A Public Health Approach to Integrate Palliative Care into a Country’s Health-Care System: Guidance as Provided by the WHO

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Abstract

Many people across the globe are in need of quality palliative care (PC), of which a majority live in low- and middle-income countries. However, many still see their needs unmet. It is estimated that only 14% of people in need of PC actually receive it. To improve access to PC as a core component of health systems, the WHO developed evidence-based tools on how to integrate PC into national health systems, across disease groups and levels of care. The current chapter provides an overview of this WHO Public Health Approach to Palliative Care, and discusses the seven components that were set out as a practical guidance for policy makers and program managers at national or subnational level to plan and implement PC services integrated into existing healthcare services. The components discussed are: (1) the development of appropriate PC policies, (2) the scaling up and integration of PC into the healthcare system, (3) the improvement of pain relief medicines access, (4) the strengthening of human resources for PC, (5) the establishment of palliative care services, (6) the setting of standards for evaluating PC services, and (7) the costing of PC services.

1 The Need for Palliative Care Globally

Every year, an estimated 20 million people globally are in need of palliative care in the last year of their life, with even more requiring palliative care in their preceding years (Connor and Bermedo 2014). 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. For these children, the evidence of models and outcomes of care is very scarce (Harding et al. 2014a). In 2014, it was estimated that only 14% of people needing palliative care at the end of life actually receive it. An analysis of global palliative care provision found that 33% of countries had no known activity (Connor and Bermedo 2014). In recent years the field of global health has begun to address the underdeveloped field of palliative care, with growing evidence of need, models, and outcomes that are appropriate for local health systems (Harding and Higginson 2014).

With other organizations, the WHO sees access to palliative care as a fundamental right. 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. 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. This has been further strengthened by the WHO universal health coverage (UHC) policy which “means that all people have access to the health services they need (prevention, promotion, treatment, rehabilitation and palliative care) without the risk of financial hardship when paying for them” (World Health Organization 2018a). The current chapter provides an overview of the approach and practical guidance suggested by the WHO for policy-makers or program managers at national or subnational level to plan and implement palliative care services, integrated into existing health-care services. It is a condensed version of the WHO document “Planning and Implementing Palliative Care Services: A Guide for Programme Managers” (World Health Organization 2016). In proposing the approaches, the WHO has paid specific attention to feasibility for low- and middle-income settings.
2 Definitions

The World Health Organization has defined palliative care as 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 (World Health Organization 2018b). 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.

Primary palliative care refers to the core elements of palliative care (e.g., aligning treatment with a patient’s preferences, basic symptom management) that are provided by all physicians and health-care workers caring for chronically or terminally ill patients.

Specialist or specialized palliative care refers to palliative care provided by health-care professionals or teams that mostly care for chronically or terminally ill patients, are specialized in addressing more complex palliative care needs (e.g., negotiating a difficult family meeting, addressing hidden existential distress, and managing refractory symptoms), and have received specific training for these skills (Quill and Abernethy 2013).

3 Core Aspects of the WHO Public Health Approach for Palliative Care

What constitutes a comprehensive public health strategy?

The published strategy builds on the WHO Public Health Strategy pioneered in the 1990s (Stjernswärd et al. 2007). The strategy assumes a responsibility for national health systems to include palliative care in the continuum of care for people with serious chronic, life-limiting health problems, linking it to prevention, early detection, and treatment programs. A good palliative care system is one that is integrated into primary health care, community- and home-based care, but also into informal care, such as care provided by family and community volunteers. Integrated palliative care implies that specialist palliative care is just one component of palliative care service delivery. All health-care providers are to be trained in pain management and the needs of patients with life-threatening illness.

A comprehensive approach to strengthening palliative care requires addressing seven essential components:

1. The development of appropriate (national) palliative care policies
2. Scaling up and integration of palliative care into the health-care system
3. Improving access to medicines for pain relief (especially oral morphine) and to palliative care
4. Strengthening human resources for palliative care (i.e., education of policymakers, health-care workers, and the public)
5. Establishing palliative care services in accordance with the principles of universal health coverage
6. Setting standards and evaluating palliative care services
7. Costing palliative care services

All these components of the comprehensive approach are addressed below, with a more detailed elaboration on how to develop policies, establish services, and integrate palliative care into the health-care system.
Increase public awareness and empower key stakeholders

Document and share experiences

Review and evaluate, including benchmarking with experiences of other countries

Support and guide the implementation of services and training

Identify training and awareness-raising needs

Policy-makers | Health professionals and organizations | General population, carers, families

Support policy and legislation development

Develop a comprehensive national palliative care strategy (either stand-alone or integrated into other health strategies).

Review and revise policies to improve medicines availability and access

Legislative changes if necessary to support equitable access to controlled medicines

Clarify/establish local governance arrangements for palliative care

e.g. creating a national advisory committee for palliative care

Convene a national policy dialogue on palliative care with all stakeholders

Identify key stakeholders, leaders and organizations

Convene a national policy dialogue on palliative care with all stakeholders

Support apolicy and legislation development

Convene a national policy dialogue on palliative care with all stakeholders

Identify training and awareness-raising needs

Policy-makers | Health professionals and organizations | General population, carers, families

Support and guide the implementation of services and training

Review and evaluate, including benchmarking with experiences of other countries

Document and share experiences

Increase public awareness and empower key stakeholders

Fig. 1 Example of a stepwise process for developing palliative care strategies and programs
3.1 Component 1: Developing a Palliative Care Policy (Including Assessment of the Current Situation)

A first essential element of a comprehensive approach is to develop appropriate palliative care policies. 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 remain the same.

A national palliative care policy should seek to address the following elements:

- Service delivery through a continuum of care (through primary health care, community- and home-based care, and specialist palliative care services)
- Strategies to provide palliative care to all patients in need (e.g., noncommunicable diseases, HIV/AIDS, tuberculosis, older adults, children) and with attention to reaching vulnerable groups (e.g., poor, ethnic minorities, people living in institutions)
- Defining the government–civil society interface in establishment and delivery of palliative care
- Universal coverage of palliative care, through financing and insurance mechanisms
- Ensuring support for carers and families (social protection)
- Identification and allocation of resources for palliative care
- Development of national standards and mechanisms to improve quality of palliative care (see also component 6)
- Setting up a monitoring of palliative care need, access, and quality (e.g., by identifying indicators), at national and subnational levels (see also component 6)

When planning the policy, it is important to involve partners who can provide helpful input, assistance, and maybe funding:

- The Ministry of Health, but other ministries may also become involved.
- Health workers and their professional bodies.
- Social workers (or their organizations).
- NGOs.
- Academic institutions.
- National ethics committees.
- 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).

Development of a palliative care policy takes a step-by-step approach, in order to make sure that all concerns are taken into account and that there is sufficient support and a firm legal basis. Figure 1 provides an example of what this stepwise process is likely to involve.

Ideally, developing a palliative care policy should begin with an assessment of the current situation and a description of the population in need for palliative care. A needs assessment survey can be adapted to the different levels of existing information in countries. 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 aging strategies)?
- **Availability and coverage of existing palliative care services:** Where are palliative care services currently delivered (e.g., types of patients, 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 (World Health Organization 2015a) and children (World Health Organization...
2015b) 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? However, evaluation of innovative programs to roll out opioids such as the Ugandan program (Merriman and Harding 2010) found that following enactment of policies to enable opioid availability, supply problems persisted due to unwillingness to prescribe (Logie and Harding 2005).

• **Quantitative estimate of the need for palliative care:** Several approaches to determining the number of persons needing palliative care can be used (see Box 1 below). The health workforce and the number of inpatient beds/services needed to meet the need also need to be estimated.

• **Qualitative assessment,** e.g., interviews with patients and their families to identify any unmet needs for care as well as strengths, weaknesses, and barriers of the current system. This allows evaluating the capacity of key services (e.g., primary care, hospitals) for providing palliative care and identifying settings that can help in implementing actions decided upon.

**Box 1 Useful Methods for Calculating Population Need for Palliative Care**

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, and several approaches have been proposed (Higginson et al. 2007; Murtagh et al. 2014):

- **Estimates based on disease prevalence:** The 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 (Connor and Bermejo 2014). 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 14 middle- to high-income countries estimate that 38–74% of those who die need palliative care (Morin et al. 2017).

**3.2 Component 2: Developing a Strategy to Gradually Scale Up and Integrate Palliative Care into the Health-Care System**

Based on the needs assessment, a plan will be developed for scaling up coverage of palliative care services in the population. The WHO advises to plot a timeline that projects the growth in what percentage of need is being met every year. The plan clearly identifies where the need is greatest geographically and where resources already exist.

Again, there is not one single approach to expanding coverage: expanding from population centers to rural areas, from regional centers to other centers, from private to public providers, and from states or districts to national strategies are all possible scaling up strategies.

In the absence of any system of palliative care, a stepwise approach to introducing a palliative care program is advised covering policy actions, health-care financing, service delivery, workforce development, access to medicines, and information and research.

These strategies must take into account the WHO building blocks of health systems, which in palliative care take into account (to ensure services are part of the mainstream health system), workforce (training in palliative care),
governance (to ensure that opioid restrictions are well adhered to), information systems (to understand outcomes of care), and access to essential medicines (which is a common problem at all stages of the WHO pain ladder) (Harding et al. 2014b).

### 3.3 Component 3: Improving Access to Medicines for Pain Relief and Palliative Care

The national medicine policy needs to use the concept of essential medicines. This will help to

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**Table 1** WHO model list of essential medicines for palliative care (extract from the detailed list, limited to only the drug types; for details see the published WHO strategy document World Health Organization 2015b)

<table>
<thead>
<tr>
<th>Non-opioids and non-steroidal anti-inflammatory medicines (NSAIMs)</th>
<th>General</th>
<th>Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acetylsalicylic acid</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Ibuprofen</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Paracetamol</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Opioid analgesics</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Codeine</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Morphine (alternatives limited to hydromorphone and oxycodone)</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Medicines for other common symptoms in palliative care</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Amitriptyline</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Cyclizine</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Dexamethasone</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Diazepam</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Docusate sodium</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Fluoxetine</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Haloperidol</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Hyoscine butylbromide</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Hyoscine hydrobromide</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Lactulose</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Loperamide</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Metoclopramide</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Midazolam</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Ondansetron</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Senna</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

Source: Adapted from World Health Organization 2015b

**Fig. 2** Where palliative care is provided. (Source: adapted from Kumar and Numpeli 2005 and Government of India 2014)
set priorities for the health-care system, promote
equity and sustainability in the pharmaceutical
sector, and provide a framework for identifying
national goals and commitments.

To determine what are the essential medicines,
the WHO has published model lists of essential
medicines for palliative care in adults and in chil-

dren (see Table 1). They include medicines for pain
relief and for the most common symptoms in pal-
liative care. From these model lists, countries,
regions, or districts can propose a list of essential
medicines that is in line with their own needs (cfr.
component 1) and resources. When an essential
medicine list is finalized, it should be made widely
available. The intended use, legitimacy, and
authority of the list should be clear to all.

A next step is access to the medicines for those
in need. The vast majority of patients with pallia-
tive care needs do not have access to essential
medicines. Countries should, therefore, imple-
ment strategic plans to ensure access to many
medications, including internationally controlled
medications. The WHO has published guidelines
to help countries to develop and implement
a policy to make these medicines available
to all those who need it (World Health Organiza-
tion 2015a).

Continuing barriers to opioid availability for
medical use in, for instance, sub-Saharan Africa
include overly restrictive controlled medicines’
laws; use of stigmatizing language in key docu-
ments; inaccurate actual opioid consumption
estimation practices; knowledge gaps in the dis-
tribution, storage, and prescription of opioids;
critical shortage of prescribers; and high out-of-
pocket financial expenditures for patients against
a backdrop of high levels of poverty (Namisango
et al. 2017).

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Table 2  Trained health workers are able to perform palliative care tasks safely and effectively

<table>
<thead>
<tr>
<th>Pain management</th>
<th>Medical doctor</th>
<th>Non-physician clinician</th>
<th>Nurse</th>
<th>Community health worker</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conduct pain assessment(s)</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Treat mild, moderate, and severe pain using chronic pain management guidelines, including oral morphine</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Teach the patient and caregiver how to give pain medicine, including oral morphine</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Prevent, recognize, and treat the side effects of pain medications</td>
<td>x</td>
<td>x</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Advise on non-pharmacological methods of controlling pain</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Treat extreme, nonresponsive pain appropriately, including through the use of steroids where indicated</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Symptom management</th>
<th>Medical doctor</th>
<th>Non-physician clinician</th>
<th>Nurse</th>
<th>Community health worker</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manage other common symptoms (weight loss, nausea, fever, diarrhea, trouble sleeping, anxiety, etc.)</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Psychosocial support and end-of-life care</th>
<th>Medical doctor</th>
<th>Non-physician clinician</th>
<th>Nurse</th>
<th>Community health worker</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counseling, psychosocial and spiritual support</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Support for the patient at end of life</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Support for caregivers, family members, and children</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Supervision</th>
<th>Medical doctor</th>
<th>Non-physician clinician</th>
<th>Nurse</th>
<th>Community health worker</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supervise non-physician clinicians, nurses, and community health workers in above activities</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supervise nurses and community health workers in above activities</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supervise community health workers in above activities</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: WHO guidelines on task shifting (Task shifting: rational redistribution of tasks among health workforce teams 2008)
3.4 Component 4: Strengthening Human Resources for Palliative Care

The fourth component of the comprehensive strategy is concerned with training and education. Increasing the skills and awareness of palliative care among the health workforce is critical to improving access to and quality of palliative care. While specialist training in palliative care is important, a basic training in palliative care principles and good pain management should also be implemented for all health professionals by integrating it into their training. Because most practicing health professionals have received limited or no training in palliative care in their preservice training, strategies should also include in-service training.

Because much of the care for dying persons and those with advanced chronic conditions with palliative care needs will occur in the community and in various health-care settings (see Fig. 2) and will include health professionals who are generalists and not specialist practitioners, palliative care training in primary care and community care is essential. This training should include a focus on increasing the ability for primary care professionals to identify people potentially in need of palliative care.

The WHO strategies to strengthen human resources for palliative care assume that different health workers are able to perform palliative care tasks safely and effectively (see Table 2). The level of skills, and hence the level of training required for different types of health providers as suggested by the WHO, can be as follows:

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

Ensuring that core tasks and skills are built requires training to various health-care professionals and to informal carers:

- **All palliative care providers** have a responsibility for communication and smooth information transfer and need training in management of both physical and emotional problems, as well as in communication.
- **Community health workers and other community workers dedicated to palliative care** have a range of tasks related to assisting other members of the palliative care team as well as giving guidance and support to the patient and family members, e.g., including developing an individualized home-based care plan for each patient, routinely conducting comprehensive assessments of palliative care needs, answering questions and providing information, providing treatments and instructing the family in this task, training the patient and family in care and comfort-giving procedures, and checking that they are being carried out.
- **Staff nurses at primary, secondary, and tertiary care facilities** have a range of supervisory, coordination, and teaching roles, provide specialist nursing procedures such as care of lymphedema and stoma, and ensure documentation of home care.
- **Physicians and authorized prescribers at primary and secondary care facilities** are able to provide management of severe symptoms, prescribe medicines, and train and advise staff, patients, and families.
- **Providers at tertiary care level (including the hospital)** are skilled to provide inpatient care for patients with intractable pain and other symptoms, including, e.g., radiotherapy and other treatments available only at this level. They are able to maintain patients pain-free.
- **Family** has to understand the nature and prognosis of the disease and recommended treatment. It is the health worker’s role to ensure this, to involve the family in joint decision-making, and to guide the family in best practices of palliative care. Both family and other informal carers can be taught to provide home-based care.
Finally, an effort should also be made in educating the public and policy-makers to make sure that they understand what it is, who can use it, and how to benefit from it. This will increase the chance that people who need palliative care will ask for it and access it. One strategy includes involvement of the media to disseminate information of educational value while avoiding sensationalism.

3.5 Component 5: Establishing Palliative Care Services

Establishing and implementing palliative care services is a next core component of the comprehensive strategy. Before establishing palliative care services, it is good to determine the minimum tasks of palliative care services.

3.5.1 Minimum Tasks of Services

Palliative care services can be provided in any health-care setting and also in patients’ homes and should 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.
- Care for families and caregivers.
- Clarify the patient’s values and determine culturally appropriate goals of care.

The essential practices for palliative care include physical care, psychological/emotional/spiritual care, care planning and coordination, and communication.

(i) Identifying who could benefit from palliative care and assessing and reassessing needs

First, a system of timely identification of palliative care needs to become a feature of all health-care settings. Pain that disrupts daily life activities, breathlessness at rest, or functional decline can, for instance, be clinical indicators that result in further palliative care assessment. A multidimensional assessment of physical, emotional, social, spiritual, and cultural needs, values, and preferences of both patients and families is then needed. This can be done with validated short screening instruments such as the Edmonton Symptom Assessment Scale (ESAS) and the Palliative Outcome Score (POS) as adapted by the African Palliative Care Association (African POS). As needs can change, assessments should be repeated regularly throughout the course of the disease.

(ii) Relieving pain and other symptoms

Palliative care services need to treat pain and other symptoms experienced by adults and children and should aim to maintain or improve the quality of life and optimize physical and cognitive function throughout the course of illness. This requires (1) treatment of the underlying causes of symptoms (respecting a balance between expected benefit and burden from the intervention), pharmacological (see list of essential medicines above) and/or non-pharmacological (e.g., mouth or skin care, lymphatic drainage, physiotherapy) treatment of any symptom, and attention to each patient’s values and needs. The patient and/or family caregivers, as appropriate, should be involved in decision-making about the treatment plan. A key task for low- and middle-income countries is to ensure that the relief of pain and symptoms is evidenced – it is not enough to develop and deliver services; their outcomes must be proven at the individual and facility level. This has been successfully achieved in sub-Saharan Africa (Defilippi and Downing 2013).

(iii) Addressing spiritual, psychological, and social needs

Palliative care services pay attention to the psychological, emotional, social, and financial well-being of patients and family members.
Bereavement support is also a core component of palliative care. In low- and middle-income countries, spiritual concerns may be the greatest contributing factor to quality of life in advanced illness (Selman et al. 2011), and caring for a family member can push poor families into greater poverty (Streid et al. 2014).

Another core task for palliative care services is to support family caregivers. This includes assessing their needs as they too often have unmet needs and problems including, for instance, physical and psychological morbidity and social isolation.

### 3.5.2 Setting Up Services

Palliative care services can be established in a number of different ways. There is no single best starting point, and the approaches suggested by the WHO need to be seen as complementary and depending on capacity and context and taking into account the country’s social and health system context. However, in all cases, it is important to assess which services are already providing palliative care, including in the non-governmental sector, and to build on these existing resources.

Depending on the local situation, a country may, for instance, 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

---

**Table 3** Categories of palliative care services

<table>
<thead>
<tr>
<th>Category</th>
<th>Palliative care approach</th>
<th>Specialist support for general palliative care</th>
<th>Specialist palliative care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute care</td>
<td>Hospital</td>
<td>Volunteer hospice service</td>
<td>Hospital palliative care support team</td>
</tr>
<tr>
<td>Long-term care</td>
<td>Nursing home, residential home</td>
<td>Home palliative care teams</td>
<td>Inpatient hospice</td>
</tr>
<tr>
<td>Home care</td>
<td>General practitioners, community nursing teams</td>
<td>Home palliative care teams</td>
<td>Home palliative care teams, day-care center</td>
</tr>
</tbody>
</table>

Source: EAPC (Radbruch et al. 2009) adapted from (Nemeth and Rottenhofer 2004)

**Table 4** Minimum requirements for a home-based palliative care service

<table>
<thead>
<tr>
<th>Basic infrastructure</th>
<th>Central meeting point</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Storage facilities (including for controlled drugs)</td>
</tr>
<tr>
<td></td>
<td>Transport for team and home-care kit</td>
</tr>
<tr>
<td></td>
<td>Method of communication (e.g., mobile telephone)</td>
</tr>
<tr>
<td>Personnel</td>
<td>Doctor</td>
</tr>
<tr>
<td></td>
<td>Nurse</td>
</tr>
<tr>
<td></td>
<td>Volunteers or community health workers</td>
</tr>
<tr>
<td>Home-care kit</td>
<td>Medications (including morphine)</td>
</tr>
<tr>
<td></td>
<td>Equipment</td>
</tr>
<tr>
<td></td>
<td>Documentation</td>
</tr>
<tr>
<td>Finance</td>
<td>Salaries for team members</td>
</tr>
<tr>
<td></td>
<td>Transportation/vehicle hire</td>
</tr>
<tr>
<td></td>
<td>Rental for room/storage facility</td>
</tr>
<tr>
<td></td>
<td>Communication and printing</td>
</tr>
<tr>
<td></td>
<td>Medication and equipment costs</td>
</tr>
</tbody>
</table>
### Table 5  Key human resources required for a community-based palliative care service

<table>
<thead>
<tr>
<th>Tasks</th>
<th>Suggested minimum training</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Community volunteers/health workers</strong></td>
<td></td>
</tr>
<tr>
<td>Untrained sensitized volunteers</td>
<td>Sensitization course (approx. 2 h) covering basics of palliative care, home care, communication</td>
</tr>
<tr>
<td><strong>Trained volunteers</strong></td>
<td>Basic palliative care course for volunteers (approx. 16 h 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</td>
</tr>
<tr>
<td><strong>Community health workers</strong></td>
<td>Basic palliative care course for community health workers (approx. 3–6 h) covering communication skills, emotional support, patient assessment, reporting to higher level</td>
</tr>
<tr>
<td><strong>Health-care professionals</strong></td>
<td></td>
</tr>
<tr>
<td>Nurses</td>
<td>Staff nurses with mid-level training in palliative care supported by nurses or auxiliary nurses with basic foundation training in palliative care (3 months/400 h)</td>
</tr>
<tr>
<td>Doctors</td>
<td>Physicians with training in palliative care</td>
</tr>
</tbody>
</table>

Source: Adapted from (Guidelines for developing palliative care services 2009)

### Table 6  Minimum staffing required for a hospital-based palliative care service

<table>
<thead>
<tr>
<th>Role</th>
<th>Capacity/skills required</th>
<th>Position</th>
<th>Availability</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Doctor (required)</strong></td>
<td>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</td>
<td>Regular staff</td>
<td>Full-time or part-time, depending on workload</td>
</tr>
<tr>
<td><strong>Nurses (required)</strong></td>
<td>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</td>
<td>Regular staff</td>
<td>Full-time</td>
</tr>
<tr>
<td>Psychologists or counselors (recommended)</td>
<td>Team member Trained counselor with orientation to special needs in palliative care</td>
<td>Regular/visiting</td>
<td>Full-time</td>
</tr>
<tr>
<td>Auxiliary nurses/palliative nursing aides</td>
<td>Team member Assisting staff nurses in clinical work</td>
<td>Regular staff</td>
<td>Full-time</td>
</tr>
<tr>
<td><strong>Pharmacist</strong></td>
<td>Team member</td>
<td>Regular staff</td>
<td>Part-time</td>
</tr>
<tr>
<td>Social workers (recommended)</td>
<td>Team member Trained social worker with orientation to special needs in palliative care</td>
<td>Regular/visiting</td>
<td>Full-time/part-time</td>
</tr>
<tr>
<td>Volunteers (recommended)</td>
<td>Additional support to the team Specific to their role</td>
<td>Visiting</td>
<td>Part-time</td>
</tr>
</tbody>
</table>

Source: Adapted from (Guidelines for developing palliative care services 2009)
5. Setting up a stand-alone palliative care center or hospice
6. Taking an integrated approach in a district

Table 3 provides an overview of different categories of palliative care services. The WHO manual provides a guideline for establishing each of these services.

Setting Up a Palliative Home-Care Service or Integrating Palliative Home Care into Existing Home-Care Services

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. A basic home-based palliative care service can be set up quite simple. The minimum essential requirements for a home-care service are listed in Table 4.

Establishing Palliative Care in a Community Setting

Community-based palliative care services are those offered at a community health center or that are run with community participation. 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. Typically these services are provided by both health-care professionals and community health workers/volunteers (Table 5).

Integrating Palliative Care Services into a Regional or General Hospital

In sub-Saharan Africa, 38–46% of patients at a national referral hospital were found to have life-limiting illness (Lewington et al. 2012; Jacinto et al. 2015). All hospitals involved in the treatment of patients with cancer should have a palliative care service, and this can enable improvements in costs and outcomes for patients and families in low- and middle-income countries (Desrosiers et al. 2014). 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. 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 (Table 6).

Establishing a Palliative Care Service for Children, Including Neonates

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 (Table 7).

Setting Up a Stand-Alone Palliative Care Center or Hospice

A stand-alone palliative care center or hospice may have several roles and functions. When planning to set up such a center, 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. 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
Table 7  Ideal health workforce for a pediatric palliative care service

<table>
<thead>
<tr>
<th>Role</th>
<th>Competencies</th>
<th>Position</th>
<th>Availability</th>
</tr>
</thead>
</table>
| Doctor with pediatric knowledge or pediatrician    | Team member and as consultant/attending physician  
  - 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 pediatric experience and knowledge | Team members/ coordinator  
  - 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  
  - 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  
  - 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 counselor or child psychologist | Full- or part-time |
| Teacher                                             | Team member  
  - 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           |

(continued)
Table 7 (continued)

<table>
<thead>
<tr>
<th>Role</th>
<th>Competencies</th>
<th>Position</th>
<th>Availability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chaplain/spiritual care worker</td>
<td>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</td>
<td>Ideally regular staff; often a volunteer</td>
<td>Part-time</td>
</tr>
<tr>
<td>Care workers/ community caregivers for home care and day care</td>
<td>30-day course on all aspects of palliative care, pediatric care, childhood development and play, and children’s rights</td>
<td>Regular staff</td>
<td>Full-time</td>
</tr>
<tr>
<td>Occupational therapist/ physiotherapist/ nutritional therapist/speech, play, music therapists</td>
<td>Introduction to pediatric palliative care; 5-day course</td>
<td>Ad hoc consultants or volunteers</td>
<td>Part-time</td>
</tr>
<tr>
<td>Child psychologist</td>
<td>Introduction to pediatric palliative care; 5-day course</td>
<td>Ad hoc consultant</td>
<td>Part-time</td>
</tr>
<tr>
<td>Neonatologist</td>
<td>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</td>
<td>Consultant/advisor</td>
<td>Part-time</td>
</tr>
</tbody>
</table>

Source: WHO Planning and implementing palliative care services (World Health Organization 2016)

food, utilities, mobile telephone and travel subsidy, and the lending of equipment (Table 8).

**Taking an Integrated Approach in a Region**

There is no one-size-fits-all public health approach to integrating palliative care into different levels of care or types of services as much depends on services already existing. Nevertheless, there are a number of general principles for success:

- The approach must acknowledge the resources and structures that a health system in an area has at its disposal and respect its values.
- The approach must be dynamic and responsive to the needs of the area.
- It 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 to be seen as a medical approach that belongs only to health providers; it is an approach everyone needs to embrace for effective working in a health-care area.

Palliative care integration requires different steps: invitation, initiation, innovation, and implementation.
<table>
<thead>
<tr>
<th>Role or function</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospice home-care service</td>
<td>Can be a very cost-effective service, serving the most patients with the least resources</td>
<td>Less convenient for teaching and training except on a one-to-one basis</td>
</tr>
<tr>
<td></td>
<td>Needs little space – only office space with workstations and storage space for medications and equipment</td>
<td>Difficult for donors to see the service and how their donations make a difference</td>
</tr>
<tr>
<td></td>
<td>Most patients prefer to stay in their own homes; many may not be fit to travel to seek health care</td>
<td>Volunteers do not have a center to meet, as they are scattered, working with patients at their homes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>May be difficult for staff to travel to visit patients in challenging localities or at night</td>
</tr>
<tr>
<td>Inpatient hospice service</td>
<td>The environment can be controlled and adjusted to provide hospitable, respectful, and individualized care</td>
<td>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</td>
</tr>
<tr>
<td></td>
<td>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</td>
<td>Patients may prefer to be cared for or to die in their own homes and may not wish to be at a hospice</td>
</tr>
<tr>
<td></td>
<td>With both patients and staff present in the same place, training and education is facilitated</td>
<td>Because of distance, cost, or convenience, it may not be practical for families to visit often</td>
</tr>
<tr>
<td></td>
<td>Donors have a clear view of the effect of their donations</td>
<td>If many deaths occur at a hospice, patients may become unsettled. The hospice may be labeled as a death house</td>
</tr>
<tr>
<td></td>
<td>Volunteers may congregate and have a better sense of belonging</td>
<td></td>
</tr>
<tr>
<td></td>
<td>It is easier to do community outreach as there is a place where people can meet</td>
<td></td>
</tr>
<tr>
<td>Hospice day-care service</td>
<td>Patients can stay at their own homes and still receive specialized care at a hospice</td>
<td>Transportation often has to be provided unless the family can bring the patient</td>
</tr>
<tr>
<td></td>
<td>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</td>
<td>Specialized transport (e.g., ambulances with wheelchair facilities or stair crawls) may be needed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Travel is constrained by travel time as much as by distance</td>
</tr>
<tr>
<td></td>
<td>A good place to deploy volunteers and engage the community</td>
<td>Patients may be exhausted by the time they reach the day-care center</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Group activities may not suit all patients</td>
</tr>
<tr>
<td>Education center</td>
<td>Patients are concentrated in one location, providing enough clinical material for teaching</td>
<td>The patient’s and family’s privacy must be safeguarded</td>
</tr>
<tr>
<td></td>
<td>Groups of trainees may be accommodated if proper facilities are available</td>
<td>Requirement for clinical staff to do teaching necessitates a reduction in their workload</td>
</tr>
<tr>
<td></td>
<td>Requirement for clinical staff to do teaching will drive their own learning and raise standards</td>
<td>Having positions for trained teaching staff involves more costs</td>
</tr>
<tr>
<td>Research center</td>
<td>An academic culture is good for attracting staff of high caliber</td>
<td>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</td>
</tr>
</tbody>
</table>

Source: WHO Planning and implementing palliative care services (World Health Organization 2016)
**Step 1: Invitation**
This step requires:

1. Engaging political leadership. Regional health-care bodies are in most cases government entities, structured as part of local and national government. Therefore engaging with the political leadership of a region is an important process.
2. Advocating about palliative care: sustained advocacy about palliative care that is open and explicit, non-threatening and positive.
3. Providing information about need: evidence of need will be required, i.e., informed data that illustrate the local burden of disease, end-of-life care requirements, and inpatient, outpatient, discharge, and follow-up processes. Political leadership needs to understand the current and foreseeable problems if need is not addressed. Those who can best inform leaders of the need are the staff of hospitals, health centers 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. 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 (see section on policy development).

**Step 2: Initiation**
Once an invitation (however broad or wide) to develop an integrated approach has been established, initiation of the approach can begin. This requires:

1. Wide stakeholder engagement, including with isolated centers of care. 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 centers and the challenges they face allows them to become stakeholders in the larger conversation.
2. Making a business case for developing an integrated approach to palliative care by showing how the integrated approach will demonstrate effectiveness and efficiency. Gaps and barriers in services must also be identified (e.g., beliefs about death, views on dying, geographical distance).

**Step 3: Innovation**
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.

**Step 4: Implementation**
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 regional 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.
3.6 Component 6: Setting Standards and Evaluating Palliative Care Services

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. Services can be compared with similar initiatives in other locations, which will provide the technical basis for political decisions about the development of the service, including the provision of further funding and support. Both the African Palliative Care Association and the Hospice Palliative Care Association of South Africa have developed standards that have been widely taken up and offer useful templates (African Palliative Care Association 2018).

Evaluation of national/regional programs allows monitoring to progress toward the predefined program goals and the targets of different phases, enables comparisons between different population groups, and provides an opportunity for continuous quality improvement interventions in critical areas. Populations with disproportionately high risk factors can be given specific attention.

3.7 Component 7: Costing Palliative Care Services

To cost palliative care services, both direct costs and indirect costs can be determined. The total annual budget, 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 needs to be presented. The highest costs are related to personnel costs, unlike in other health-care services in which the costs of treatments are higher.

The total costs can be compared with the expected sources of funding. Additionally it may be worthwhile comparing the costs to the possible reduction in health-care costs by the establishment of palliative care services. By reducing avoidable hospitalization, emergency department presentations, and unnecessary treatments, palliative care can save health-care resources and costs while providing a better quality of life (Smith et al. 2014).

4 Conclusion

The WHO has developed a comprehensive public health approach to integrate palliative care into a national health-care system that provides policy-makers or program managers at national or subnational level with practical guidance. The seven components of this approach need to be addressed: (1) developing a palliative care policy, (2) scaling up and integrating palliative care into the health-care system, (3) improving access to medicines for pain relief and palliative care, (4) training and education those who hold a stake in palliative care, (5) establishing and implementing palliative care services, (6) setting quality standards for palliative care services and evaluating these, and (7) costing the palliative care services.

The WHO insists that there is no one-size-fits-all approach. A country’s specific context needs to be acknowledged and respected. Countries may, for instance, differ in needs, prevailing views and values, availability of resources, basic health-care characteristics, and services already existing. Low- and middle-income countries have an even greater need to deliver cost-effective services that are developed to meet prevailing health conditions, fit within cultural preferences and practices, and are feasible within existing health systems. Therefore, the WHO palliative care public health strategy requires local evidence to inform development of services (Harding et al. 2013).

References


Guidelines for developing palliative care services. Hyderabad: MNJ Institute of Oncology & Regional Cancer Centre; 2009.


