supported by nurses or auxiliary nurses with basic foundation training in palliative care (3 months/400 hours). |
| Doctors | Provide medical support and supervision for nurses and CHCs, home visits, and outpatient and inpatient care. | | Physicians with training in palliative care (see Table 3). |

Source: Adapted from (14).

How to set up a community-based palliative care service

Establishing a palliative care service in a community involves either integrating the care into the routine activities of an existing CHC or, where there is no CHC, setting up a new service (Figure 4).

Integrating palliative care into a community health centre

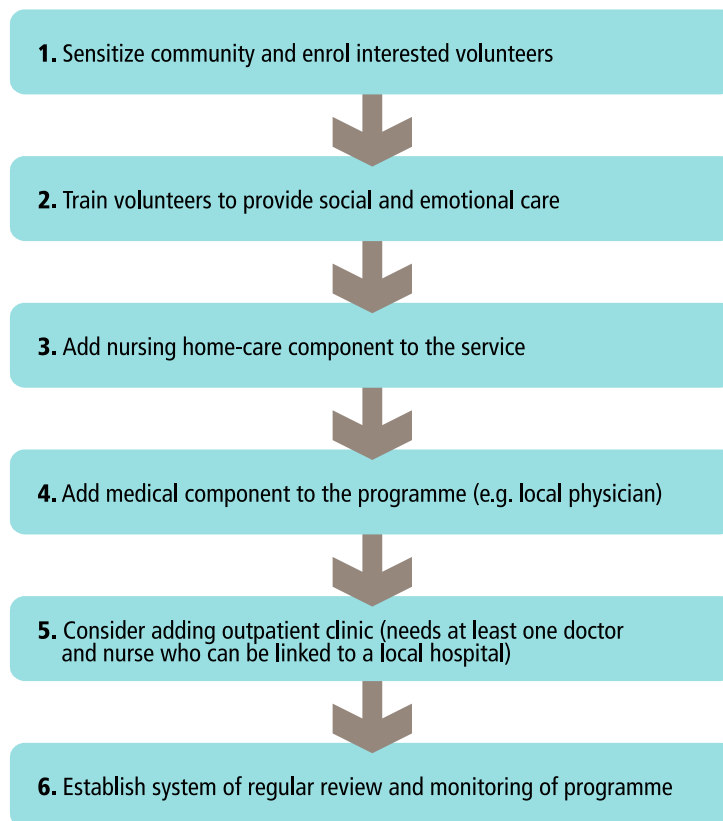
1. **Advocacy to build support:** If a CHC already exists, initial efforts should focus on trying to integrate palliative care services into the centre's existing services. However, care must be taken not to add more responsibilities to an already overburdened staff without either adding more staff or reducing existing responsibilities. Advocacy can focus on the savings resulting from investment in palliative care services, by reducing hospital admissions and length of stay (15).
Sensitization of existing staff: The medical and moral reasons for palliative care should be introduced to the CHC staff to elicit buy-in. Make clear that palliative care services will not overburden them.
2. **Training:** Ideally, training should be provided first to the medical doctor(s), clinical officer(s) or assistant doctor(s) at the CHC. They should receive at least 35 hours of combined theoretical and practical training in basic palliative care (Annex 5). Once trained, the medical staff can participate in the training of nurses and community health workers or volunteers. At least one nurse, and preferably two, at each CHC also should receive 35 hours of training in basic palliative nursing care. The nurse(s) and doctor(s) can then participate in training community health workers or volunteers. Existing community health workers already trained in some home-care services should receive at least 3–6 hours of training in recognizing uncontrolled physical or psychological distress or significant social distress and reporting these to a supervisor at the CHC. New volunteers can be trained with the 16-hour curriculum described below.
3. **Services:** At a minimum, the CHC should provide outpatient palliative care. It can also support home care by supervising community health workers or volunteers, by sending nursing and/or medical staff to visit patients at home as needed, or by keeping in touch with patients or families by mobile telephone. In addition, CHCs that have inpatient beds can provide uncomplicated end-of-life care for a maximum of one or two inpatients at any one time if the families are unable to care for the patient at home (care at a CHC will be much cheaper than in a hospital).

Setting up a new community-based palliative care service

In most situations it is recommended to take a step-by-step approach, as follows:

1. **Conduct sensitization and advocacy to build support:** In any area there will be people interested in helping others. The first step is to hold an awareness meeting/discussion for people who are likely to be interested in helping. All the groups/organizations involved in social/health-care activities in the region should be invited. The meeting should ideally be convened by a "neutral" local body to ensure participation from different interest groups and organizations. Programme facilitators should appeal to as broad an audience as possible. Concern should be expressed about incurably ill patients in the region, and ways to help them should be discussed. Persons willing to spend a short time each week to assist such patients should be registered as volunteers.
2. **Train volunteers:** A sample curriculum for a 16-hour basic volunteer training course (basic nursing care, communication skills and emotional support) is included in Annex 4. Using a standardized form/template, the trained volunteers should document the problems of incurably ill patients in their neighbourhood. It is important to have weekly review meetings of the new volunteers to discuss solutions to the problems they document. A social support programme should be started with the volunteers to supply food to starving families, educational support to patients' children, emotional support to patients and families and to meet other needs. An information contact point should be set up, possibly in a space available from one of the volunteers (e.g. a local shop, public library premises). Begin collecting funds, manpower and other resources, and link with the nearest palliative care unit if there is one.

3. **Add a nursing component to the programme.** It may take 1–2 months for the local group to establish a stable social support system and to raise money to employ a part-time nurse. The best long-term option is to obtain the services of a nurse in the neighbourhood and to encourage them to take training in palliative care. Nurse-led home-care programmes can be started and, in certain situations, nursing help might be available from a nearby palliative care unit. The nurses' protocol can be a guide for nurse-led home care. It is important to establish a culture of meticulous documentation and review.
4. **Add the medical component.** This is often the most difficult part due to the scarcity of trained doctors. One possible option is to obtain help with medical issues from a local doctor. The doctor should be encouraged to take training in palliative care, and self-study can be facilitated by a regular supply of relevant reading material. The health system must ensure the training of specialized personnel.
5. **Consider adding a regular outpatient clinic.** This should be considered once the home-care service is established. However, starting an outpatient clinic is more expensive than initiating a home-care service. The availability of a trained doctor and nurse is a prerequisite for the clinic. The clinic can often be linked to a local hospital.
6. **Establish a system of regular review and evaluation.** Any palliative care or supportive service usually generates appreciation from local people. Nevertheless, it is important not to become complacent; there should always be active attempts to identify areas for improvement.
7. **Continue with steps 1 and 2.**

Figure 4. Process for starting a new community palliative care service

Source: Adapted from (14).

Case example: The Kerala Neighbourhood Network in Palliative Care in India

The Kerala Neighbourhood Network in Palliative Care (NNPC) is a community-led initiative that recognizes the need for a different model of care for people with chronic and incurable diseases, as opposed to acute illnesses (16, 17). There is coverage, good access to palliative care in the home, and quality. Doctors and nurses provide clinical care and trained volunteers provide psychosocial support. Community ownership also applies to funding, with people in the community donating a few rupees at a time and collection boxes sited in shops and bus stations, and there is good media and political support. The programme is being replicated in the state of Puducherry, in some districts of West Bengal, in Imphal in Manipur and in a few districts in Tamil Nadu. In Jakarta, Indonesia, the Community Network in Palliative Care (CNPC) which started recently is also based on the NNPC model. The NNPC has received attention from palliative care services in the United Kingdom and the model has been adapted for use at Weston Hospice Care (18) in Somerset.

The NNPC works on the principle of community participation, facilitated by civil society and religious organizations, local government, political parties and district administrations. The NNPC programme can be facilitated by various agencies, though in Kerala the process was initiated by civil society organizations with the local government joining as partners later thanks to a policy decision by the State Government of Kerala. The programmes in the South Indian state of Puducherry and in Indonesia were initiated by local NGOs. In West Bengal, the first project was initiated by one district administration, with civil society groups joining later, while in Manipur the facilitator was a local hospital. Different facilitators attract different groups of volunteers from the community. Irrespective of the primary facilitating platform, the programmes work on the same principles of ensuring local ownership through voluntary contributions of time and money from the community and attracting the maximum number of stakeholders.

3.4 Setting up a hospital-based palliative care service

All hospitals involved in the treatment of patients with cancer should have a palliative care service. Any hospital that caters for people with other chronic diseases – such as HIV/AIDS, chronic respiratory diseases, heart failure and chronic renal diseases – should also consider a palliative care service. However, it may not be possible to offer a service to all patients in need immediately.

A hospital-based palliative care service improves patient outcomes. The on-site availability of various specialities and diagnostic procedures makes the care more comprehensive and makes it easier to control symptoms. Hospital-based palliative care also facilitates the discussion of the patient's values, diagnosis, prognosis and agreement about the goals of care. A hospital-based service, in fact, generally reduces a patient's length of stay in hospital and enables a smooth transition to care in the community. There is also evidence that it may reduce the use of non-beneficial or harmful treatments near the end of life.

Apart from the benefits for specific patients, a hospital-based palliative care service shows the positive impact of palliative care to all hospital staff, helping health workers in other disciplines learn about palliative care and promoting its further use. The on-site service thus reinforces palliative care as a core component of routine health care

Options for a hospital-based palliative care service

A hospital-based palliative care service can involve one or more of the following options (14):

- an outpatient palliative care clinic;
- a palliative care consultation service for hospital inpatients;
- a palliative care day-care service;
- an inpatient palliative care unit;
- a palliative care outreach/home-care service.

An outpatient palliative care clinic can offer low-cost care to a large number of patients and, when coupled with an inpatient consultation service, is the best model if resources and start-up funding are limited. A clinic can always be expanded later. Care can be provided by a nurse, social worker or doctor (or ideally a team including all three). Psychologists and faith workers also perform important roles in some settings. Patients may be referred to the clinic for pain management, symptom control, nursing needs or psychosocial support. However, patients must be mobile in order to attend the clinic.

A palliative care consultation service for hospital inpatients offers consultations to inpatients of other departments of the hospital. The service can be a simple add-on to an outpatient clinic using the same staff. The consultation service has potential to build the capacity of other staff in pain management and palliative care. However, staff looking after inpatients may lack the skills to manage pain relief and symptoms correctly between palliative care consultations.

A day-care service can be added to an outpatient clinic or inpatient consultation service in order to offer stabilization of symptoms, respite for caregivers and counselling of both patient and family. The service can also deal with longer procedures, such as draining of ascitic fluid and wound care, as well as injections and education of family caregivers. Day care can also play an important social role (e.g. providing food and companionship) or rehabilitative function (e.g. physiotherapy or occupational therapy).

An inpatient palliative care unit has dedicated palliative care beds (which can be reprofiled from existing beds) with staff trained in palliative care present 24 hours a day. Such a unit enables more consistent

care to be provided and also makes it easier to monitor quality and to create a more accommodating environment for family members. An inpatient palliative care unit may also serve as a demonstration unit and training hub for the rest of the hospital.

A palliative care outreach/home-care service (see Section 3.2) is a mobile service that brings care to patients who are not able to travel to seek treatment. This kind of service requires little infrastructure and places minimal demands on the hospital. Care can be delivered by the staff of the palliative care outpatient clinic and one of the important features of the outreach service is that it harnesses the strengths of family caregivers.

How to set up a hospital-based palliative care service

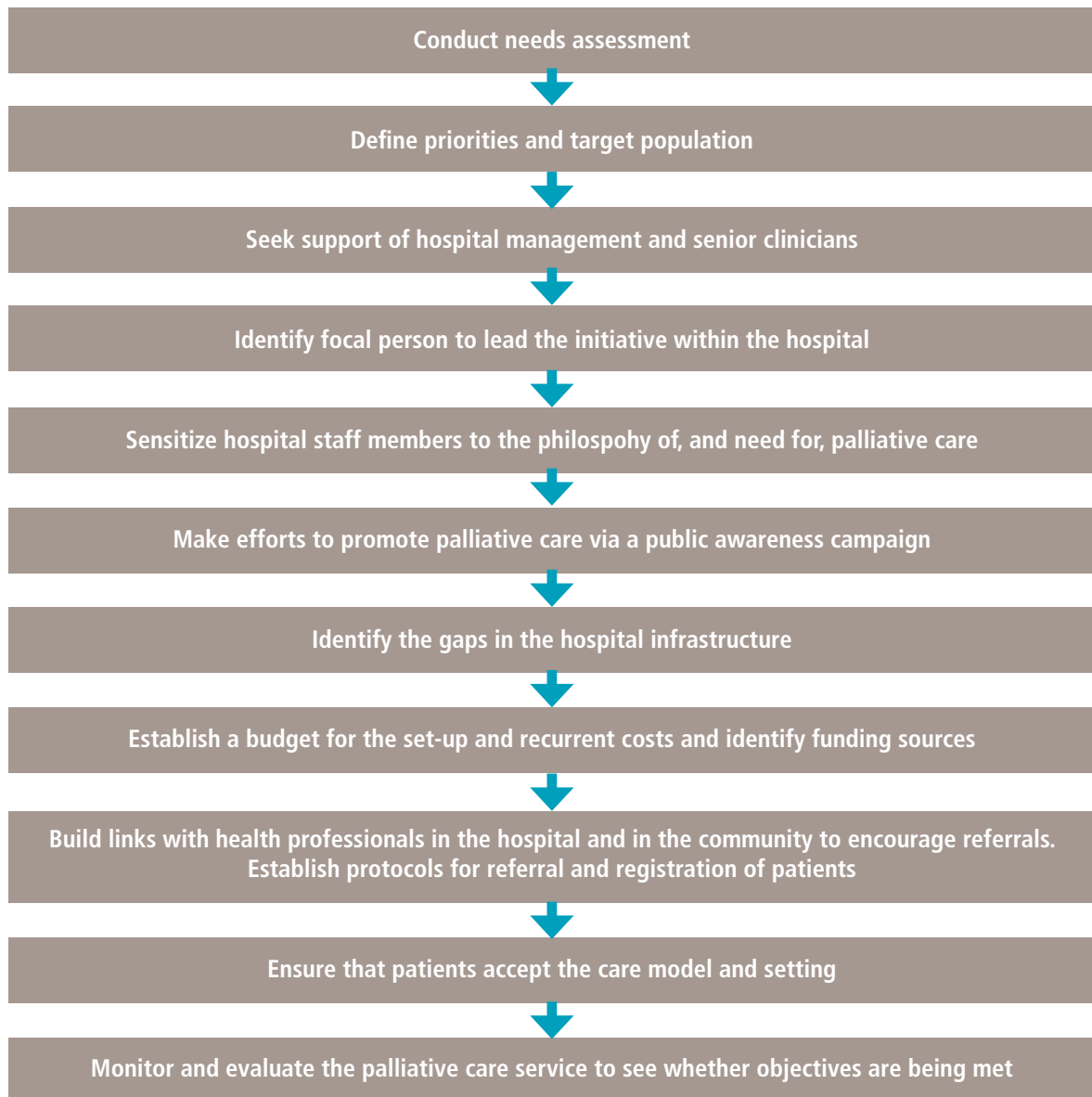
The steps in establishing a palliative care service in a hospital are summarized in Figure 5. The process should begin with a needs assessment that considers the needs and services for palliative care within the geographical population covered by the hospital.

On the basis of the needs assessment, an initial target population should be identified for the new hospital-based service. The target population should be realistic in terms of the resources available. At the beginning, the service could focus on patients with terminal cancer (as more than 80% of these patients will suffer severe pain and other symptoms that can require urgent relief (2)), and then could be progressively expanded to cover all patients with serious, chronic, life-limiting health problems. It is a matter of equity and human rights that the service should plan to expand to cover all patients in need of palliative care, as many non-cancer chronic conditions require palliative care.

The hospital-based palliative care service must include measures to guarantee the availability of the essential medicines for palliative care (see Annex 1 and 2). In particular, the hospital must ensure that it has an adequate and uninterrupted supply of oral morphine.

In planning the physical location of the service, it is important to bear in mind that patients who need palliative care may not be mobile and may need more than one caregiver to look after them. All facilities need to be easily accessible to trolleys and wheelchairs. There must also be space for family members to be present with the patient.

Figure 5. Process for starting a new hospital-based palliative care service



Source: Adapted from (14).

Staffing the hospital-based palliative care service

There are many ways of staffing a hospital palliative care service. The required and recommended providers, and their core responsibilities, are listed in Table 5. Additional professionals – including a psychologist, pharmacists, physiotherapist, spiritual care providers, dietician and volunteers – would strengthen the team and the service offered.

Table 5. Minimum staffing required for a hospital-based palliative care service

| | Role | Capacity/skills required | Position | Availability |
|---|--------------------------------|---|------------------|---|
| Doctor (required) | Team manager/member | Training in palliative care and communication skills. As a minimum, a course with a theoretical component and at least 10 days' practical. Ideally a specialist qualification in palliative care. | Regular staff | Full-time or part-time, depending on workload |
| Nurses (required) | Team member | Training in palliative care and communication skills. As a minimum, a course with a theoretical component and at least 10 days' practical. Ideally a more specialized qualification in palliative care. | Regular staff | Full-time |
| Psychologists or counsellors (recommended) | Team member | Trained counsellor with orientation to special needs in palliative care. | Regular/visiting | Full-time |
| Auxiliary nurses/ Palliative nursing aides | Team member | Assisting staff nurses in clinical work. | Regular staff | Full-time |
| Pharmacist | Team member | | Regular staff | Part-time |
| Social workers (recommended) | Team member | Trained social worker with orientation to special needs in palliative care. | Regular/visiting | Full-time/part-time |
| Volunteers (recommended) | Additional support to the team | Specific to their role. | Visiting | Part-time |

Source: Adapted from (14).

3.5 Setting up a palliative care service for children

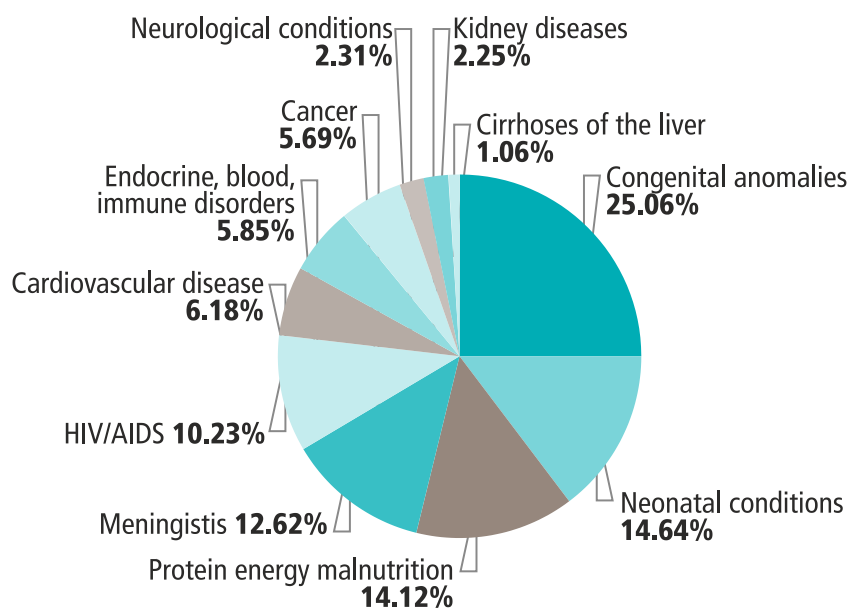
Palliative care for children includes physical, emotional, spiritual and social care; it also takes into account the developmental needs from neonate to young adult. The family (including siblings and the extended family) is seen as the unit of care.

Although palliative care for persons of any age has many similarities, palliative care for children represents a special area of care. It involves active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not the child receives treatment directed at the disease. The role of the health providers is to both evaluate and alleviate a child's physical, psychological and social distress.

Each year, 1.2 million children need palliative care in the last year of their life. The range of conditions requiring palliative care is larger in children than in adults because it includes some conditions that are seen only in childhood with early mortality (Figure 6), such as neonatal conditions, genetic anomalies, congenital conditions, neurological conditions (including cerebral palsy), and rare diseases.

Palliative care for children can be provided in a variety of locations:

- In the home
- At a primary health care clinic
- In hospital
- In a children's home or orphan care centre
- In a day-care centre
- Within a paediatric service
- Within a general palliative care or hospice service
- Within a family medicine service
- Within a hospice inpatient unit.

Figure 6. Children in need of palliative care by disease group


Source: WHO, 2014 (19).

Minimum staffing requirements

In a resource-limited setting, the minimum workforce required to provide a paediatric palliative care service would be a nurse and a doctor, supported by community health care workers, all who have paediatric palliative care knowledge and competence. In settings with more resources, a team would include a paediatrician, psychologists, social workers and other allied health therapists. In many settings, team leaders are nurses.

As resources allow, a broader multidisciplinary team could be considered, as described in Table 6. Irrespective of whether the service is home-based, inpatient unit or hospital care, the core team could be the same, with access to other therapies as necessary.

Table 6. Ideal health workforce for a paediatric palliative care service

| Role | Competencies | Position | Availability | |
|--|---|--|---------------|------------------------|
| Doctor with paediatric knowledge or paediatrician | Team member and as consultant/attending physician | <ul style="list-style-type: none"> Palliative care for children; 10-day course includes theory and practical experience. Communication skills with children and families. Understanding of childhood development and children's rights. | Regular staff | Part-time, as required |
| Registered nurses – preferably with paediatric experience and knowledge | Team members/coordinator | <ul style="list-style-type: none"> Palliative care for children; 10-day course includes theory and practical experience. Communication skills with children and families. Understanding of childhood development and children's rights. | Regular staff | Full-time |
| Staff and auxiliary nurses | Team members | <ul style="list-style-type: none"> Palliative care for children; 10-day course includes theory and practical experience. Communication skills with children and families. Understanding of childhood development and children's rights. Nutrition. | Regular staff | Full-time |

| | | | | |
|---|--|--|--|--------------------|
| Social worker | Team member for psychosocial care, with access to social security/ grants where available | <ul style="list-style-type: none"> ■ Palliative care for children; 10-day course includes theory and practical experience. ■ Communication skills with children and families. ■ Understanding of childhood development and children's rights. | Regular staff – not all countries have access to social workers and may use a trained counsellor or child psychologist | Full- or part-time |
| Teacher | Team member | <ul style="list-style-type: none"> ■ Palliative care for children; 10-day course includes theory and practical experience. ■ Communication skills with children and families. ■ Understanding of childhood development and children's rights. | Regular staff | Full- or part-time |
| Chaplain/ spiritual care worker | Team member | <ul style="list-style-type: none"> ■ Palliative care for children; 10-day course includes theory and practical experience. ■ Communication skills with children and families. ■ Understanding of childhood development and children's rights. | Ideally regular staff; often a volunteer | Part-time |
| Care workers/ community caregivers for home care and day care | Team members | <ul style="list-style-type: none"> ■ 30-day course on all aspects of palliative care, paediatric care, childhood development and play, and children's rights. | Regular staff | Full-time |
| Occupational therapist/ physiotherapist/ nutritional therapist/ speech, play, music therapists | Team members | <ul style="list-style-type: none"> ■ Introduction to paediatric palliative care; 5-day course. | Ad hoc consultants or volunteers | Part-time |
| Child psychologist | Team member | <ul style="list-style-type: none"> ■ Introduction to paediatric palliative care; 5-day course. | Ad hoc consultant | Part-time |
| Neonatologist | Consultant or team member depending on the focus of the programme and number of neonates cared for | <ul style="list-style-type: none"> ■ Palliative care for children; 10-day course includes theory and practical experience. ■ Communication skills with children and families. ■ Understanding of childhood development and children's rights. | Consultant/ advisor | Part-time |

Requirements for a palliative care service for children

In addition to staff with training and competency in paediatric palliative care, other important requirements must also be taken into account when setting up a palliative care service for children. For instance, active total care and protection of the child requires an adequate number of staff and access to essential paediatric palliative care medicines, ideally in paediatric formulations. Materials are needed for play, creative expression and developmental stimulation, and food (including baby formula) must be appropriately nutritious for the child's age and stage of development.

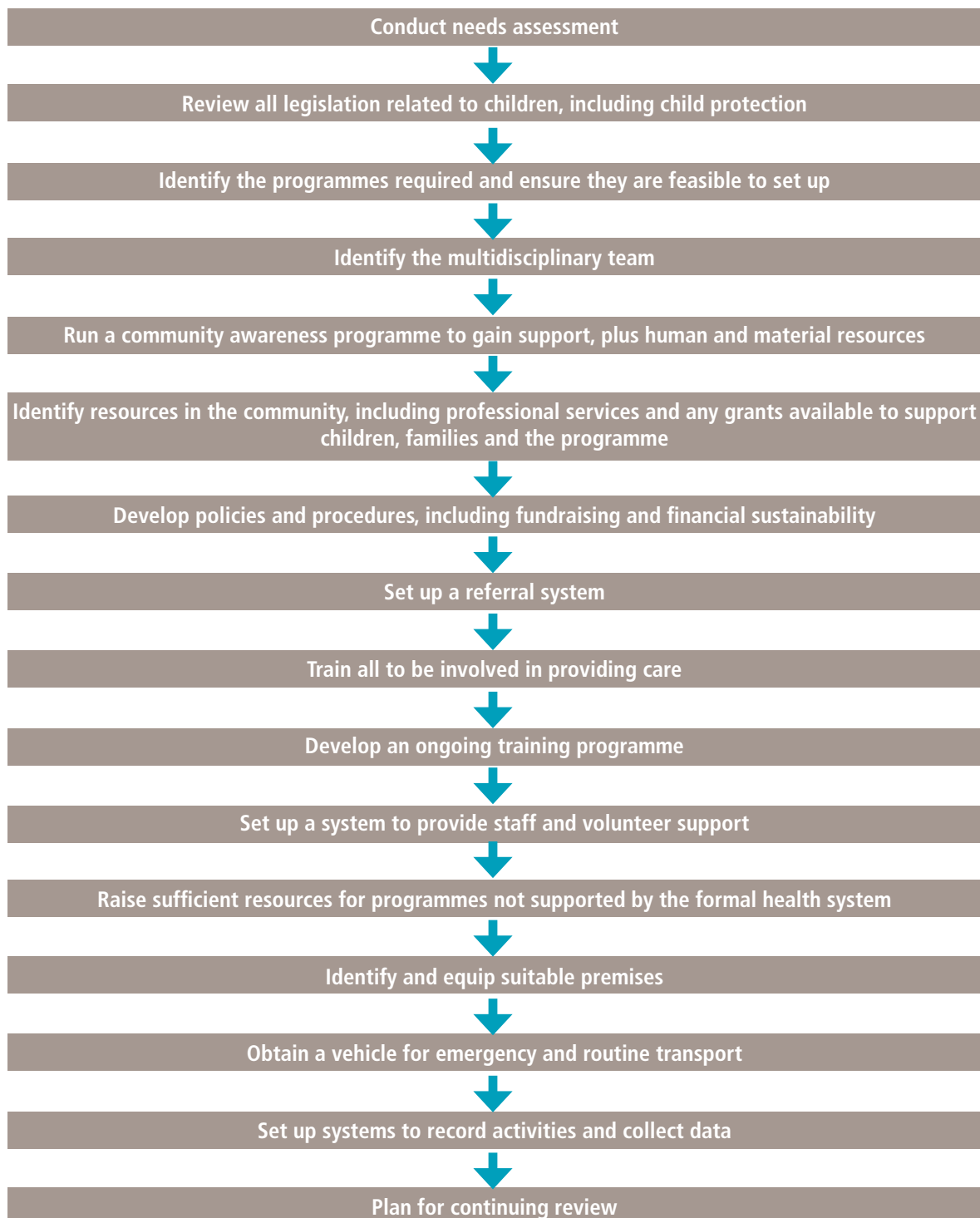
It is essential for a palliative care service for children to have access to specialist advisors in view of the complex needs of children with rare diseases and complex symptoms. At the same time, the service must

ensure that children’s rights are protected, transport services are available, and a that there is a system for referring patients to other services – including the transition to adult palliative care services. Record-keeping must be comprehensive and the care team must have assessment tools for different ages and developmental stages, including tools for non-verbal children and those with neurological impairment.

Process for developing a palliative care service for children

The steps by which a palliative care service for children can be established are outlined in Figure 7.

Figure 7. Steps for establishing a pediatric palliative care service



Case example: Providing palliative care for children through a partnership between the formal health services and an NGO in South Africa

St Nicholas Children's Hospice (now Sunflower Children's Hospice) was set up in 1998 in Bloemfontein Free State, South Africa, to meet the needs of children with HIV/AIDS (before antiretroviral therapy became available) as well as other children with life-limiting conditions and severe disabilities. Its development can be described as follows:

Support was obtained from the Department of Health and premises were provided within the grounds of the National District Hospital. The hospice staff – professionals, community caregivers, teachers and volunteers were trained in a 10-day course of theory and practice. They had previously completed general palliative care training. Ongoing training is also available.

Medical care is provided by the Departments of Family Medicine and Paediatrics, both working with the University of the Free State and the Bloemfontein Free State Health Department. Medicines, therapists and acute care admission are the responsibility of primary, secondary and tertiary hospitals.

Sunflower House, a 15-bed unit, offers home-based care, day care, and inpatient care for end-of-life, symptom management and initiation of therapy. Other services include bereavement support, education, stimulation and play.

The Department of Family Medicine provides undergraduate training in palliative care of children for the Department of Health Sciences, and training at both undergraduate and postgraduate levels at the University of the Free State. Training includes experience in patient care and home-based care through programmes of Sunflower Children's Hospice.

Community involvement and support is maintained through student placements, volunteer services, faith organizations, schools and service clubs.

The partnership between the NGO and the government means that a continuum of care is provided from the children's home, the Sunflower House inpatient unit and the hospitals. Care is coordinated through the Department of Family Medicine by doctors trained in palliative care. Costs are shared, with the hospice raising funds for staff, transport and medicines not provided by the hospitals.

3.6 Setting up a stand-alone palliative care centre or hospice

A stand-alone palliative care centre or hospice may have several roles and functions (Table 7). When planning to set up such a centre, it is important to be clear which function it will have, and if more than one function is envisaged, in what order they should be established.

Scope of services and support provided

Before establishing a stand-alone centre, there needs to be clear consideration of whether there is a real need for the service and, if so, what the scope of the care should be. The basic elements of palliative care should be present – medical, nursing, psychological, social and spiritual support – but the level of care depends on local resources, the availability and capabilities of staff, and their training. Depending on the target group of patients, the care provided may need to include financial support and basic necessities – such as food, utilities, mobile telephone and travel subsidy, and the lending of equipment. The different roles that could be provided by a stand-alone palliative care centre or hospice are as follows:

■ Hospice home-care service

Patients stay in their own homes and are cared for by their families. The hospice team visits patients at home to provide medical care, nursing advice and psychosocial support. A 24-hour telephone support service is essential but is possible only in urban areas. Rural areas are best served if palliative care is integrated into the primary health care system.

■ Inpatient hospice service

Patients receive care while staying in the hospice. The level of care depends on the capabilities of the staff, and how the hospice is viewed in the spectrum of health-care services. This may range from highly skilled medical and nursing care, similar to that hospitals but in a more peaceful environment, to very basic medical care with the hospice acting as a shelter for terminally ill patients with no homes or caregivers.

■ Hospice day-care service

Patients stay in their own homes and travel to the hospice centre during the day for medical consultation, nursing care, rehabilitation and/or social activities. An outpatient clinic may be added to the day-care service. This service may be a more efficient use of resources if the patient is sufficiently fit to travel.

■ Education centre

A palliative care centre or hospice may be ideal for teaching and training of its own staff, other health-care workers, medical and nursing students and the public. It can showcase the palliative care philosophy and approach to care.

■ Research centre

A culture of research will drive continuous improvement of care and contribute to the evidence on which practice is based. All services should undertake audit and service evaluation, but a research centre makes this a particular focus.

Integration of care between the hospital, hospice home care, inpatient hospice care and day care is essential. Attention must be given to easing the transition from one service to another, so that no patient is overlooked. Table 7 outlines some of the advantages and disadvantages of each of these hospice functions.

Other considerations will include whether essential medications, including oral morphine, are available, and whether longer-term funding (domestic and external) can be assured and suitable – and readily accessible – premises can be found. Staff will also need special training and it is best if there is capacity for continuing education. Even before the palliative care centre is launched it is important to plan how to carry out publicity and promote community involvement. And of course there need to be systems for referrals and management of information.

Table 7. Different roles and functions of a stand-alone palliative care centre or hospice

| Role or function | Advantages | Disadvantages |
|---------------------------|---|---|
| Hospice home-care service | <ul style="list-style-type: none"> ■ Can be very a cost-effective service, serving the most patients with the least resources. ■ Needs little space – only office space with work-stations, and storage space for medications and equipment. ■ Most patients prefer to stay in their own homes; many may not be fit to travel to seek health care. | <ul style="list-style-type: none"> ■ Less convenient for teaching and training except on a one-to-one basis. ■ Difficult for donors to see the service and how their donations make a difference. ■ Volunteers do not have a centre to meet, as they are scattered, working with patients at their homes. ■ May be difficult for staff to travel to visit patients in challenging localities or at night. |

| | | |
|----------------------------------|--|--|
| <p>Inpatient hospice service</p> | <ul style="list-style-type: none"> ■ The environment can be controlled and adjusted to provide hospitable, respectful and individualized care. ■ Patients and families can be given intensive care and support at a level not possible in a hospital, whether it is physical care of the patient or psychosocial care of both patient and family. ■ With both patients and staff present in the same place, training and education is facilitated. ■ Donors have a clear view of the effect of their donations. ■ Volunteers may congregate and have a better sense of belonging. ■ It is easier to do community outreach as there is a place where people can meet. | <ul style="list-style-type: none"> ■ Highly-skilled medical and nursing care, if provided, is the most expensive form of palliative care, costing as much or possibly more than hospital care. ■ Patients may prefer to be cared for or to die in their own homes, and may not wish to be at a hospice. ■ Because of distance, cost or convenience, it may not be practical for families to visit often. ■ If many deaths occur at a hospice, patients may become unsettled. The hospice may be labelled as a death house. |
| <p>Hospice day-care service</p> | <ul style="list-style-type: none"> ■ Patients can stay at their own homes and still receive specialized care at a hospice. ■ The hospice day care may provide custodial care for the patient during the day when family members are at work, thus enabling the patient to stay at home, at least until such time as the patient is unable to travel. ■ A good place to deploy volunteers and engage the community. | <ul style="list-style-type: none"> ■ Transportation often has to be provided unless the family can bring the patient. ■ Specialized transport (e.g. ambulances with wheelchair facilities or stair crawls) may be needed. ■ Travel is constrained by travel time as much as by distance. ■ Patients may be exhausted by the time they reach the day-care centre. ■ Group activities may not suit all patients. |
| <p>Education centre</p> | <ul style="list-style-type: none"> ■ Patients are concentrated in one location, providing enough clinical material for teaching. ■ Groups of trainees may be accommodated if proper facilities are available. ■ Requirement for clinical staff to do teaching will drive their own learning and raise standards. | <ul style="list-style-type: none"> ■ The patient's and family's privacy must be safeguarded. ■ Requirement for clinical staff to do teaching necessitates a reduction in their workload. ■ Having positions for trained teaching staff involves more costs. |
| <p>Research centre</p> | <ul style="list-style-type: none"> ■ An academic culture is good for attracting staff of high calibre. | <ul style="list-style-type: none"> ■ Research requires considerable investment in time and money. Most clinicians are not trained in research and need to be trained. Time must be reserved for research and trained staff must be dedicated to doing it. |

Target group of patients

The palliative care centre or hospice needs clarity on the types of patients it will accept since this will help determine the kind of care provided. For instance, the focus of the palliative care centre may be:

■ The disease:

Some palliative care centres may focus on cancer patients, others on HIV/AIDS, or strokes and dementia. Other hospices accept patients with any chronic life-limiting condition in need of palliative care. A decision should also be made as to whether children or adults, or both, should be accepted.

■ The prognosis:

The focus of the centre may be the patient's prognosis for survival and recovery, or it may be solely the patient's need for palliative care whatever the prognosis. A decision also has to be made as to whether

the service will follow patients only until discharge after stabilization of symptoms or social conditions or will follow them until death and will continue to support grieving family members. Admission and discharge criteria are essential for any palliative care centre or hospice. There should be a mechanism for return to the hospice programme when a patient who was stable experiences a crisis that worsens the pain or illness.

- **Geographical location:**

This is particularly important for home care since travel time by staff will limit the size of the catchment area. For inpatient hospice care, accessibility for visiting family members may be another limitation. There are some good examples of computer and mobile technology being used to support patients in rural and remote areas.

- **Socioeconomic condition of the patients:**

Some palliative care centres may be set up to serve the very poor or the homeless, and services may be restricted to these persons. Although universal coverage is the aspiration, limited resources may constrain care for all.

- **Family members:**

Some centres allow family members to stay with the patient while others may allow them only to visit. A further decision must be made as to the maximum number of guests allowed per patient.

Human resources

Before a palliative care service is established there must be clarity on what mix of paid staff and volunteers is best and which professional staff will be needed and with what level of expertise. Needs will vary according to the type of service to be provided. While the team should be interdisciplinary, the amount and level of input from different disciplines will depend on the care envisaged and the availability of staff.

For home care, a nurse is often the main care manager, calling in other resources as needed. In settings with more resources, there will be an interdisciplinary team with a team coordinator. Special training in symptom assessment and case management is needed in addition to nursing expertise. For an inpatient service, nursing staff with different levels of expertise will be present 24 hours a day and will form the largest group of the interdisciplinary team. A day-care service may be managed by an occupational therapist, physiotherapist or nurse manager.

The amount of medical input may depend on the resources available. It may be provided either by a specialist in palliative care or by general or family physicians with some training in palliative care. If it is intended to create a centre of excellence and training, specialist palliative care physicians and nurses will be needed. If it is difficult to recruit and retain highly trained palliative care specialists, options such as joint appointments or service-level agreements for staff from hospital palliative care services may be necessary.

Medical social workers and counsellors are core members of the interdisciplinary hospice team. Junior members with little clinical experience may need mentoring from experienced workers.

Other allied health professionals, such as occupational, physio- and speech therapists, may be needed either part-time or full-time. They will require training in handling patients with advanced disease whose conditions are expected to deteriorate and where the aim of care is to maximize function and quality of life.

The role of volunteers must be carefully considered. Volunteers often enrich a hospice service and sometimes are the mainstay of manpower, but training and coordination are necessary so they are not without cost. Apart from caring for patients, volunteers can join governing boards, raise funds and awareness, or help with organization, administration and maintenance of a hospice.

Reliable availability of essential medications

The availability of essential medications, especially oral morphine, is of crucial importance in pain and symptom management. In many countries where palliative care is not well established, such medications are available only in hospitals; consequently, providing them for patients at home or at the hospice may require collaboration from hospital staff. One achievement of Hospice Africa Uganda is in making available prescription of oral morphine by nurses, and becoming the sole supplier of oral morphine in the country. Training in the appropriate use of controlled medicines is crucial to ensure that prescribers are confident and do not have unnecessary fears about prescribing these medicines. Regulatory and policy changes may be required to ensure appropriate access to essential controlled medicines (see Section 4.3).

Funding

Funds may be derived from foundations, donations from the public, legacies, subsidies from the government and co-payment by the end-users, or a combination of these. Many palliative care centres or hospices start off as community projects, often funded by charitable bodies. For sustainability, government funding should be sought to cover part, if not all, of the service provided, since the goal is integration of palliative care services into the health system. However, some fundraising from the general public is beneficial as it promotes community awareness and ownership. In Kerala, India, where micro-donations from the public are the mainstay of funding for pain and palliative care services, government support supplements this.

Case example: Palliative care financing in Costa Rica

Palliative care facilities in Costa Rica are financed by public funds. State establishments receive a budget from the Costa Rican Social Security and some receive funding from the Social Protection Board, which receives funds from national lotteries. The independent units are funded by the Social Protection Board and contributions from civil society organizations. Many of the adult and paediatric palliative care programmes are also supported by an association or foundation that raises funds for patient care.

Source: (20).

The role of external support in training, funding and the workforce

In low- and middle-income countries where palliative care services are not yet functioning and awareness is patchy, there is a role for overseas support in training. This may be in the form of training-of-trainers programmes, overseas clinical fellowships for selected health professionals, embedding of trained professionals from overseas to work in cancer units, and seed-funding of services. The essence of such initiatives, which must be addressed from the beginning, is the eventual sustainability of the venture from local resources. Occasional palliative care seminars and presentations at conferences on related topics, such as oncology or surgery, have limited effect apart from increasing awareness. It is the training of personnel for starting and sustaining services, together with government support, that will drive the development of palliative care in such countries.

Case example: Development of a stand-alone palliative care centre in Brasov, Romania

In 1992 the original idea was to start a hospice home-care service within the city of Brasov, funded entirely by a foundation from the United Kingdom. Consultancy services were also started in the government hospital. Over six years, the hospice received support from a series of palliative care nurses from the United Kingdom, supplemented by occasional visits from doctors. This helped to build local staff capabilities. The hospice home-care service was later expanded to cover the surrounding region with the opening of two satellite centres.

An education and training centre was started in 1997. This led to a growing training programme, not only for internal staff but for the rest of the country, and even for neighbouring countries. Project funding enabled research by clinical staff. No dedicated research staff were hired.

In 2002, land was donated by the local government for an inpatient hospice of 19 beds, 13 for adults and 6 for children. This was needed for patients who could not be managed at home and for respite care for families. A day-care centre and outpatient clinic was also started in the same building.

Government funding for inpatient hospice care came when palliative care beds became available in government hospitals in 2005. Ministry of Health funding was obtained in 2010 for the home-care service. Day-care funding came partially from the Social Services department. Current funding relies on 8% from overseas, 17% from government, 26% from trusts, 22% from businesses, 13% from individuals, 12% from local fundraising, 1% from courses, and 1% from other sources.

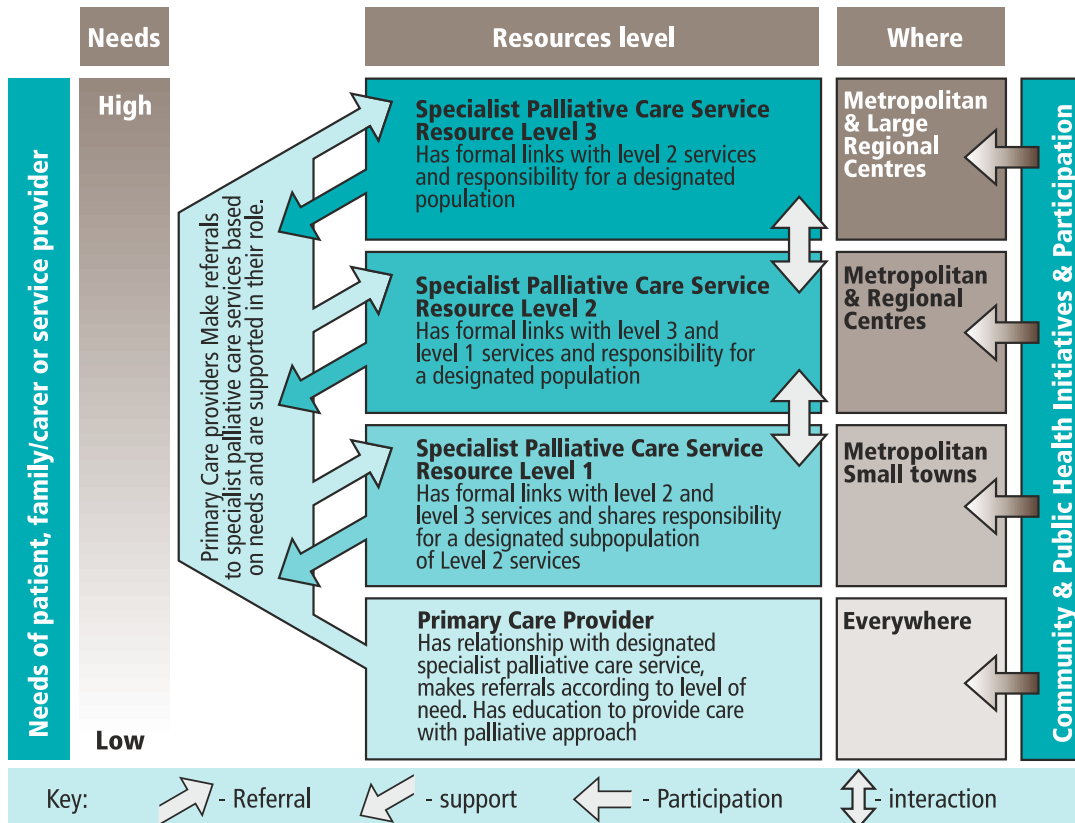
The hospice does a lot of advocacy – promoting standards and clinical protocols, pushing for changes in the law on opioids, and calling for improved staffing for palliative care. Some of this work is supported by overseas grants.

3.7 Establishing an integrated approach in a district

The previous sections have looked at how to start by establishing palliative care services through a range of entry-points: a hospital, a home-care service, a stand-alone palliative care centre or a community setting. Services can be started in any or all of those ways but strong and effective palliative care depends on services that are linked and coordinated at each level of the health system. This is important to ensure that there are good links between hospital and home, and between specialist and general care, that human resources are used as efficiently as possible, and that both family and patient experience a seamless transition through all parts of the health system that they need to interact with.

There is no one-size-fits-all approach to integrating palliative care into different levels of care or types of services (Figure 8) as it depends on existing services. However, there are a number of general principles for success.

Figure 8. An example of integration between different levels of palliative care services



Source: Palliative Care Australia (11).

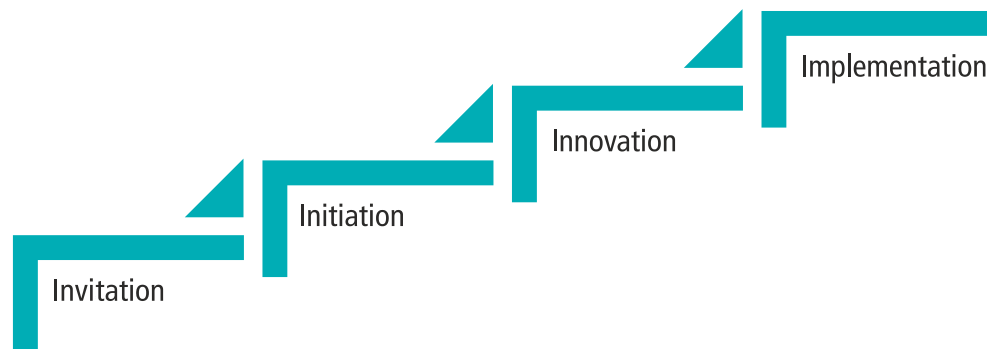
What makes for successful integration?

The Tropical Health and Education Trust (THET) integrated palliative care project (21) worked to strengthen palliative care integration in four African countries (Kenya, Rwanda, Uganda and Zambia) between 2012 and 2015. The project worked with three large hospitals in each country to strengthen palliative care within the hospitals, as well as to train and build community provider networks and referral pathways within the catchment area of each hospital. A number of lessons were learned through this project about different models for integrating palliative care services between parts of the health system:

- The establishment of an integrated palliative care approach within a district must respect the values that a district health service is built on, and must acknowledge the resources and the structures that the district health system has at its disposal.
- The approach must be dynamic and responsive to the needs of the district.
- An integrated palliative care approach should be based on co-production and co-development of services set in a context of shared knowledge about palliative care.
- Palliative care is not a medical approach that belongs only to health providers; it is an approach everyone needs to embrace for effective district working.

Stages of integration

Palliative care integration requires invitation, initiation, innovation and implementation (Figure 9).

Figure 9. Steps required in integration of palliative care

Invitation

Although district health systems are organized differently in different countries, there are common components. These include leadership capacity, resources, data management and decision-making.

1. Engage political and district leadership: While those in charge of the district health service have the responsibility of managing the health of the district, they do not do so in isolation. Districts are in most cases government entities, structured as part of local and national government. Therefore engaging with the political leadership of a district is an important process.
2. Advocate about palliative care: Invitations to develop this integrated approach within a district are most likely to come through sustained advocacy about palliative care that is open and explicit, non-threatening and positive.
3. Provide information about need: District leaders require evidence of need, i.e. informed data that illustrate the local burden of disease, end-of-life care requirements, and inpatient, outpatient, discharge and follow-up processes. They need to understand the current and foreseeable problems if the need is not addressed. Those who can best inform leaders of the need are the staff of hospitals, health centres and clinics, persons living with non-curable illnesses, their caregivers, local faith communities, educators and local businesses – all of whom interact directly or indirectly with individuals who need care. Data are often available through health information systems, hospital and clinic records, records from community health workers and volunteers, NGOs and private services. However, such data are often neither standardized nor accessible to those who can use it most effectively.

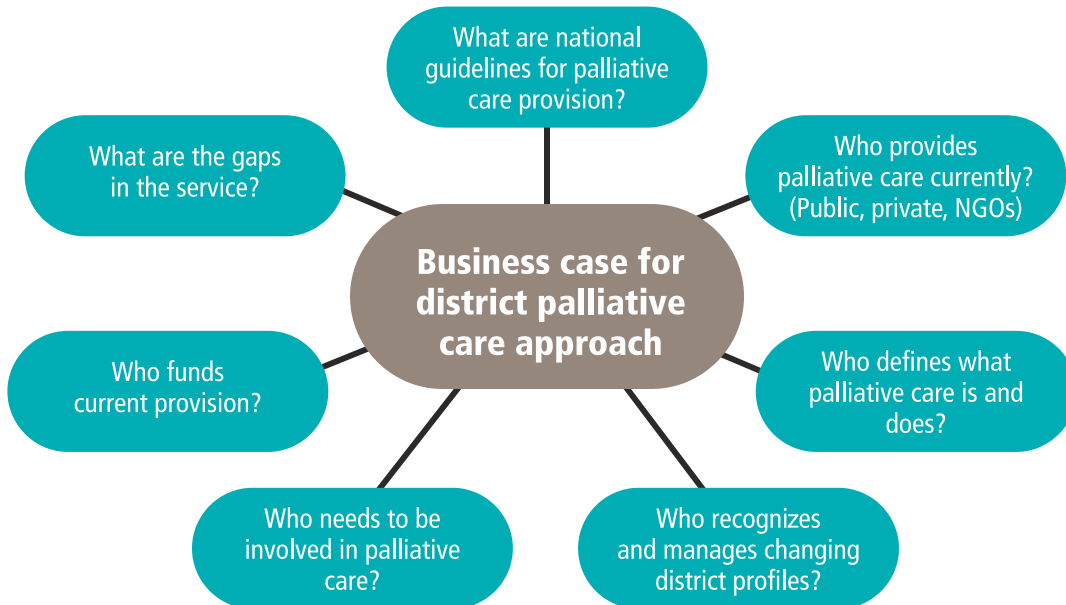
Initiation

Once an invitation (however broad or wide) to develop an integrated approach has been established, initiation of the approach can begin. Initiation requires planning and wide stakeholder engagement.

1. Engage widely, including isolated centres of care: Integration involves moving palliative care services from isolated “islands of excellence” and embedding these services within the infrastructure, resource chain and workforce planning of a district. However, bypassing existing institutions which have delivered specific care in isolation from the rest of the health service rarely contributes to effective integration. Recognizing the strengths of these individual centres and the challenges they face allows them to become stakeholders in the larger conversation.
2. Make a business case for developing an integrated approach to palliative care: Show how the integrated approach will demonstrate effectiveness and efficiency. Palliative care needs to appear in the district health budget in order to stabilize its development and make it sustainable.

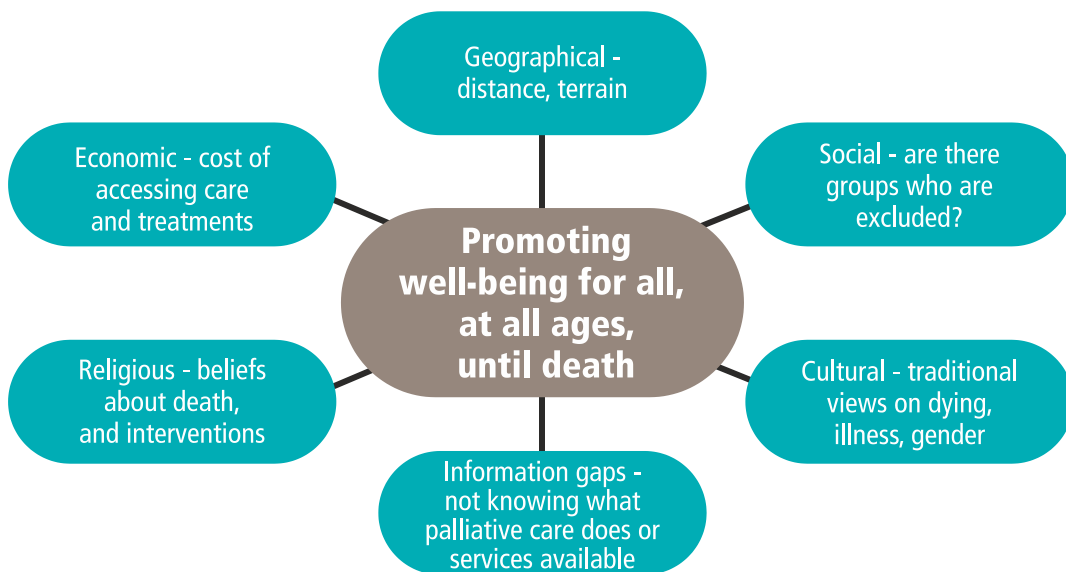
Questions that can be most helpful in making the business case for an integrated approach include those shown in Figure 10.

Figure 10. Integrating palliative care into district health services – questions to consider



In addition to the questions in Figure 10, an integrated approach must also take account of the gaps in services in order to bring about change (Figure 11). As shown, gaps may be due to geographical, economic or religious factors, or they be caused by a person’s social situation, cultural attitudes or simply lack of information.

Figure 11. Identifying palliative care gaps and barriers in district health services



Innovation

Integration requires an innovative approach. Having created the awareness and the openness to begin developing changes in services, opportunities need to be found to develop and trial new ways of delivering care. Some districts have engaged local businesses to run competitions in schools and companies to elicit innovative ideas on new ways of developing and delivering services, and ways of engaging all community members in understanding palliative care.

Implementation

For implementation of palliative care integration, key success factors are likely to be:

- Senior management agrees that palliative care is part of the role of all health workers, rather than seeing palliative care as a speciality that requires separate health workers.
- Palliative care is embedded in the health-care continuum, making it an essential component of primary care. It is seen as a normal health-care activity rather than a specialist one.
- Opportunities in the national palliative care context (e.g. training, financing, legislation, regulation of drugs) are used to build ownership of them at district level.
- The infrastructure for delivery is in place. This usually does not mean setting up new services but rather uniting separate services and systems to become part of the whole. The system enables services to be in the right place at the right time, supported by people with the right skills and the right resources to care.

The emphasis is not on expensive tools or high-end technology but on seamlessness. It requires the 11 Ps of palliative care to be in place (Figure 12).

Figure 12. The 11 Ps of successful palliative care integration

| PATIENTS who receive care and who also give care to others |
|--|
| 1. A Plan of action that captures the vision and outlines the way in which the district envisions palliative care. |
| 2. National Policies applied at district level that support the vision |
| 3. Palliative care Preceptorship – training before service and during service |
| 4. A district-wide referral Pathway connecting hospitals, clinics, NGOs, and others |
| 5. Protocols to improve decision-making |
| 6. Purposeful prescribing – shared documentation, secure systems, skilled pharmacists |
| 7. Procurement systems that ensure consistent medication availability |
| 8. Performance systems that ensure quality and adapt to change |
| 9. Partnerships – a functional network of organizations and support |
| 10. Pastoral care and support |
| 11. Presence – community awareness of palliative care services |
| PEOPLE who plan, deliver, oversee, and participate in care |

Source: Grant L. (reproduced with permission).

Case example: The role of community volunteer workers in Homa Bay, Kenya

Each of the 47 counties in Kenya has its own ministry which oversees the community units, each unit having a population of some 5000 living in 1000 households. Ten community volunteer workers (CVWs) monitor these households (1 CVW for 100 households) on public health issues such as sanitation, disease outbreaks and immunizations. They report to the head of the community unit, the community health extension workers (CHEWs) who in turn communicate to and from a facility-based health extension worker. Public health reports are presented to the township Public Health Officer (PHO). Homa Bay Hospital, a 300-bed district hospital serving 57 000 people, used this system as a platform for sensitizing, mobilizing and referring patients in need of palliative care in Homa Bay township.

The PHO in charge of this township received five days' training in palliative care. In agreement with the Ministry of Health, and in collaboration with trained staff at Homa Bay Hospital, the PHO trained CHEWs and CVWs in the community units in the township in early identification and referral of patients with palliative care needs, as well as in nutrition, hygiene and awareness of cancer and other diseases. Advice was also given on legal issues such as will-making. Additionally, training was given to faith and business leaders, raising awareness and creating partnerships of care.

Source: adapted from (21).

Case example: Integrating palliative care into the Moi Teaching and Referral Hospital (MTRH) catchment area in Kenya

The Moi Teaching and Referral Hospital (MTRH) is an 800-bed referral hospital serving a catchment area of 16.24 million people. It is the second national referral hospital in the country. The hospital established an adult palliative care unit in 2010 and a paediatric service in 2011. The unit provides both care for inpatients who are referred by a clinical team and an outpatient service. There is also an intermittent day-care service. The hospital has morphine and most essential palliative care medicines readily available. Referral and discharge arrangements include assessment by a social worker. A 24-hour mobile telephone hotline is used both for referrals and for follow-up after patients are discharged. There is a good patient registration system with monthly reports.

Under the leadership of the deputy director of nursing, MTRH has adjusted its programme to expand its catchment area:

1. **A modular training programme** was developed. Each of the three modules had a classroom component followed by practice-based implementation supported by mentorship. The aim was to build capacity and sustainability within the hospital setting.
2. Because it is a national referral centre, the hospital did not have direct referral links with the community. It therefore set up a programme of **basic training in five satellite hospitals** to enable them to correctly refer and receive referrals and provide services.
3. MTRH has carried out internal training sessions for health professionals, and for nursing and medical students **in its role as a teaching hospital**. During the project, palliative care was introduced into the undergraduate medical curriculum, and MTRH will take medical undergraduate students on clinical rotation.

The training in the satellite hospitals has led to the establishment of new services. Three of the five hospitals have morphine available, and at least one has developed a dispersed palliative care team which receives referrals, holds monthly clinics and runs community sensitization programmes.

The modular style of training led to a greater number of staff with a level of expertise in palliative care. Hospital medical staff are continually sensitized to increase their profile in this large hospital.

MTRH provides a model of how vision and leadership can overcome the challenges of integrating a palliative care service into a large teaching hospital. Even while facing challenges in changing attitudes in their own hospital, the MTRH team continues to have a wider impact through in-house specialist training and by providing training and mentoring to satellite hospitals.

Source: adapted from (21).



4 Components of a comprehensive approach to palliative care

4.1 What is a comprehensive approach?

National health systems are responsible for including palliative care in the continuum of care for people with serious chronic, life-limiting health problems, linking it to prevention, early detection and treatment programmes. A comprehensive approach to strengthening palliative care requires national policies and plans, availability of essential medicines (especially oral morphine), education of policy-makers, health-care workers, and the public, and implementation of palliative care services in accordance with the principles of universal health coverage.

A sustainable, quality and accessible palliative care system needs to be integrated into primary health care, community and home-based care, as well as supporting care providers such as family and community volunteers. Specialist palliative care is one component of palliative care service delivery, but all health-care providers should be trained in pain management and the needs of patients with life-threatening illness. Providing palliative care should be considered an ethical duty for health professionals.

This section discusses how to take a strategic approach to strengthening palliative care that can be applied to national or subnational levels.

4.2 Developing a palliative care policy

A palliative care policy can take many forms. Whether it is a stand-alone policy, part of a national health plan, or an element of a national NCD, HIV/AIDS or cancer control strategy, the principles outlined in this section remain the same.

A national palliative care policy, whether stand-alone or as part of another key health strategy, should seek to address the following elements:

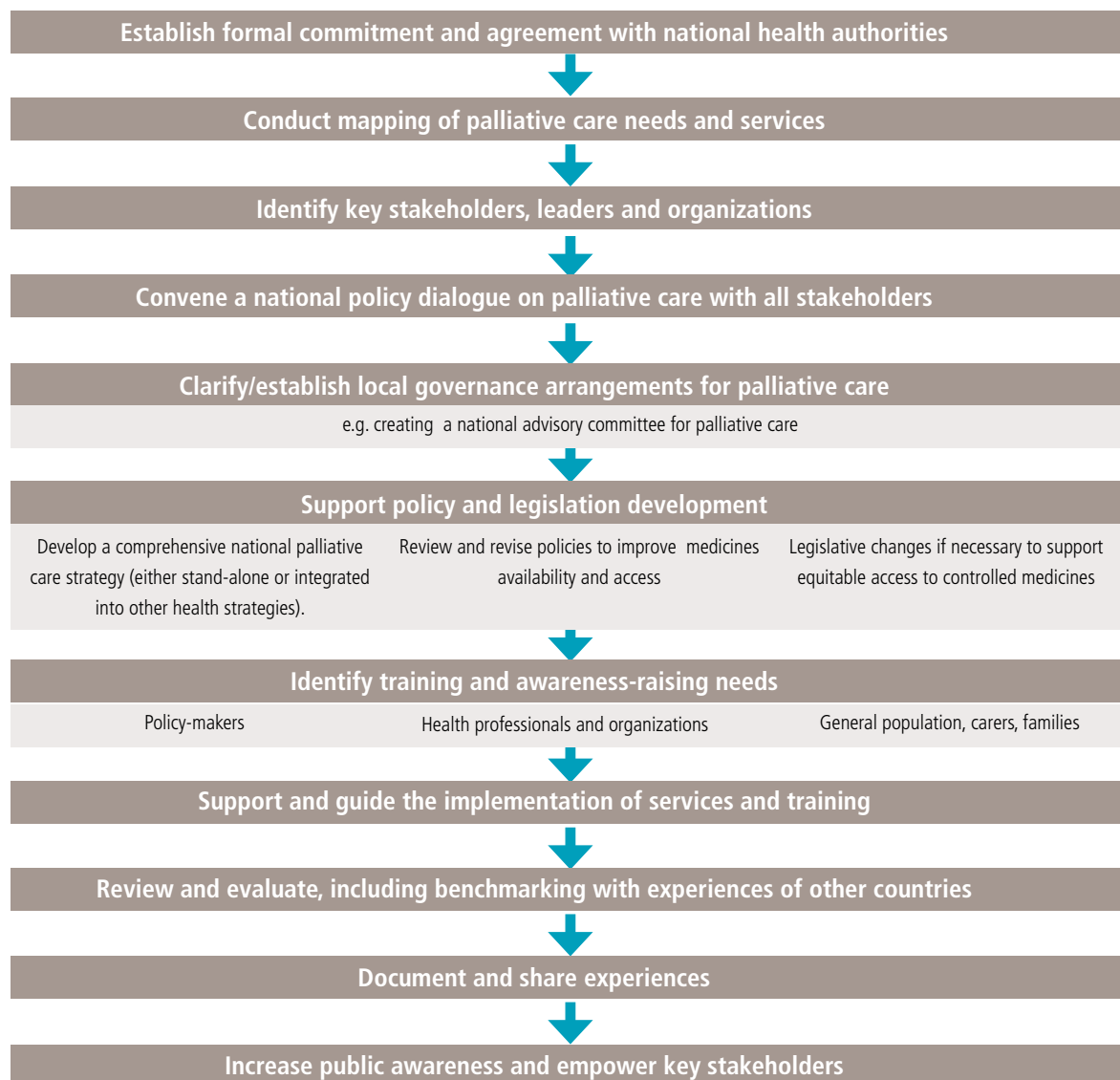
- Service delivery through a continuum of care (through PHC, community and home-based care, and specialist palliative care services)
- Strategies to provide palliative care to all patients in need (NCDs, HIV/AIDS, TB, older adults, children) with attention given to reaching vulnerable groups (poor, ethnic minorities, people living in institutions)
- Defining the government–civil society interface in establishment and delivery of care
- Universal coverage, through financing and insurance mechanisms
- Ensuring support for carers and families (social protection)
- Identification/allocation of resources for palliative care
- Development of national standards and mechanisms to improve quality of palliative care
- Identifying indicators and establishing monitoring of palliative care need and access, at national and subnational levels – including access to medicines.

When planning the policy, it is important to involve partners who can provide helpful input, assistance and maybe funding. National partners will include the Ministry of Health, but other ministries may also become involved. Health workers and their professional bodies should certainly be involved, as should social

workers (or their organizations), NGOs, academic institutions, national ethics committees and funding bodies (including potentially private-sector groups). International partners should also be considered – especially the WHO country office, but also representatives of other United Nations agencies, international NGOs working on palliative care, and international technical experts.

The development of a palliative care policy should proceed step-by-step to ensure that all concerns are taken into account and that there is sufficient support, and a sound legal basis, to ensure the policy’s success. Figure 13 provides an example of what this step-wise process is likely to involve.

Figure 13. Example of a step-wise process for developing palliative care strategies and programmes



Case example: Establishing a palliative care policy in Malawi

Malawi's national palliative care policy was approved in 2014, and gives its rationale and its links to other policies – including equity, access to pain medicines, capacity-building, resource allocation, patient and family participation, coordination, referral, education and communication, care for children, and research. The policy describes implementation arrangements at each level of Malawi's health-care system, as well as the roles of professional and other regulatory bodies, civil society, health-care training institutions, central medical stores and patients and their families. The policy also provides for a monitoring and evaluation framework of palliative care activities in the country. Since its adoption, the following key achievements have been made:

1. A national palliative care need estimate has been completed.
2. National reporting mechanisms for palliative care are in place at the Ministry of Health.
3. The government is covering 58% of all palliative care provision while churches and NGOs cover the rest.
4. Local reconstitution of morphine powder into oral morphine is in place.
5. Morphine is now available in government and faith-based health units.
6. Palliative care training has been boosted and the country has over 300 trainers.

Source: (22).

Situation assessment

Planning a palliative care policy should begin with an assessment of the current situation and population need for palliative care. A needs assessment survey can be adapted to the different levels of existing information in countries, ranging from very basic to complete. It is important to consider factors such as the following:

- *The policy situation related to palliative care:* Has palliative care been included in any major health policy documents (e.g. national health strategies, national cancer control plans, HIV plans, healthy ageing strategies)?
- *Availability and coverage of existing palliative care services:* Where are palliative care services currently delivered (which types of patients, at which ages, in which geographical areas, at what cost)? What dimensions of care are provided? How many patients currently receive care?
- *Current availability of palliative medicines:* Are all essential palliative care medications for adults (23) and children (24) available in the country, including oral morphine and liquid formulations? What is the availability and affordability of opioids for pain relief and what restrictions are in place?
- *Quantitative estimate of the need for palliative care:* Several approaches to determining the number of persons needing palliative care can be used. It is also necessary for planning purposes to estimate the health workforce and the number of inpatient beds/services needed to meet the need.
- *Qualitative assessment:* Several methods can be used, including interviews with patients and their families to highlight any unmet needs for care, strengths, weaknesses and barriers. This is relevant to assess the capacity of key services (primary care, HIV/AIDS, district hospitals etc.) for providing palliative care and to identify settings for implementing actions.

Useful methods for calculating population need

There are a number of ways to estimate the numbers of people in a population who are likely to need palliative care at any one time:

- *Estimates based on disease prevalence:* WHO has used a method (based on prevalence of pain) for estimating the proportion of people with various diseases who require palliative care in the last year of their lives (19). This method can be used for adults and children. The need for palliative care at the end of life should be doubled to account for patients needing palliative care prior to the last year of life.
- *Estimates based on mortality:* Death registration data, where there is reliable reporting, can give good estimates of the population-based need for palliative care without the need for symptom or hospital activity data. Methods used in three high-income countries estimate that 69–82% of those who die need palliative care (25).

4.2 Scaling up and integrating palliative care into the health-care system

Based on the needs assessment, a plan can be developed for scaling up coverage of palliative care services in the population. A timeline can project growth in the percentage of need being met by year. It is essential to determine where the need is greatest geographically or where resources already exist. There is no single approach to expanding coverage: some authorities expand gradually out from population centres to rural areas. Some begin at regional centres and expand from there. Both private and public providers should be included where they exist. These efforts can be supported by development of a national strategy for scaling up and integrating palliative care into the national health care system, but state or district authorities can still develop a strategy to scale up coverage in their areas by taking a population focus.

Different activities (including inpatient care versus home-care, support of other teams, outpatient clinics and day-care hospital units) can be started gradually, based on feasibility and resources available. Planned activity in the initial phases must devote time and space to team-building. Frequently, small over-committed teams in high-need areas make the mistake of offering services and activities that are not sustainable over the mid- to long-term due to the limited resources available. This can lead to excessive workload and “burnout”.

If there is currently no system of palliative care in place, a step-wise approach to introducing a palliative care programme could be used. The steps should cover policy actions, health-care financing, service delivery, workforce development, access to medicines, and information and research. An example of such an approach is outlined in Table 8.

Table 8. Example of a step-wise approach to introducing a palliative care programme

| | Initial activities | Intermediate | Advanced |
|------------------------------|--|---|---|
| Policy actions | <ul style="list-style-type: none"> ■ Advocate with government and senior clinicians ■ Identify potential palliative care leaders and form palliative care working group, including government and clinicians ■ Conduct rapid palliative care situational analysis including services, population needs and regulatory barriers ■ Conduct public education campaign about palliative care and pain ■ Begin development of national palliative care strategy/plan | <ul style="list-style-type: none"> ■ Develop national palliative care plan with input from community and multisectoral stakeholders ■ Complete population situation assessment | <ul style="list-style-type: none"> ■ Develop protocols and standards for palliative care services in different settings ■ Include palliative care in all national policies and plans for NCDs, HIV/AIDS, TB and child health ■ Integrate palliative care (health- and social-related) at all levels of the system |
| Health-care financing | <ul style="list-style-type: none"> ■ Include funding for palliative care development in national health budget | <ul style="list-style-type: none"> ■ Include palliative care in universal health coverage package, basic health insurance package | <ul style="list-style-type: none"> ■ Provide free palliative care coverage for all qualified patients ■ Provide social protection for caregiver leave, respite care, disability |
| Service delivery | <ul style="list-style-type: none"> ■ Start a palliative care service in a defined community. For instance: <ul style="list-style-type: none"> – establish home-care palliative care service in defined community – establish palliative care service in cancer hospital ■ Identify patients with advanced life-threatening illness at different levels of care | <ul style="list-style-type: none"> ■ Establish referral and coordination mechanisms to build palliative care networks in defined districts and communities – scale up over years ■ Identify patients with advanced life-threatening illness at different levels of care ■ In a defined population area, create specialist palliative services in a referral/district hospital, supported by home-care teams ■ Expand palliative care services to all cancer centres and major general hospitals ■ Train primary care services to apply palliative approach ■ Establish children’s palliative care | <ul style="list-style-type: none"> ■ Expand population coverage of hospital and home-care palliative care to cover all districts ■ Expand home-care services to cover all districts, and cancer and non-cancer patients ■ Reinforce network of palliative care providers, including integration between levels of care ■ Include palliative care in neglected settings, including long-term care facilities for older persons, and prisons. |

| | | | |
|---------------------------------|---|---|---|
| Workforce development | <ul style="list-style-type: none"> ■ Provide training and mentoring support to clinical leaders in clinical training-of-trainers, either domestically, if possible, or otherwise regionally or overseas if necessary ■ Use in-service training modules on palliative care for health professionals, community health workers, and health volunteers working in palliative care | <ul style="list-style-type: none"> ■ Offer fellowships/mentorships for specialist palliative care and pain policy training ■ Develop a reference centre that can provide practical palliative care training for community and other practitioners ■ Include palliative care in pre-graduate curricula for doctors and nurses ■ Train primary care physicians and community nurses on assessment and management of pain and symptoms ■ Train pharmacists and prescribers to use morphine confidently and safely | <ul style="list-style-type: none"> ■ Start medical and nursing speciality or sub-speciality qualification in palliative care ■ Establish palliative care chairs at major universities |
| Access to medicines | <ul style="list-style-type: none"> ■ Review legislative/regulatory barriers to appropriate access to controlled medicines ■ Review current usage and availability of essential medicines ■ Align national list of essential palliative care medicines with WHO model list ■ Train and enable physicians who provide palliative care to use morphine confidently, beginning in selected hospitals, districts and communities where palliative care services will begin first ■ Initiate discussion between drug regulators, health regulators, police and palliative care practitioners on access to controlled medicines | <ul style="list-style-type: none"> ■ Modify laws and regulations governing opioid availability to make them readily available for pain relief in line with international drug conventions ■ Review estimated population need for essential palliative care medicines ■ Review supply and distribution system for controlled medicines ■ Ensure availability of oral morphine in all districts ■ Progressively eliminate cost, prescribing and supply chain barriers to opiate availability | <ul style="list-style-type: none"> ■ Ensure equity of access to opioid pain relief to entire population according to need, irrespective of age, diagnosis, socioeconomic status or geographical location ■ Ensure reliable supply of all essential palliative care medicines to meet demand in all areas of the country |
| Information and research | <ul style="list-style-type: none"> ■ Create a basic information system to monitor and evaluate actions at different levels of care ■ Build public understanding of palliative care | <ul style="list-style-type: none"> ■ Identify a centre of excellence that can undertake interdisciplinary research on palliative care ■ Ensure quality monitoring of service delivery | <ul style="list-style-type: none"> ■ Measure population access to palliative care by diagnosis, and social group ■ Establish PhD programmes in palliative care |

4.3 Improving access to medicines for pain relief and palliative care

Barriers to pain management in palliative care

Barriers to pain management in palliative care occur at various levels. They may be regulatory or legislative, they may be due to lack of knowledge or awareness both of health-care providers and the public, they may be caused by perverse incentives in the health system, or they may be due to poor access or affordability.

Barriers usually exist at all levels simultaneously, so a multi-pronged approach is required.

Regulatory or legislative restrictions that can interfere with palliative care include limits on who can prescribe controlled substances (e.g. only oncologists), the use of special prescription forms and limitations on who can access them, limits on the period for which medication can be prescribed (often 1–3 days instead of 14–30 days), and limits on the quantity of medication that can be prescribed per day or per patient. There may also be time limits on when a prescription can be filled, harsh penalties for errors in prescribing opiates, or requirements that multiple authorities must countersign prescriptions or that a special commission has to approve any patient receiving controlled substances. Other legislative restrictions include requirements that hospitals or pharmacies provide information about patients and their prescriptions to the police, no registration of essential palliative care medicines such as oral morphine, and requirements that physicians supervise the destruction of all injectable ampoules of controlled medicines. Pharmacies may be discouraged from dispensing palliative care medicines because of the need to have alarms and armed guards around the clock, special metal doors, and multiple manual registration journals.

All of these factors are in excess of what is required by the Single Convention on Narcotic Drugs and can limit access to those who need pain control for palliative care (4). Regulatory and policy reforms can improve this situation, and WHO can support countries in this process. All physicians, and even specially trained nurses where appropriate, should be allowed to prescribe opioid analgesia. Establishing a national authority to ensure adequate availability of controlled medicines, as well as national guidelines and policies, can help countries ensure that their approach to controlled medicines is balanced and that it avoids unnecessarily restrictive regulatory and administrative barriers.

Lack of knowledge about proper use of pain medication, and about palliative care in general, is another major barrier limiting the appropriate access to pain management in palliative care. Societal fears and taboos about death, or a lack of awareness that symptoms can be relieved, may prevent families from requesting care or active symptom control for patients who are dying. Health-care professionals may have received little training about palliative care and may be scared or reluctant to prescribe opiate analgesia because of fears or perceptions about the risk of abuse. This hesitation can be overcome by embedding palliative care in the training curricula for all health professionals – especially doctors, pharmacists and nurses – as well as through educational campaigns for those who are already practising. It is important to ensure that there is a core group of professionals with extra training in palliative care. Public awareness-raising about palliative care and the possibility for pain management can improve demand. In lower-resource settings, the training of volunteers can improve knowledge and attitudes to palliative care in the community.

Perverse incentives in health systems may also prevent patients from being offered palliative treatment and pain management. In some countries, where hospitals and doctors have a financial incentive to offer more expensive treatments to patients as a source of income, patients with terminal conditions may be offered more expensive (and ineffective) curative treatments despite the terminal stage of the disease. Performance systems that evaluate the quality of care in hospitals by in-hospital mortality rates

also contribute to a reluctance of doctors to treat patients who are likely to die. These factors can all be improved by modifying performance and evaluation systems to include appropriate measures of palliative care so that hospitals and health professionals are not disincentivized from treating patients who are dying.

Access and affordability barriers to services affect pain management in palliative care as they do many other health-care issues. The most vulnerable group in society must at least be able to access appropriate pain management. Transport costs, lack of availability of services, the impoverishing consequences of terminal illness, as well as the stigma attached to terminal diseases, all prevent those most in need from accessing pain management. In addition to addressing the regulatory and provider factors noted above, ensuring that palliative care/pain management is fully integrated into primary health care, ensuring that pain management and palliative care are included into basic packages for universal health coverage, and increasing the availability of home-based/community-based palliative care can all help improve access to pain management.

Strategies to improve access to medicines for palliative care

WHO has published guidelines to help governments eliminate unnecessary barriers to legitimate access to controlled medicines and has made them available in several languages (4). In addition, WHO has developed a number of tools and guidelines for addressing prescribing, supply chain and cost barriers, quality and safety, traditional medicines and other related issues which are available in the training section of the WHO web page on prescribing, supply chain and cost barriers.

Building national lists of essential medicines

The concept of essential medicines is central to a national medicines policy as it helps to set priorities for the health-care system. National medicines policies are crucial because they promote equity and sustainability in the pharmaceutical sector and provide a framework for identifying national goals and commitments. The WHO model lists and guidelines help countries to develop and implement a comprehensive policy, appropriate to their own needs and resources in order, to relieve the suffering of patients with palliative care needs. Palliative care medicines, including those for pain relief, are included in WHO's model lists of essential medicines for adults and children (see Annexes 1 and 2), and should be made available to all who need it. The WHO lists include opioid and non-opioid medicines for pain relief, as well as medicines for the most common symptoms in palliative care.

The selection of essential medicines, including essential medicines for palliative care, is a two-step process:

1. Market approval of a pharmaceutical product is usually granted on the basis of efficacy, safety and quality, and rarely on the basis of a comparison with other products already on the market, or cost. This regulatory decision defines the availability of a medicine in the country.
2. Public medicine procurement and insurance schemes usually have mechanisms to limit procurement or reimbursement of medicine costs. For these decisions, an evaluation process is necessary, based on comparisons between various medicine products and on considerations of value for money. This second step leads to a list of essential medicines.

Implementing a national list of essential medicines

When an essential medicines list is finalized, it should be made widely available. The intended use, legitimacy and authority of the list should be clear to all. Unfortunately, the vast majority of the patients who have palliative care needs and are in pain do not have access to these essential medicines. Countries should implement strategic plans to ensure access to many medications, including internationally-controlled medications. Some key factors for successful implementation of a list of essential medicines are listed in Table 9.

Table 9. Key factors for successful implementation of an essential medicines list

- **Establish a transparent process for creating and updating the list of essential medicines, provide a voice for key stakeholders, but ensure a scientific, evidence-based process.**
- **Link the essential medicines list to clinical guidelines for diagnosis and treatment, involving both specialists and primary care providers.**
- **Actively engage support from medical opinion leaders, senior clinicians, nurses, training institutions, professional organizations, non-governmental organizations and the public.**
- **Make the list of essential medicines, formulary manuals and clinical guidelines widely available in all health-care facilities and to all health-care providers in both printed and electronic versions.**
- **Consider launching new or revised lists with the involvement of government officials, such as the Minister of Health or the President, and intensive press coverage.**
- **Make clear the specific legal or administrative authority of the essential medicines list for training, procurement, reimbursement and public information.**
- **Consider establishing an administrative or budgetary “safety valve” for the limited supply and use of non-listed medicines, e.g. by certain specialist units. This is especially important with controlled substances such as opioids, in order to prevent stock-outs.**
- **Regularly update the list so that it reflects therapeutic advances and changes in cost, resistance patterns and public health relevance.**

Improving access to essential palliative medicines

Once essential palliative medicines have been added to the country’s essential medicines list, additional steps need to be taken to achieve full access for clinical use:

1. Approval/permission of the health ministry to register the medicine

In most countries the health ministry is responsible for agreeing to register new medicines – especially controlled substances. In order for the ministry to do so there must be agreement from a variety of constituents, including the drug regulatory departments controlling access to and supply of medicines, and in some cases reporting consumption and forecasting expected use to the International Narcotics Control Board (INCB). In addition the drug policing authority (sometimes under the ministry for interior affairs) needs to be involved and may resist registration of new controlled substances because of concern at possible illicit use.

2. Importation

Once a decision is taken to register a new controlled substance an importer is needed to find a supplier and to negotiate purchase and sale. In some countries the government acts as the importer and distributor. In most countries controlled substances are already being imported and distributed and it may be easiest to negotiate the addition and registration of new controlled substances with existing manufacturers or suppliers. If the new controlled medicine is not available from existing suppliers, the importer needs to find a new supplier who is willing to provide it. In the case of oral morphine tablets or liquids, few suppliers are interested in this market because of low profit margins, especially in smaller countries.

3. Contracting, pricing and estimating

Once a supplier is found, the importer should negotiate an agreement for purchase of the new controlled substance. The supplier will want to know how much of the product will be ordered. In general, the larger the order the lower the cost per unit. However, if the order is too large there is a risk that expired medicine will be wasted and money lost but if it is too small there is a risk of running out of stock. The INCB has published guidelines for estimating the quantities of medication such as oral morphine needed for cancer and HIV patients (26).

4. Registration

Once agreement with the supplier is concluded the new controlled substance can be formally registered in the country. If the medicine is on the national essential medicines list it may be possible to waive the usual supplier fees for registration. A full dossier that includes the medicine's production, results of laboratory testing, dissolution profile and packaging details should be prepared by the supplier and must be approved by the ministry for registration to proceed.

5. Import and export licensing

After registration is complete, if the medicine comes from outside the country approval must be obtained for the supplier to export the medicine and for the importer to import it. These licences from the authorities in each country are currently issued on paper and the work has to be repeated if errors are found, causing delays. However, the INCB has launched an electronic import/export system (IE12) that will greatly streamline the import/export approval process for countries that participate.

6. Storage, distribution and stocking

The importer is responsible for receiving shipments of controlled substances and securely storing them for distribution to dispensaries such as hospitals, clinics and commercial pharmacies. Local regulations govern how stock is maintained by these dispensaries to fulfill prescriptions and orders for controlled substances. It is important that there are enough pharmacies or dispensaries available throughout the country so that patients do not have to travel long distances to obtain the medications.

7. Education of prescribers

Having a new controlled substance in dispensaries does not ensure that patients will receive the medications for symptom relief. If medical doctors and other prescribers do not order or prescribe these medications they will go unused. Prescribers will usually need to receive training in palliative care and up-to-date pain and symptom management guidelines, preferably at the bedside, to gain confidence in safe use of the medications. Some medical practitioners may have been taught to avoid controlled substances because of fear of addiction or abuse.

8. Community education

The public should be made aware when palliative care and new treatments are being introduced. In countries where access to effective pain relief has been unavailable, it is often believed that a person with cancer or another advanced chronic life-limiting illness has to suffer since nothing can be done. The public needs to know that palliative care and pain and symptom relief can be provided and that they have a right to such care and treatment.

First steps and transitions in the implementation

To change the regulations and achieve all of the above steps could take some time. In the initial stages, while specialized services are implemented, it is recommended to make some essential medicines available to those services. This will facilitate the initial provision of adequate medicines and will help generate experience in their use. Examples exist of this pragmatic approach.

Case example: Reviewing legislation to improve access to opioids in India

In 1993, a pioneering new palliative care service in Calicut Medical College in Kerala (27) tried to obtain oral morphine and encountered numerous barriers:

- fear of opioids among the medical professionals and others;
- the need for three licences that had to be valid at the same time;
- involvement of multiple government departments;
- interruptions in supply of the raw material (morphine powder) in the Government Opium and Alkaloid Factory;
- interruptions in supply of morphine tablets from the manufacturers of opioid formulations.

The involvement of the Pain and Policy Studies Group (PPSG), a WHO Collaborating Centre for Pain Policy and Palliative Care at the University of Wisconsin, which worked together with government officials and with palliative care activists in India, was a major factor in improving the situation. A public interest litigation filed in the Delhi High Court, in which a pharmacologist prayed for morphine for his mother with cancer, also gave impetus to the movement. Sustained advocacy with the government in 1998 resulted in the national government asking all state governments to simplify their narcotics regulations in line with a model that was sent to them. However, by India's constitution, the states were not bound to follow this instruction and, indeed, most did not. Sustained advocacy over many years, and many workshops in which government officials and palliative care doctors discussed the matter, succeeded in simplification of the Narcotic Drugs and Psychotropic Substances (NDPS) Act rules in many states. Nevertheless, in states which had no active palliative care movement, this led to no improvement at all.

The request of the NGO, Pallium India, to the government of Kerala in 2005 bore fruit in 2008, resulting in the declaration of a state palliative care policy (28), which attempted to integrate palliative care into the public health system. Today, more than 170 institutions in the state stock and dispense oral morphine. In recent years, support from Human Rights Watch and from WHO's Essential Medicines programme gave impetus to the movement.

Sustained advocacy over 19 years eventually led to an amendment of the NDPS Act by the national parliament in February 2014 (29) and to the subsequent declaration of state NDPS rules in May 2015. These are major steps, but continued advocacy will be needed in every state to ensure that the amended rules are implemented, without additional procedural barriers, and that doctors and nurses receive palliative care education.

Case example: Improving access to opioid pain medicines in Viet Nam

A situation analysis in Viet Nam in 2005 found that severe chronic pain was common among people with cancer and HIV/AIDS, oral morphine was virtually unavailable, and clinicians lacked adequate training in pain relief. National guidelines on palliative care for cancer and HIV/AIDS patients were issued by the Ministry of Health in 2006. Steps were taken to address opiophobia and improve safe access to opioids for medical uses, and two ministry officials participated in the International Pain Policy Fellowship (IPPF) offered by PPSG.

Vietnamese laws and regulations affecting opioid accessibility – 38 in total – were identified and translated into English. During a training course and conference on opioid policy, these laws and regulations were reviewed to identify elements that were inconsistent with WHO's concept of balance or that created barriers to safe opioid accessibility.

Rather than try to change laws or prime ministerial decrees, it was decided that it was necessary only to change the ministry's regulations. An action plan was drafted and in 2007 a workshop on opioid policy was held at which all major stakeholders were invited to discuss the plan. Stakeholders included the Ministry of Police and the United Nations Office of Drugs and Crime, as well as WHO, the Viet Nam Drug Administration, the Vietnamese national institutes of cancer and infectious disease, and international NGOs.

The action plan, agreed by all participants, called for the Palliative Care Working Group and the Ministry of Health to pursue several key objectives:

Revise the ministry's opioid prescribing regulations according to WHO guidelines.

Work with the Drug Administration of Vietnam (DAV) and the domestic pharmaceutical industry to increase production or importation of morphine in the most useful preparations, including 10 mg immediate-release tablets.

Educate physicians, nurses and health-care officials on the importance and safety of opioid analgesics, on the low risk of dependency syndrome among patients with advanced life-threatening illnesses, on the national guidelines on palliative care, and on the new opioid prescribing regulations.

In response to the revised opioid prescribing regulations (see table), the DAV removed restrictions on the number of pharmacies allowed to dispense opioids. Since the start of the project, morphine consumption has increased each year and in 2010 was nine times greater than in 2003. The number of hospitals offering palliative care has increased from 3 to 15. Important factors for success were strong and consistent leadership at the ministry, consistent and available technical assistance from experts in clinical palliative care and opioid policy, and sensitivity to the social and historical determinants of opiophobia.

Summary of Viet Nam's outpatient opioid prescribing regulations before and after the intervention:

| Element of opioid prescribing regulation | Old opioid prescribing regulation | Revised opioid prescribing regulation (2008) |
|---|--|--|
| Maximum prescription period | 7 days | 30 days |
| Maximum dose | 30 mg/day | No limit |
| Required period to keep prescription record | 5 years | 2 years |
| Plan for morphine availability | None | Every district |
| Restriction based on diagnosis | No cancer or AIDS diagnosis = no opioid prescription | No cancer or AIDS diagnosis = 7-day maximum prescription |

Source: (30).

Case example: Setting up domestic manufacture of morphine solution in Uganda

In its five-year Strategic Health Plan for 2000–2005, Uganda became the first African country to state that palliative care was an essential service for all citizens. Since then, the government has worked to improve the availability of opiate medications. It added liquid morphine to its essential drugs list and adopted a new set of guidelines for handling of Class A drugs for health-care practitioners. The Ministry of Health also started importing oral morphine powder and providing oral morphine solution to public health facilities at no cost. Between 2000 and 2008, opioid consumption in morphine equivalence has increased four-fold from less than 0.2 mg per person to almost 0.8 mg per person. Teams from other countries have visited Uganda in order to learn how to set up similar systems.

Source: (31).

4.4 Strengthening human resources for palliative care

Increasing the skills and awareness of palliative care among the health workforce is critical to improving access to palliative care. Specialist training in palliative care is important, but all health professionals should have a basic knowledge of palliative care principles and good pain management.

Despite this, most health professionals receive limited or no training in palliative care in their pre-service training. In-service training is needed for those already delivering care, and palliative care must be integrated into the training of health workers and allied health workers.

Who are palliative care providers?

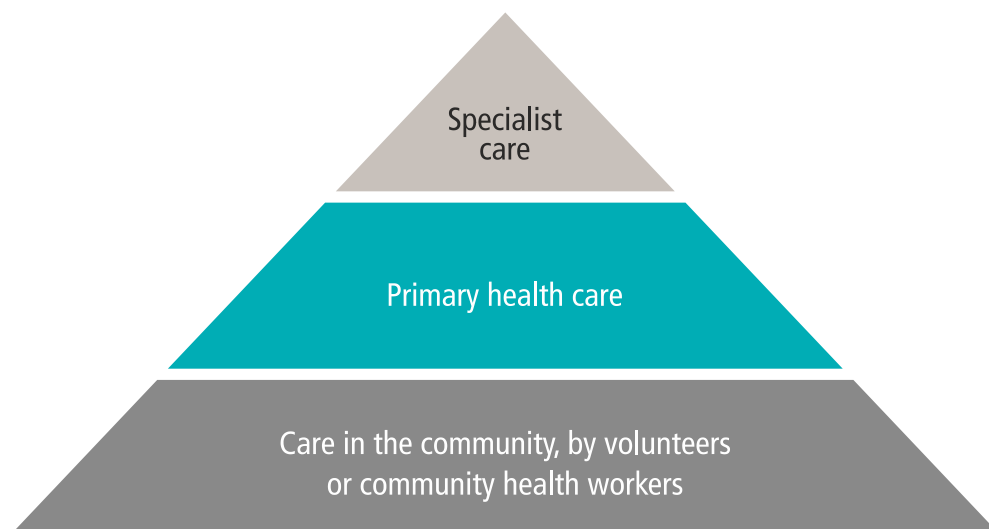
Palliative care is best delivered through a multidisciplinary team. Providers at all levels of care, from palliative care medical specialists to trained volunteers, work together to ensure the best quality of life for the patient (see Figure 14).

In tertiary care settings, the team may include an oncologist, an internal medicine physician, a radiotherapist, a radiotherapy technician, a psychologist or counsellor, a nutritionist, a physiotherapist, an oncology nurse, a pharmacist, a social worker and a palliative care nurse.

In resource-poor settings, community health workers or trained volunteers – supported, trained and supervised by primary- and secondary-level health-care professionals – are the principal providers of palliative care. Trained community nurses (auxiliary nurses/palliative nursing aides), if permissible within the system, can play a major role in delivery of care. Family members also have a large role in caring for patients at home, and they need to be supported.

Primary care and community care are essential to provide palliative care services to the large majority of people in need. Much of the care of dying persons has to occur in the community and in all health-care settings, mainly conducted by health professionals who are generalists and not specialist practitioners. Most people with advanced chronic conditions with palliative care needs are living in the community and, with the right training, primary care professionals should be able to identify them.

Figure 14. Where palliative care is provided



Source: Adapted from (16, 29).

Defining core tasks and skills

Core roles and responsibilities for palliative care providers

Palliative care services require skills in managing the complications of disease (and treatment), managing pain and other symptoms, providing psychosocial care for patients and families, and caring for the dying and the bereaved. Additionally, the palliative care team should also have skills in communication, decision-making and spiritual understanding. Understanding these roles and responsibilities helps a palliative care team function effectively, and helps inform training needs.

This section describes some of the key tasks and responsibilities of all providers of palliative care and the more specific responsibilities of community health workers, staff nurses, physicians at primary and secondary care levels, and providers at tertiary level, including in hospitals

The roles described below are not fixed. Each country should adapt the roles of different providers in ways that best meet the needs of particular settings.

Roles for all palliative care providers

All palliative care providers share a responsibility for communication and information transfer. There should be a smooth transfer of medical information between the different health professionals responsible for patient care. Where appropriate, this involves efficient exchange and sharing of medical records between community and tertiary-care teams. Providers need special focused training in management of both physical and emotional problems, as well as in communication.

Roles of community health workers/palliative nursing aides

Community health workers and other community workers dedicated to palliative care should coordinate their activities with caregivers at primary and secondary levels. The community workers will have roles in assisting other members of the palliative care team as well as giving guidance and support to the patient and family members. Some specific tasks of community health workers and palliative nursing aides include:

- developing an individualized home-based care plan for each patient;
- in some cases, providing treatments and instructing the family in this task;
- facilitating access to supplies and medicines;
- visiting the patient's home according to a regular schedule in order to anticipate problems and if possible prevent them; reporting problems to a higher level and providing follow-up;
- training the patient and family in care and comfort-giving procedures and checking that they are being carried out;
- routinely conducting comprehensive assessment of the patient's physical, psychosocial and spiritual needs, and communicating the findings to providers at all three levels of health care;
- based on the assessments, paying particular attention to ensure the availability of treatment, including for pain management.
- answering questions, providing information and keeping records;
- encouraging the family to keep the patient involved in their daily life as much as possible;
- helping/supporting/guiding the family in nursing care and care of bedridden patients (if training has been received).

Roles of staff nurses at primary, secondary and tertiary care facilities

Staff nurses have a range of supervisory, coordination and teaching roles. They are involved in the coordination, supervision and monitoring of home care, including patient care by volunteers, and they also act in a liaison role between the community care system and secondary and tertiary care institutions. Staff nurses are responsible for supervising and monitoring the work of auxiliary nurses and nursing aides, as well as training these staff members and volunteers. The staff nurses provide specialist nursing procedures such as care of lymphoedema and stoma. They also ensure documentation of home care.

Roles of physicians and authorized prescribers at primary and secondary care facilities

Physicians and other authorized prescribers provide management of severe symptoms, prescribe medicines and train and advise staff, patients and families. For instance, physicians and prescribers:

- visit the community from time to time to train home-based care workers and community health workers and to learn about the conditions in which they work and in which their patients live;
- participate in palliative care training and services organized at district and secondary facility levels;
- support and supervise the community team and provide the patient with treatment and care;
- prescribe analgesics, including oral morphine, and medicines for the symptomatic treatment of other problems;
- supply medicines to the patient or caregivers for use either immediately or when needed;
- prescribe, provide, supervise, support and maintain supplies for the community health workers who do home visits;
- advise and educate the patients, families and community carers on how to prevent and manage common problems such as contractures and bedsores;
- refer patients to higher facilities for acute problems that are best managed there;
- help arrange transportation for patients to these locations;
- provide short-term inpatient care for severe symptom management;
- provide distance supervision and assistance through telephone consultations.

Roles of providers at tertiary care level, including the hospital

Providers at the tertiary level, including at the hospital, will provide inpatient care, including radiotherapy and other treatments available only at this level, for patients with intractable pain and other symptoms. They also provide outpatient emergency care, if feasible and if agreed by the patient and family, for symptoms causing great distress. Using national protocols, patients are maintained pain-free as far as is possible, using appropriate strong opioid dosages if necessary. Providers at this level report back to, and may hold distance consultations with, referring providers.

The role of the family in palliative care

The family plays an essential role in palliative care. The health worker's role is to ensure that the patient and his/her family understand the nature and prognosis of the disease, and recommended treatment. Family members also have their own needs for support, health and social care. With the help of health workers, the family will be involved in joint decision-making, will be kept informed of medical decisions, including

changes in carers and treatment, and should be guided in best practices of palliative care. The patient's family and other carers can be taught to provide home-based care.

Task-shifting

Countries should consider how to use the available health workforce in a cost-effective way while introducing or expanding palliative care to the community. A number of palliative care activities can be transferred from specialized doctors to other health professionals. WHO has developed a series of global recommendations for task-shifting of palliative care services for patients with HIV/AIDS (33). These principles may be useful in providing palliative care services more generally (see Table 10).

Table 10. Trained health workers able to perform palliative care tasks safely and effectively

| | Medical doctor | Non-physician clinician | Nurse | Community health worker |
|---|----------------|-------------------------|-------|-------------------------|
| Pain management | | | | |
| Conduct pain assessments(s) | x | x | x | x |
| Treat mild, moderate and severe pain using chronic pain management guidelines, including oral morphine | x | x | x | |
| Teach the patient and caregiver how to give pain medicine, including oral morphine | x | x | x | x |
| Prevent, recognize and treat the side-effects of pain medications | x | x | x | |
| Advise on non-pharmacological methods of controlling pain | x | x | x | x |
| Treat extreme, non-responsive pain appropriately, including through the use of steroids where indicated | x | x | | |
| Symptom management | | | | |
| Manage other common symptoms (weight loss, nausea, fever, diarrhoea, trouble sleeping, anxiety etc.) | x | x | x | |
| Psychosocial support and end-of-life care | | | | |
| Counselling, psychosocial and spiritual support | x | x | x | x |
| Support for patient at end of life | x | x | x | x |
| Support for caregivers, family members and children | x | x | x | x |
| Supervision | | | | |
| Supervise non-physician clinicians, nurses and community health workers in above activities | x | | | |
| Supervise nurses and community health workers in above activities | x | x | | |
| Supervise community health workers in above activities | x | x | x | |

Source: WHO guidelines on task-shifting (33).

The requirement that opioids can be prescribed only by medical doctors creates another bottleneck to access to palliative care. This can be overcome by empowering nurses or clinical officers (medical assistants), where they exist, to prescribe, renew doctors' prescriptions, hold stock for patients or supervise community health workers.

The delegation of tasks must be implemented only if there are adequate checks and balances to protect both health-care providers and the people receiving treatment and care. Some countries have changed

policies and regulations to allow nurses and clinical officers to prescribe opioid medicines in order to provide service coverage for pain relief.

Case example: Task-shifting in Uganda

In 2004 Ugandan law was amended to allow nurses and clinical officers, once they have completed a nine-month palliative care course, to prescribe morphine.

The Clinical Palliative Care Course trains palliative care nurses and clinical officers to prescribe morphine appropriately and effectively. By 2007, 53 individuals had already graduated. This nine-month course consists of eight weeks of theory, one 12-week residential period at Hospice Africa Uganda sites (a palliative care specialist experience), one 10-week palliative care/HIV placement (at specialist HIV care organizations and Mulago Hospital), and one 10-week session back in their own place of work, where they are expected to plan implementation of their palliative care service following completion of the course. The course graduate is expected to take a lead in coordinating palliative care in their district, arrange case conferences and continuing medical education sessions for those working in palliative care, and advocate to incorporate palliative care into district and community plans for finance and support.

Initially, a few graduates encountered constraints when they returned if palliative care had not been well defined at their place of work in advance. To address this, before a trainee is accepted in the programme, course directors are now asking employers to guarantee that the trainee will work in palliative care for at least two years after graduation.

Source: (34).

Strengthening palliative care in the primary care workforce

The European Association of Palliative Care (EAPC) guidelines on development of primary palliative care (35) suggest the following strategy to strengthen palliative care in primary care:

1. Identify key individuals or organizations in your country interested in the development of palliative care in the community (e.g. GP organizations, palliative care specialists).
2. Convene a meeting or working group to identify and discuss local challenges and solutions.
3. Use the EAPC taskforce's database on palliative care in the community to contact experts who may be able to provide specific guidance on relevant issues.
4. Seek to establish improvements in each of the four domains of the public health model in order to create a balanced system of provision.
5. Collate data supporting the need for, and potential outcomes of, palliative care in the community

Developing skills and training

Training for health-care professionals

All health providers should have some training in palliative care and pain management. The level of training required by different types of health providers can be delivered as follows:

- core palliative care skills for all health-care professionals – e.g. doctors, nurses, pharmacists, social workers, psychologists (including trainees and practising professionals);
- advanced palliative care skills for health-care professionals seeing a large number of patients with advanced illnesses – e.g. cancer, HIV/AIDS, dementia;
- expert palliative care skills for specialist palliative care professionals who will work in specialized palliative care units and will help to train others.

Priorities for strengthening training will depend on the type of services being established. For instance, if a palliative care plan focuses on home-based care services in a target area, educational efforts should concentrate on raising awareness in the target community and training health-care workers, community leaders and family caregivers in basic home-based care. Health-care workers at community level should be trained and supervised by professionals from the district level.

For a palliative care programme to be effective, education should be synchronized with the introduction of the new services which will include making oral morphine and other essential medications available. Health workers trained in palliative care often become discouraged because they lack the resources to do their work. One option is to organize in-service training in the target area for the palliative care teams, with the support of the local authorities. With this type of training, health-care providers remain connected to their working environment and contribute to organizing and implementing the palliative care services as team members learn together.

When initiating a palliative care programme in a low- or middle-income country, education and training should be provided for all health workers in the target area. The following steps will ensure that priority services for the majority of patients are in place in a relatively short time:

1. First, provide basic training (20–40 hours) for the health-care providers working at the primary and community levels.
2. Second, provide intermediate-level training (60–80 hours) for the physicians and nurses who are dealing with cancer patients at the secondary and tertiary levels.
3. Third, provide proficiency (specialized) training (3–6 months) to the specialized teams or palliative care units at the secondary and tertiary levels.
4. Finally, provide undergraduate training in medical and nursing schools.

The African Palliative Care Association has a core palliative care curriculum (36), and a core competencies framework, which have been used by some countries in Africa. The EAPC also developed a set of core competencies for palliative care professionals (37). Many other free training courses and resources are available online.

Case example: Integrating palliative medicine into medical and nursing school curricula in Colombia

Following the recommendations of World Health Assembly resolution WHA67.19 on strengthening palliative care education and delivery at primary care and undergraduate levels, representatives of the International Association for Hospice and Palliative Care (IAHPC), Fundación FEMEBA (Argentina) and the Department of Palliative Medicine, Aachen University (Germany) joined forces to develop and implement a project in Latin America called “Transforming the System”. The project aimed to promote the teaching of palliative care in the medical and nursing schools and its integration into the undergraduate curriculum in countries throughout the region.

The project was piloted in Colombia in 2014–2015 and was implemented in several steps:

1. An initial visit to six universities when the representatives met with faculty and students to understand and evaluate their perceptions of, and interest in, palliative care. Most reacted positively to the proposal.
2. A workshop to identify the palliative care competencies at undergraduate level for physicians and nurses. The workshop included participants from 17 medical/nursing schools in Colombia. Participants agreed by consensus on the competencies developed by the group and the resulting summary was distributed, translated into English, and both Spanish and English versions were uploaded to the IAHPC website for educational purposes (38).

- a. Participants discussed projects for improvement, expansion and the introduction of palliative care into the medical and nursing curricula. The workshop also provided opportunities for networking and for sharing ideas, resources and experiences
 - b. Universities are now using the resulting competencies as a model to develop their own palliative care curricula, tailored to meet the needs of their patients while taking into account their own resources and the educational needs of their students.
3. A third stage was planned for December 2015 to demonstrate novel methods of teaching palliative care using the materials from the workshop.

A similar approach is planned for other Latin American countries, including Argentina in 2016.

Source: Adapted from (39,40).

Educating the public and policy-makers

To increase the likelihood that people who need palliative care will access the required services, it is important for the general public to understand what palliative care is, who should be referred for services, what those services are, and how patients and families can benefit from palliative care programmes. The general public can play a role in palliative care – e.g. by volunteering to help teams of health professionals.

It is particularly important for policy-makers to understand that palliative care is part of the continuum of care for cancer, HIV/AIDS and other diseases, that it can be integrated into the existing health-care system at relatively low cost, and that it requires opioids to be available across all levels of care.

The media need to be involved in disseminating reliable information of educational value, while avoiding sensationalism. This can be achieved by putting journalists in touch with patients with advanced illness who wish to talk about the importance of pain relief to their quality of life. Safeguards should be put in place to ensure that the media respect the dignity and rights of patients and their families. The media should also be informed of the needs of patients and their families for support and care.

4.5 Setting standards and evaluating palliative care services

This section describes how to measure progress towards strengthening palliative care, and to how to measure and improve the quality of services. National palliative care standards describe what is necessary when establishing and operating a palliative care service. Indicators to measure the structure, process and outcomes of palliative care are important for evaluating and improving the quality of services. Doing this from the beginning of a palliative care service helps authorities to determine the value of palliative care to the national health-care system and helps to ensure that access to a quality palliative care service is being achieved.

Evaluating overall progress in palliative care development

All providers of palliative care should be committed to continuous improvement of the quality of their services. Data collected from quality indicators are a primary source of information for improving services. When possible, palliative care services should be able to compare their quality indicator results with other similar services. A basic framework for indicators that can be used to assess the key domains of a national or regional programme is described in Table 11.

Table 11. Sample indicators for assessing overall palliative care development

| | |
|-------------------------------------|---|
| Policy indicators | Existence of a current national palliative care plan/programme (yes/no) |
| | Palliative care included in the basic package for universal health coverage |
| | Laws and regulations in place for safe and effective opioid prescribing, in line with international drug conventions |
| Education indicators | Proportion of medical schools which include palliative care education in undergraduate curricula (i.e. ratio of medical schools with palliative care at undergraduate level to total medical schools) |
| | Proportion of nursing schools which include palliative care education in undergraduate curricula (i.e. ratio of nursing schools with palliative care at undergraduate level to total nursing schools) |
| | Number of specialized palliative care educational programmes for physicians, accredited by the national responsible authority (absolute number), with specialized palliative care education defined as specialty, sub-specialty, master, or diploma, as defined by the respective competent authority |
| Service provision indicators | Inclusion of palliative care in the list of services provided at primary care level |
| | Number of palliative care services per million inhabitants |
| | Number of accredited/specialized physicians working in palliative care per 1 million inhabitants |
| | Number of communities that own and provide palliative care services |
| Medication indicators | Consumption of strong opioids per cancer death (mg per number of deaths) |
| | WHO essential medicines for palliative care all included in national list of essential medicines |
| | Proportion of districts where oral morphine is available in primary health care |
| Outcomes | Percentage of deaths with access to palliative care |
| | Number of palliative care patients cared for per 100 000 inhabitants |

Any palliative care service should include an evaluation method from the beginning in order to ensure that effective programmes are maintained and resources are not wasted on ineffective programmes. Evaluation of a national/regional programme not only allows providers to monitor progress toward the predefined programme goals, as well as the interim goals and targets of different phases, but also enables comparisons between different population groups and provides the opportunity for continuous quality improvement interventions in critical areas. Populations with disproportionately high risk factors can be given specific attention. The service can be compared with similar initiatives in other locations, and the evaluation will provide the technical basis for political decisions about the development of the service, including the provision of further funding and support.

Measuring palliative care quality

It is also important to assess the quality of the palliative care provided. A number of outcome measures and indicators are available to measure the quality of palliative care (41,42). Standardized clinical tools should be used to measure symptom burden and functional ability regularly.

Palliative care poses some special challenges in terms of measurement. Patients are very ill and have difficulty communicating. Family members can evaluate their own care but are not always the best persons to evaluate the patient's experience (although they may be more accurate than health-care providers).

A number of palliative care domains can serve as a framework for measuring the quality of palliative care:

1. Structure and process of care (e.g. training and education for professionals; providing continuity of care).
2. Physical aspects of care (e.g. measuring and documenting pain and other symptoms; assessing and managing symptoms and side-effects).
3. Psychological and psychiatric aspects of care (e.g. measuring, documenting and managing anxiety, depression and other psychological symptoms; assessing and managing the psychological reactions of patients/families).
4. Social aspects of care (e.g. conducting regular patient/family care conferences to provide information, discuss goals of care, and offer support to the patient or family; developing and implementing comprehensive social care plans).
5. Spiritual, religious and existential aspects of care (e.g. providing information about availability of spiritual care services to the patient or family).
6. Cultural aspects of care (e.g. incorporating cultural assessments such as the locus of decision-making and preferences of patient or family regarding the disclosure of information and truth-telling, language and rituals).
7. Care of the imminently dying patient (e.g. recognizing and documenting the transition to the active dying phase; ascertaining and documenting patient/family wishes about the place of death; implementing a bereavement care plan).
8. Ethical and legal aspects of care (e.g. documenting patient/surrogate preferences for care goals, treatment options and the care setting; making advance directives; promoting advanced care planning).

Other dimensions to consider

Utilization outcomes

Most research on the cost impact of palliative care has shown more appropriate use of health care resources and reductions in hospitalization. Measuring the utilization of health care resources is important – especially inpatient care, which is the most expensive resource in any health-care system.

Public awareness measurement

It is important to measure public attitudes to palliative care and relief of suffering. Standardized representative surveys of the public can be undertaken over time to measure changes in attitudes. These surveys usually ask the public what services they believe would be important if they or someone they love were to be faced with a life-threatening illness.

Setting standards for palliative care

The European Association for Palliative Care has developed a consensus paper on norms and standards for hospice and palliative care in Europe (9). The African Palliative Care Association has developed standards for providing quality palliative care across Africa (43). Over 30 countries have national palliative care standards (see <http://thewhpca.org/resources/category/standards-clinical-guidelines-and-protocols> for examples) that can be used as models to help countries to develop their own.

National standards are distinct from but related to clinical standards, guidelines, protocols and standard operating procedures that are usually used to describe how to care for a patient or symptom. National

standards can vary in complexity and content. At a minimum, the following content should be included:

- governance and management of palliative care services;
- eligibility for palliative care;
- description of the interdisciplinary team, indicating required and optional disciplines;
- qualifications and training required to work in a palliative care service;
- types of services that must be provided by each discipline;
- recommended staffing ratios and caseload;
- education, training and staff support;
- clinical assessment and interdisciplinary plan of care development;
- record-keeping requirements and medical record maintenance;
- safety and infection control policies;
- medication, supplies and equipment;
- continuity of care;
- ethical issues;
- quality assessment and performance improvement;
- palliative care in different settings (inpatient, clinic, day care, home care);
- palliative care to special populations (children, persons with communicable diseases, non-cancer patients, vulnerable groups).

Case example: African Palliative Care Association standards for providing quality palliative care across Africa

The African Palliative Care Association recognized that, in addition to increasing coverage of palliative care across the region, it was important to ensure the quality of care provided. In Africa, the primary mode of palliative care service delivery is home-based care which depends predominantly on volunteers. In addition to addressing staff recruitment and retention, it is imperative that African palliative care providers ensure that home-based care services provide an acceptable standard of patient care. Clear standards are also important in replicating palliative care at different levels of the health-care system and in different delivery models. The African Palliative Care Association standards for providing quality palliative care across Africa (43) target all who provide services and training to people living with life-threatening illnesses.

The standards elaborate the quality requirements or criteria for each level of service delivery. Three levels are used:

Level 1: Primary/basic. This level represents what is essential, or the minimum package for palliative care.

Level 2: Secondary/intermediary. This represents intermediary services which provide a wide range of care components.

Level 3: Tertiary/specialist. This represents what is desirable for a specialist palliative care service for people with life-threatening illnesses.

The standards were developed by palliative care stakeholders across Africa and globally, following wide consultation and participation, and will be reviewed regularly so that they remain relevant and up-to-date.

Case example: Self-assessment tool and star-rating system developed in South Africa

The Hospice Palliative Care Association of South Africa (HPCA) has developed an accreditation system to describe the level of development of services according to a star-rating system, with hospices accredited by the Council for Health Services Accreditation of Southern Africa (CoHSASA) being designated as “5-star hospices”. The HPCA accreditation system has an online self-assessment tool that enables member organizations to log in and complete a survey of required standards. Hospices can request an assessment visit when moving from one star-rating to the next and when preparing for an external accreditation visit from CoHSASA. This accreditation system provides quality assurance in monitoring community-based organizations and promoting quality palliative care for patients and families.

4.6 Costing palliative care services

Cost impact of palliative care

There is significant evidence that palliative care – whether through hospice, hospital-based or home-based care – results in reduced hospital and total health-care costs (15,44–48) by reducing avoidable hospitalization, emergency department presentations, and unnecessary treatment. Palliative care in residential care facilities for older persons may also reduce referrals to hospitals (49). This means that providing palliative care services may actually lower the cost of health care, at the same time as providing a better quality of life for palliative care patients

Costing palliative care

As in the case of other health care services, palliative care has both direct and indirect costs. Direct costs include both fixed and variable expenses. It is useful to determine the measurement that will help in planning. This may be the total annual budget, or it can be units such as cost per day, cost per patient per month, cost per inpatient day, cost per inpatient episode of care, or cost per home or clinic visit.

The cost of palliative care is mostly related to personnel costs, unlike other health-care services in which the costs of treatment are higher. Funding is another key issue, as most services adapt to their available funding.

Case examples: Two costing models from Europe and Africa

1. Costing model from Romania

This model (50) calculates four metrics: 1) cost per inpatient day, 2) cost per home visit, 3) home-care cost per month, and 4) cost per case. Two spreadsheets are available – one for calculating inpatient cost and one for home-based care cost. Local costs for personnel, medications, supplies and other items are inserted in the workbook to generate results. The Romanian costing model showed a cost of US\$ 96.58 per inpatient day, a cost of US\$ 30.37 for a home visit (average for all disciplines), a cost of US\$ 723.60 per month for home care, and US\$ 1367.71 per episode of home care (which included an average of 45 visits).

2. Costing model from the Hospice and Palliative Care Association of South Africa.

The outputs from this model are for either home-based care or inpatient unit: 1) cost per patient day, 2) cost per month, 3) cost per patient per month, 4) cost per average episode of care. In South Africa the average cost for home care per month was US\$ 96 and for an inpatient day was US\$ 91. However, palliative care costs are only one part of the equation. This cost can be offset by reductions in other expenses, especially hospitalization.



5

Other WHO tools and resources

Clinical management in palliative care

WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses, WHO Geneva 2012 (available in English and Spanish): http://www.who.int/medicines/areas/quality_safety/guide_perspainchild/en/

Palliative care: Symptom management and end-of-life care guidelines. Integrated management of Adult/Adolescent Illness (2004) (available in English and French): http://www.who.int/hiv/pub/imai/primary_palliative/en/

PAHO Palliative care clinical guidelines/manual (in Spanish): http://www.paho.org/hq/index.php?option=com_content&view=article&id=5045%3Aguidelines-and-manuals%3A-palliative-care&catid=3402%3Ahds0201f-palliative-cancer-&lang=en

Clinical Protocol: Palliative care for people living with HIV/AIDS. WHO Regional Office for Europe (available in English and Russian): <http://www.euro.who.int/en/health-topics/communicable-diseases/hivaids/publications/pre-2009/hivaids-treatment-and-care2.-clinical-protocols-for-the-european-region/protocol-3.-palliative-care-for-people-living-with-hivaids>

Policy and programme design

Cancer control: Palliative care. WHO guide for effective programmes (2007) (available in English and Spanish): http://www.who.int/cancer/publications/cancer_control_palliative/en/

Palliative care for older people: better practices. WHO Regional Office for Europe (2011) (Available in English, Russian and Spanish): <http://www.euro.who.int/en/health-topics/noncommunicable-diseases/cancer/publications/2011/palliative-care-for-older-people-better-practices>

Palliative care: the solid facts. WHO Regional Office for Europe (2004) (Available in English, Russian and Spanish): <http://www.euro.who.int/en/health-topics/noncommunicable-diseases/cancer/publications/pre-2009/palliative-care.-the-solid-facts>

Uganda advancing the integration of palliative care in the National Health System (2013) <http://www.who.int/evidence/sure/PCBFullReportSept2013.pdf>

Monitoring palliative care

Palliative care for noncommunicable diseases: a global snapshot in 2015 (2016) (available in Arabic, Chinese, English, French, Russian and Spanish): <http://www.who.int/ncds/management/palliative-care/palliative-care-NCDs/en/>

Global atlas on palliative care at the end of life (2014) <http://www.who.int/cancer/publications/palliative-care-atlas/en/>
 NCD toolkit: Indicator 20 - Access to Palliative Care <http://www.who.int/nmh/ncd-tools/indicator20/en/>

Advocacy and communications

WHO fact sheet on palliative care (available in Chinese, English, French, Russian and Spanish):

<http://www.who.int/mediacentre/factsheets/fs402/en/>

Infographic on palliative care (available in Arabic, Chinese, English, French, Russian, Portuguese and Spanish):

<http://www.who.int/ncds/management/palliative-care/pc-infographics/en/>

References

1. Global atlas on palliative care at the end of life. London: World Hospice and Palliative Care Alliance; 2014.
2. Higginson IJ. Health care needs assessment: palliative and terminal care. In: Stevens A, Raftery J, editors. Health care needs assessment. Oxford/New York: Radcliffe Medical Press; 1997.
3. Seya M-J, Gelders SFAM, Achara OU, Milani B, Scholten WK. A first comparison between the consumption of and the need for opioid analgesics at country, regional, and global levels. *J Pain Palliat Care Pharmacother*. 2011;25(1):6–18.
4. Ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines. Geneva: World Health Organization; 2011 (http://whqlibdoc.who.int/publications/2011/9789241564175_eng.pdf?ua=1, accessed 14 September 2016).
5. De Lima L, Bennett MI, Murray SA, Hudson P, Doyle D, Bruera E, et al. International Association for Hospice and Palliative Care (IAHPC) list of essential practices in palliative care. *J Pain Palliat Care Pharmacother*. 2012;26(2):118–22.
6. Clark D. Total pain: the work of Cicely Saunders and the hospice movement. *Am Pain Soc Bull*. 2000;10(4):13–5.
7. WHO guidelines on the pharmacological treatment of persisting pain in children with medical illness. Geneva: World Health Organization; 2012.
8. Hudson P, Payne S. Family caregivers and palliative care: current status and agenda for the future. *J Palliat Med*. 2011;14(7):864–9.
9. Radbruch L, Payne S, the Board of Directors of the European Association for Palliative Care). White Paper on standards and norms for hospice and palliative care in Europe. Part 1. Recommendations from the European Association for Palliative Care. *Eur J Palliat Care*. 2009;16(6):278–89.
10. Nemeth C, Rottenhofer I. Abgestufte Hospiz- und Palliativversorgung in Österreich. Vienna: Österreichisches Bundesinstitut für Gesundheitswesen; 2004 (http://www.hospiz.at/pdf_dl/oebig_studie.pdf, accessed 14 September 2016).
11. A guide to palliative care service development: a population based approach. Canberra: Palliative Care Australia; 2005.
12. Indian Association of Palliative Care, CanSupport. Guidelines for home based palliative care services. New Delhi: CanSupport; 2007.
13. Defilippi KM, Cameron S. Promoting the integration of quality palliative care: the South African Mentorship Program. *J Pain Symptom Manage*. 2007;33(5):552–7.
14. Guidelines for developing palliative care services. Hyderabad: MNJ Institute of Oncology & Regional Cancer Centre; 2009.
15. Smith S, Brick A, O'Hara S, Normand C. Evidence on the cost and cost-effectiveness of palliative care: a literature review. *Palliat Med*. 2014;28(2):130–50.
16. Kumar S, Numpeli M. Neighborhood network in palliative care. *Indian J Palliat Care*. 2005;11(1):6.
17. Sallnow L, Kumar S, Numpeli M. Home-based palliative care in Kerala, India: the neighbourhood network in palliative care. *Prog Palliat Care*. 2010;18(1):14–7.
18. Abel J, Bowra J, Walter T, Howarth G. Compassionate community networks: supporting home dying. *BMJ Support Palliat Care*. 2011;1(2):129–33.
19. World Health Organization. How many people at the end of life are in need of palliative care worldwide? In: Global atlas on palliative care at the end of life. London: World Hospice and Palliative Care Alliance; 2014.

20. Pastrana T, De Lima L, Wenk R, Eisenclas J, Monti C, Rocafort J, et al. Atlas de cuidados paliativos en Latinoamerica: Costa Rica. Houston (TX): International Association for Hospice & Palliative Care; 2012 (http://cuidadospaliativos.org/uploads/2012/10/atlas/09_Costa_Rica.pdf, accessed 14 September 2016).
21. University of Edinburgh, Makerere University Palliative Care Unit, African Palliative Care Association. Final evaluation report for the Integrate Palliative Care Project. London: Tropical Health & Education Trust; 2015 (https://www.africanpalliativecare.org/images/stories/pdf/THET_IPCP_Evaluation_Repor.pdf, accessed 14 September 2016).
22. Luyirika EB, Namisango E, Garanganga E, Monjane L, Ginindza N, Madonsela G, et al. Best practices in developing a national palliative care policy in resource limited settings: lessons from five African countries. *Ecancermedalscience*. 2016;10:652.
23. WHO Model List of Essential Medicines, 19th List. Geneva: World Health Organization; 2015 (http://www.who.int/entity/selection_medicines/committees/expert/20/EML_2015_FINAL_amended_JUN2015.pdf?ua=1, accessed 20 August 2016).
24. WHO Model List of Essential Medicines for Children, 5th List. Geneva: World Health Organization; 2015 (http://www.who.int/entity/selection_medicines/committees/expert/20/EMLc_2015_FINAL_amended_JUN2015.pdf?ua=1, accessed 20 August 2016).
25. Murtagh FE, Bausewein C, Verne J, Groeneveld EI, Kaloki YE, Higginson IJ. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliat Med*. 2014;28(1):49–58.
26. Report of the International Narcotics Control Board on the availability of internationally controlled drugs. Ensuring adequate access for medical and scientific purposes. Vienna: International Narcotics Control Board; 2011 (https://www.incb.org/documents/Publications/AnnualReports/AR2010/Supplement-AR10_availability_English.pdf, accessed 14 September 2016).
27. Rajagopal MR, Kumar S. A model for delivery of palliative care in India - the Calicut experiment. *J Palliat Care*. 1999;15(1):44–9.
28. Pain and palliative care policy 2008. Kerala: Government of Kerala, India; 2008 .
29. Government of India. Narcotic Drugs and Psychotropic Substances Amendment Act 2014. Gazette of India, 10 March 2014 (<http://www.indiacode.nic.in/acts2014/16%20of%202014.pdf>, accessed 14 September 2016).
30. Krakauer EL, Nguyen TPC, Husain SA, Nguyen THY, Joranson DE, Luong NK, et al. Toward safe accessibility of opioid pain medicines in Vietnam and other developing countries: a balanced policy method. *J Pain Symptom Manage*. 2015;49(5):916–22.
31. Global state of pain treatment. Access to medicines and palliative care. New York (NY): Human Rights Watch; 2011 (<https://www.hrw.org/sites/default/files/reports/hhr0511W.pdf>, accessed 14 September 2016).
32. Stjernswärd J, Foley KM, Ferris FD. The public health strategy for palliative care. *J Pain Symptom Manage*. 2007;33(5):486–93.
33. Task shifting: rational redistribution of tasks among health workforce teams. Global recommendations and guidelines. Geneva: World Health Organization; 2008 (<http://www.who.int/healthsystems/TTR-Task-Shifting.pdf>, accessed 14 September 2016).
34. Jagwe J, Merriman A. Uganda: delivering analgesia in rural Africa: opioid availability and nurse prescribing. *J Pain Symptom Manage*. 2007;33(5):547–51.
35. Promoting palliative care in the community: producing a toolkit to improve and develop primary palliative care in different countries internationally. European Association for Palliative Care; 2015 (<http://www.eapcnet.eu/LinkClick.aspx?fileticket=PXIXIRoSrXU%3D>, accessed 14 September 2016).

36. Palliative care core curriculum. Kampala: African Palliative Care Association; 2012 (https://www.africanpalliativecare.org/images/stories/pdf/Palliative_Care_Core_Curriculum.pdf, accessed 14 September 2016).
37. Gamondi C, Larkin P, Payne S. Core competencies in palliative care: an EAPC White Paper on palliative care education - Part 1. *Eur J Palliat Care*. 2013;20(2).
38. Transforming the system. Palliative care competencies in undergraduate education. Cali, Colombia, 27-28 November 2014. Houston (TX): International Association for Hospice and Palliative Care; 2015 (<http://hospicecare.com/uploads/2015/5/Competencies%20in%20undergraduate%20education.pdf>, accessed 14 September 2016).
39. Pastrana T, Wenk R, De Lima L. Consensus-based palliative care competencies for undergraduate nurses and physicians: a demonstrative process with Colombian universities. *J Palliat Med*. 2015;19(1):76–82 (<http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0202>, accessed 14 September 2016).
40. Pastrana T, de Lima L, Wenk R. Estudio multicéntrico sobre la comodidad y el interés en cuidados paliativos en estudiantes de pregrado en Colombia. *Med Paliativa*. 2015;22(4):136–45.
41. De Roo ML, Leemans K, Claessen SJJ, Cohen J, Pasma HRW, Deliens L, et al., EURO IMPACT. Quality indicators for palliative care: update of a systematic review. *J Pain Symptom Manage*. 2013;46(4):556–72.
42. Pasma HRW, Brandt HE, Deliens L, Francke AL. Quality indicators for palliative care: a systematic review. *J Pain Symptom Manage*. 2009;38(1):145–56.
43. Standards for providing quality palliative care across Africa. Kampala: African Palliative Care Association; 2011.
44. Penrod JD, Deb P, Luhrs C, Dellenbaugh C, Zhu CW, Hochman T, et al. Cost and utilization outcomes of patients receiving hospital-based palliative care consultation. *J Palliat Med*. 2006;9(4):855–60.
45. Morrison RS, Penrod JD, Cassel JB, Caust-Ellenbogen M, Litke A, Spragens L, et al., Palliative Care Leadership Centers' Outcomes Group. Cost savings associated with US hospital palliative care consultation programs. *Arch Intern Med*. 2008;168(16):1783–90.
46. Morrison RS, Dietrich J, Ladwig S, Quill T, Sacco J, Tangeman J, et al. Palliative care consultation teams cut hospital costs for Medicaid beneficiaries. *Health Aff Proj Hope*. 2011;30(3):454–63.
47. Serra-Prat M, Gallo P, Picaza JM. Home palliative care as a cost-saving alternative: evidence from Catalonia. *Palliat Med*. 2001;15(4):271–8.
48. Brumley R, Enguidanos S, Jamison P, Seitz R, Morgenstern N, Saito S, et al. Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. *J Am Geriatr Soc*. 2007;55(7):993–1000.
49. Ennis L, Kinley J, Hockley J, McCrone P. The cost of providing end of life care for nursing care home residents: a retrospective cohort study. *Health Serv Manage Res*. 2015;28(1-2):16–23. doi: 0951484815607541.
50. Mosoiu D, Dumitrescu M, Connor SR. Developing a costing framework for palliative care services. *J Pain Symptom Manage*. 2014;48(4):719–29.

Annex 1: WHO Model List of Essential Medicines for palliative care

Non-opioids and non-steroidal anti-inflammatory medicines (NSAIDs)

| | |
|----------------------|--|
| acetylsalicylic acid | Suppository: 50 mg to 150 mg. Tablet: 100 mg to 500 mg. |
| ibuprofen [a] | Oral liquid: 200 mg/5 mL. Tablet: 200 mg; 400 mg; 600 mg. [a]Not in children less than 3 months. |
| paracetamol* | Oral liquid: 125 mg/5 mL. Suppository: 100 mg. Tablet: 100 mg to 500 mg. * Not recommended for anti-inflammatory use due to lack of proven benefit to that effect. |

Opioid analgesics

| | |
|-----------|--|
| codeine | Tablet: 30 mg (phosphate). |
| morphine* | Granules (slow-release; to mix with water): 20 mg-200 mg (morphine sulfate). Injection: 10 mg (morphine hydrochloride or morphine sulfate) in 1mL ampoule. Oral liquid: 10 mg (morphine hydrochloride or morphine sulfate)/5 mL. Tablet (slow release): 10 mg–200mg (morphine hydrochloride or morphine sulfate). Tablet (immediate release): 10 mg (morphine sulfate). *Alternatives limited to hydromorphone and oxycodone |

Medicines for other common symptoms in palliative care

| | |
|---------------|--|
| amitriptyline | Tablet: 10 mg; 25 mg; 75 mg. |
| cyclizine [c] | Injection: 50 mg/ mL. Tablet: 50 mg. |
| dexamethasone | Injection: 4 mg/ mL in 1mL ampoule (as disodium phosphate salt). Oral liquid: 2 mg/5 mL. Tablet: 2 mg [c]; 4 mg. |
| diazepam | Injection: 5 mg/ mL. Oral liquid: 2 mg/5 mL. Rectal solution: 2.5 mg; 5 mg; 10 mg. Tablet: 5 mg; 10 mg. |

| | |
|---------------------------|--|
| docusate sodium | Capsule: 100 mg. Oral liquid: 50 mg/5 mL. |
| fluoxetine [a] | Solid oral dosage form: 20 mg (as hydrochloride). [a] >8 years. |
| haloperidol | Injection: 5 mg in 1 mL ampoule. Oral liquid: 2 mg/mL. Solid oral dosage form: 0.5 mg; 2 mg; 5 mg. |
| hyoscine butylbromide | Injection: 20 mg/mL. |
| hyoscine hydrobromide [c] | Injection: 400 micrograms/mL; 600 micrograms/mL. Transdermal patches: 1 mg/72 hours. |
| lactulose [c] | Oral liquid: 3.1–3.7 g/5 mL. |
| loperamide | Solid oral dosage form: 2 mg. |
| metoclopramide | Injection: 5 mg (hydrochloride)/mL in 2 mL ampoule. Oral liquid: 5 mg/5 mL. Solid oral form: 10 mg (hydrochloride). |
| midazolam | Injection: 1 mg/mL; 5 mg/mL. Solid oral dosage form: 7.5 mg; 15 mg. Oral liquid: 2mg/mL [c]. |
| ondansetron [c] [a] | Injection: 2 mg base/mL in 2mL ampoule (as hydrochloride). Oral liquid: 4 mg base/5 mL. Solid oral dosage form: Eq 4 mg base; Eq 8 mg base. [a]>1 month. |
| senna | Oral liquid: 7.5 mg/5 mL. |

[c] = requires specialist diagnostic or monitoring, or specialist training or medical care for use in children.

Source: WHO Model List of Essential Medicines, 19th List. Geneva: World Health Organization; 2015.

Annex 2: WHO Model List of Essential Medicines for Palliative Care for Children

Non-opioids and non-steroidal anti-inflammatory medicines (NSAIDs)

| | |
|---------------|---|
| ibuprofen [a] | <p>Oral liquid: 200 mg/5 mL.</p> <p>Tablet: 200 mg; 400 mg; 600 mg.</p> <p>[a]Not in children less than 3 months.</p> |
| paracetamol* | <p>Oral liquid: 125 mg/5 mL.</p> <p>Suppository: 100 mg.</p> <p>Tablet: 100 mg to 500 mg.</p> <p>* Not recommended for anti-inflammatory use due to lack of proven benefit to that effect.</p> |

Opioid analgesics

| | |
|-----------|---|
| morphine* | <p>Granules (slow-release; to mix with water): 20 mg-200 mg (morphine sulfate).</p> <p>Injection: 10 mg (morphine hydrochloride or morphine sulfate) in 1 mL ampoule.</p> <p>Oral liquid: 10 mg (morphine hydrochloride or morphine sulfate)/5 mL.</p> <p>Tablet (slow release): 10 mg–200mg (morphine hydrochloride or morphine sulfate).</p> <p>Tablet (immediate release): 10 mg (morphine sulfate).</p> <p>*Alternatives limited to hydromorphone and oxycodone.</p> |
|-----------|---|

Medicines for other common symptoms in palliative care

| | |
|-----------------|--|
| amitriptyline | Tablet: 10 mg; 25 mg; 75 mg. |
| cyclizine | <p>Injection: 50 mg/ mL.</p> <p>Tablet: 50 mg.</p> |
| dexamethasone | <p>Injection: 4 mg/ mL in 1 mL ampoule (as disodium phosphate salt).</p> <p>Oral liquid: 2 mg/5 mL.</p> <p>Tablet: 2 mg; 4 mg.</p> |
| diazepam | <p>Injection: 5 mg/mL.</p> <p>Oral liquid: 2 mg/5 mL.</p> <p>Rectal solution: 2.5 mg; 5 mg; 10 mg.</p> <p>Tablet: 5 mg; 10 mg.</p> |
| docusate sodium | <p>Capsule: 100 mg.</p> <p>Oral liquid: 50 mg/5 mL.</p> |

| | |
|-----------------------|---|
| fluoxetine [a] | Solid oral dosage form: 20 mg (as hydrochloride). [a] >8 years. |
| hyoscine hydrobromide | Injection: 400 micrograms/mL; 600 micrograms/mL. Transdermal patches: 1 mg/72 hours. |
| lactulose | Oral liquid: 3.1–3.7 g/5 mL. |
| midazolam | Injection: 1 mg/ mL; 5 mg/ mL. Solid oral dosage form: 7.5 mg; 15 mg. Oral liquid: 2mg/ mL. |
| ondansetron [a] | Injection: 2 mg base/mL in 2mL ampoule (as hydrochloride). Oral liquid: 4 mg base/5 mL. Solid oral dosage form: Eq 4 mg base; Eq 8 mg base. [a] >1 month. |
| senna | Oral liquid: 7.5 mg/5 mL. |

Source: WHO Model List of Essential Medicines for Children, 5th List. Geneva: World Health Organization; 2015.

Annex 3: Sample basic equipment and medicines for a palliative care home-care kit

Basic medical equipment and supplies

Equipment

- Stethoscope
- Blood pressure apparatus
- Torch
- Thermometer
- Tongue depressors
- Forceps

Supportive equipment

- Backrests
- Air mattresses
- Water mattresses
- Suction machines
- Nebulizers
- Wheel chairs
- Walking frames
- Bath chairs
- Bed pans/commodes

Supplies

- Dressing supplies
- Cotton
- Scissors
- Gauze pieces
- Gauze bandages
- Dressing trays
- Gloves
- Micropore tape
- Transfusion supplies
- IV sets
- Intracath and butterfly needles
- Syringes and needles
- Tubes and bags
- Suction catheters
- Urinary catheters
- Condom catheters
- Urine bags
- Feeding tubes

Source: Indian Association of Palliative Care, CanSupport. Guidelines for home based palliative care services. New Delhi: CanSupport; 2007.

Medicines

Pain control

- Paracetamol
- Ibuprofen
- Diclofenac
- Codeine phosphate
- Tramadol
- Morphine
- Gabapentine

Gastrointestinal symptom control

- Metoclopramide
- Domperidone
- Dexamethasone
- Bisacodyl
- Loperamide
- Oral rehydration salts
- Ranitidine

Wound management

- Betadine lotion and ointment
- Metrogl jelly
- Hydrogen peroxide

Psychological symptom management

- Diazepam
- Halperidol
- Amitriptyline

Antibiotics and antifungals

- Ciprofloxacin
- Metronidazole
- Amoxyillin
- Fluconazole

Nutritional supplements

- High protein and calories food supplements
- Iron, vitamin and mineral supplements

Other miscellaneous

- Spirit
- Lignocaine jelly
- Ethamsylate
- Deriphylline
- Cough preparations

Source: Indian Association of Palliative Care, CanSupport. Guidelines for home based palliative care services. New Delhi: CanSupport; 2007.

Annex 4: Sample curriculum for a 16-hour training programme in palliative care for community volunteers

Introduction to palliative care: 1 hour

- History and philosophy of palliative care
- Palliative care as part of a continuum of care
- Global perspectives
- Local situation
- Palliative care as part of primary health care

Role of the community: 1 hour

- Community participation
- Role of volunteers in the care of the incurably and terminally ill
- Neighbourhood network in palliative care

Communication skills: 6 hours

- Basics of communication
- Breaking bad news
- Addressing emotional reactions
- Offering emotional support

Assessment of patients: 1 hour

Home care: 1 hour

Care of the dying: 2 hours

Nursing care for patients with advanced diseases: 3 hours

- Prevention and management of bed sores
- Stoma care
- Universal precautions
- Management of lymphoedema

Care of the elderly: 1 hour

Source: Institute of Palliative Medicine, WHO Collaborating Centre for Community Participation in Palliative Care and Long Term Care, Kerala, India.

Annex 5: Sample curriculum in basic palliative care for doctors and clinical officers

Day 1

- 1.1 Palliative care basic training course: Goals and Agenda

Slide presentation

- 1.2 Epidemiology of cancer and other serious chronic illnesses in the country

Slide presentation

- 1.3 Palliative care: Definitions and Principles

Slide presentation

- 1.4 Palliative care needs and available services in the country

Slide presentation

- Palliative care assessment: Approach to the Patient in Need of Palliative Care

Slide presentation

- 1.6 Ethical issues and patient-physician communication in palliative care: Principles and Practice

Slide presentation

- 1.7 Giving bad news

Role play

Day 2

- 2.1 Pain assessment and treatment

Slide presentation

- 2.2 Adjuvant pain medicines / Adverse effects of pain medicines

Slide presentation

- 2.3 Opioid policy and barriers to opioid analgesia

Slide presentation

- 2.4 Adult learning theory

Slide presentation

- 2.5 Pain cases

Small or large group discussion

Day 3

- 3.1 Dyspnea assessment and treatment
Slide presentation
- 3.2 Dermatology in palliative care
Slide presentation
- 3.3 Nausea/vomiting assessment and treatment
Slide presentation
- 3.4 Constipation/diarrhoea assessment and treatment
Slide presentation
- 3.5 Constitutional symptoms assessment and treatment
Slide presentation
- 3.6 Dyspnea case
Small or large group discussion
- 3.7 Gastrointestinal symptom case
Small or large group discussion

Day 4

- 4.1 Psychological distress in the terminally ill: depression and anxiety
Slide presentation
- 4.2 Altered mental status: delirium and dementia
Slide presentation
- 4.3 Loss, grief and bereavement
Slide presentation
- 4.4 Psychosocial support in palliative care
Slide presentation
- 4.5 Psychosocial assessment
Role play
- 4.6 Social and spiritual suffering
Group discussion
- 4.7 Teaching clinicians about professional bereavement / Memorial ceremony
Group activity

Day 5

5.1 Integrating palliative care into the health care system: Global models and Local needs

Slide presentation

5.2 The palliative care team

Slide presentation

5.3 Palliative care strategic planning: What can you do in your home institution?

Group work and discussion

Final examination

Annex 6: World Health Assembly resolution WHA67.19 “Strengthening of palliative care as a component of comprehensive care throughout the life course”

The Sixty-seventh World Health Assembly,

Having considered the report on strengthening of palliative care as a component of integrated treatment throughout the life course;¹

Recalling resolution WHA58.22 on cancer prevention and control, especially as it relates to palliative care;

Taking into account the United Nations Economic and Social Council’s Commission on Narcotic Drugs’ resolutions 53/4 and 54/6 respectively on promoting adequate availability of internationally controlled licit drugs for medical and scientific purposes while preventing their diversion and abuse, and promoting adequate availability of internationally controlled narcotic drugs and psychotropic substances for medical and scientific purposes while preventing their diversion and abuse;

Acknowledging the special report of the International Narcotics Control Board on the availability of internationally controlled drugs: ensuring adequate access for medical and scientific purposes,² and the WHO guidance on ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines;³

Also taking into account resolution 2005/25 of the United Nations Economic and Social Council on treatment of pain using opioid analgesics;

Bearing in mind that palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual;

Recognizing that palliative care, when indicated, is fundamental to improving the quality of life, well-being, comfort and human dignity for individuals, being an effective person-centred health service that values patients’ need to receive adequate, personally and culturally sensitive information on their health status, and their central role in making decisions about the treatment received;

Affirming that access to palliative care and to essential medicines for medical and scientific purposes manufactured from controlled substances, including opioid analgesics such as morphine, in line with the three United Nations international drug control conventions,⁴ contributes to the realization of the right to the enjoyment of the highest attainable standard of health and well-being;

Acknowledging that palliative care is an ethical responsibility of health systems, and that it is the ethical duty of health care professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured, and that end-of-life care for individuals is among the critical components of palliative care;

¹ Document 67/31.

² Document E/INCB/2010/1/Supp.1.

³ Ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines. Geneva: World Health Organization; 2011.

⁴ United Nations Single Convention on Narcotic Drugs, 1961, as amended by the 1972 Protocol; United Nations Convention on Psychotropic Substances, 1971; United Nations Convention against Illicit Traffic in Narcotic Drugs and Psychotropic Substances, 1988.

Recognizing that more than 40 million people currently require palliative care every year, foreseeing the increased need for palliative care with ageing populations and the rise of noncommunicable and other chronic diseases worldwide, considering the importance of palliative care for children, and, in respect of this, acknowledging that Member States should have estimates of the quantities of the internationally controlled medicines needed, including medicines in paediatric formulations;

Realizing the urgent need to include palliation across the continuum of care, especially at the primary care level, recognizing that inadequate integration of palliative care into health and social care systems is a major contributing factor to the lack of equitable access to such care;

Noting that the availability and appropriate use of internationally controlled medicines for medical and scientific purposes, particularly for the relief of pain and suffering, remains insufficient in many countries, and highlighting the need for Member States, with the support of the WHO Secretariat, the United Nations Office on Drugs and Crime and the International Narcotics Control Board, to ensure that efforts to prevent the diversion of narcotic drugs and psychotropic substances under international control pursuant to the United Nations international drug control conventions do not result in inappropriate regulatory barriers to medical access to such medicines;

Taking into account that the avoidable suffering of treatable symptoms is perpetuated by the lack of knowledge of palliative care, and highlighting the need for continuing education and adequate training for all hospital- and community-based health care providers and other caregivers, including nongovernmental organization workers and family members;

Recognizing the existence of diverse cost-effective and efficient palliative care models, acknowledging that palliative care uses an interdisciplinary approach to address the needs of patients and their families, and noting that the delivery of quality palliative care is most likely to be realized where strong networks exist between professional palliative care providers, support care providers (including spiritual support and counselling, as needed), volunteers and affected families, as well as between the community and providers of care for acute illness and the elderly;

Recognizing the need for palliative care across disease groups (noncommunicable diseases, and infectious diseases, including HIV and multidrug-resistant tuberculosis), and across all age groups;

Welcoming the inclusion of palliative care in the definition of universal health coverage and emphasizing the need for health services to provide integrated palliative care in an equitable manner in order to address the needs of patients in the context of universal health coverage;

Recognizing the need for adequate funding mechanisms for palliative care programmes, including for medicines and medical products, especially in developing countries;

Welcoming the inclusion of palliative care actions and indicators in the WHO comprehensive global monitoring framework for the prevention and control of noncommunicable diseases and in the global action plan for the prevention and control of noncommunicable diseases 2013–2020;

Noting with appreciation the inclusion of medicines needed for pain and symptom control in palliative care settings in the 18th WHO Model List of Essential Medicines and the 4th WHO Model List of Essential Medicines for Children, and commending the efforts of WHO collaborating centres on pain and palliative care to improve access to palliative care;

Noting with appreciation the efforts of nongovernmental organizations and civil society in continuing to highlight the importance of palliative care, including adequate availability and appropriate use of internationally controlled substances for medical and scientific purposes, as set out in the United Nations international drug control conventions;

Recognizing the limited availability of palliative care services in much of the world and the great avoidable suffering for millions of patients and their families, and emphasizing the need to create or strengthen, as appropriate, health systems that include palliative care as an integral component of the treatment of people within the continuum of care,

1. URGES Member States:⁵

1. to develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes;
2. to ensure adequate domestic funding and allocation of human resources, as appropriate, for palliative care initiatives, including development and implementation of palliative care policies, education and training, and quality improvement initiatives, and supporting the availability and appropriate use of essential medicines, including controlled medicines for symptom management;
3. to provide basic support, including through multisectoral partnerships, to families, community volunteers and other individuals acting as caregivers, under the supervision of trained professionals, as appropriate;
4. to aim to include palliative care as an integral component of the ongoing education and training offered to care providers, in accordance with their roles and responsibilities, according to the following principles:
 - (a) basic training and continuing education on palliative care should be integrated as a routine element of all undergraduate medical and nursing professional education, and as part of in-service training of caregivers at the primary care level, including health care workers, caregivers addressing patients' spiritual needs and social workers;
 - (b) intermediate training should be offered to all health care workers who routinely work with patients with life-threatening illnesses, including those working in oncology, infectious diseases, paediatrics, geriatrics and internal medicine;
 - (c) specialist palliative care training should be available to prepare health care professionals who will manage integrated care for patients with more than routine symptom management needs;
5. to assess domestic palliative care needs, including pain management medication requirements, and promote collaborative action to ensure adequate supply of essential medicines in palliative care, avoiding shortages;
6. to review and, where appropriate, revise national and local legislation and policies for controlled medicines, with reference to WHO policy guidance,⁶ on improving access to and rational use of pain management medicines, in line with the United Nations international drug control conventions;
7. to update, as appropriate, national essential medicines lists in the light of the recent addition of sections on pain and palliative care medicines to the WHO Model List of Essential Medicines and the WHO Model List of Essential Medicines for Children;
8. to foster partnerships between governments and civil society, including patients' organizations, to support, as appropriate, the provision of services for patients requiring palliative care;
9. to implement and monitor palliative care actions included in WHO's global action plan for the prevention and control of noncommunicable diseases 2013–2020;

⁵ And, where applicable, regional economic integration organizations.

⁶ Ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines. Geneva: World Health Organization; 2011.

2. REQUESTS the Director-General:

1. to ensure that palliative care is an integral component of all relevant global disease control and health system plans, including those relating to noncommunicable diseases and universal health coverage, as well as being included in country and regional cooperation plans;
2. to update or develop, as appropriate, evidence-based guidelines and tools on palliation, including pain management options, in adults and children, including the development of WHO guidelines for the pharmacological treatment of pain, and ensure their adequate dissemination;
3. to develop and strengthen, where appropriate, evidence-based guidelines on the integration of palliative care into national health systems, across disease groups and levels of care, that adequately address ethical issues related to the provision of comprehensive palliative care, such as equitable access, person-centred and respectful care, and community involvement, and to inform education in pain and symptom management and psychosocial support;
4. to continue, through WHO's Access to Controlled Medicines Programme, to support Member States in reviewing and improving national legislation and policies with the objective of ensuring balance between the prevention of misuse, diversion and trafficking of controlled substances and appropriate access to controlled medicines, in line with the United Nations international drug control conventions;
5. to explore ways to increase the availability and accessibility of medicines used in palliative care through consultation with Member States and relevant networks and civil society, as well as other international stakeholders, as appropriate;
6. to work with the International Narcotics Control Board, the United Nations Office on Drugs and Crime, health ministries and other relevant authorities in order to promote the availability and balanced control of controlled medicines for pain and symptom management;
7. to further cooperate with the International Narcotics Control Board to support Member States in establishing accurate estimates in order to enable the availability of medicines for pain relief and palliative care, including through better implementation of the guidance on estimating requirements for substances under international control;⁷
8. to collaborate with UNICEF and other relevant partners in the promotion and implementation of palliative care for children;
9. to monitor the global situation of palliative care, evaluating the progress made in different initiatives and programmes in collaboration with Member States and international partners;
10. to work with Member States to encourage adequate funding and improved cooperation for palliative care programmes and research initiatives, in particular in resource-poor countries, in line with the Programme budget 2014–2015, which addresses palliative care;
11. to encourage research on models of palliative care that are effective in low- and middle-income countries, taking into consideration good practices;
12. to report back to the Sixty-ninth World Health Assembly in 2016 on progress in the implementation of this resolution.

Ninth plenary meeting, 24 May 2014 A67/VR/9

⁷ International Narcotics Control Board, World Health Organization. Guide on estimating requirements for substances under international control. New York: United Nations; 2012.



**World Health
Organization**

**World Health Organization
20, Avenue Appia
1211 Geneva 27
Switzerland**

**Tel.: +41 22 791 21 11
Fax: +41 22 791 31 11**

www.who.int

ISBN 978 92 4 156541 7

