

# WHY PALLIATIVE CARE IS AN ESSENTIAL FUNCTION OF PRIMARY HEALTH CARE





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# Introduction

World Health Assembly Resolution 67.19 states that universal access to palliative care – the prevention and relief of suffering due to serious or life-threatening health problems or their treatment – is an ethical imperative: “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 “palliative care is an ethical responsibility of health systems ...” (1). The Health Assembly also asserted that integration of palliative care into public health care systems is essential for achievement of Sustainable Development Goal (SDG) 3.8 (universal health coverage, UHC) and that this integration is especially important “at the primary care level”. How can this ethically imperative integration be achieved? What changes are needed? And what will it cost?









# What palliative care entails

WHO defines palliative care as the prevention and relief of suffering of adult and paediatric patients and their families facing the problems associated with life-threatening illness (2). These problems include physical, psychological, social and spiritual suffering of patients, and psychological, social and spiritual suffering of family members. Palliative care (3):

- entails early identification and impeccable assessment and treatment of these problems;
- enhances quality of life, promotes dignity and comfort, and may also positively influence the course of illness;
- provides accompaniment for the patient and family throughout the course of illness;
- should be integrated with and complement prevention, early diagnosis and treatment of serious or life-limiting health problems;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life;
- provides an alternative to disease-modifying and life-sustaining treatment of questionable value near the end of life, and assists with decision-making about use of life-sustaining treatment;
- is applicable to those living with long-term physical, psychological, social or spiritual sequelae of serious or life-threatening illnesses or of their treatment;
- accompanies and supports bereaved family members after the patient's death, if needed;
- seeks to mitigate the pathogenic effects of poverty on patients and families, and seeks to protect them from suffering financial hardship due to illness or disability;
- does not intentionally hasten death, but provides whatever treatment is necessary to achieve an adequate level of comfort for the patient in the context of the patient's values;
- should be applied by health care workers at all levels of health care systems, including primary care providers, generalists and specialists in many disciplines and with various levels of palliative care training and skill, from basic to intermediate to specialist;
- encourages active involvement by communities and community members;
- should be accessible at all levels of health care systems and in patients' homes; and
- improves continuity of care and strengthens health systems.

The specific types and severity of suffering vary by geopolitical situation, socioeconomic conditions and culture. People in low- and middle-income countries (LMICs) often endure less healthy social conditions. They also typically have less access to prevention, diagnosis and treatment of health problems, to social supports and to specialized services of many kinds, than people in high-income countries. Palliative care should never be considered a substitute for prevention, diagnosis and treatment of common causes of suffering and death such as cancer, drug resistant tuberculosis (TB), cardiovascular disease or mental illness, and palliative care workers have a responsibility to advocate for these interventions wherever they are not yet accessible (3). However, failure to integrate palliative care with disease prevention, diagnosis and treatment is indefensible. Planning and implementation of palliative care services must be based on assessment of the types and extent of inadequately prevented or relieved physical, psychological, social or spiritual suffering (4,5).

## Access to palliative care

Despite compelling evidence of a huge burden of remediable suffering, and of the effectiveness of palliative care to relieve suffering, palliative care is rarely accessible in LMICs (6). Inequality of access to palliative care is one of the largest disparities in global health care (4). Various barriers have impeded the development and accessibility of palliative care services. A major barrier is a misunderstanding of what constitutes palliative care; in particular, it is not always understood that palliative care is:

- not only for the dying, but for any patient suffering in association with serious or life-threatening health problems;
- not an *alternative* to disease prevention and treatment but should be integrated with them.

Additional barriers to the development and accessibility of palliative care include:

- lack of a national palliative care policy, a national palliative care strategic plan and national palliative care clinical guidelines in many countries;
- lack of basic, intermediate and specialist training programmes in palliative care;
- lack of staff positions in hospitals and primary care centres that include palliative care as an official responsibility, and that enable clinicians with appropriate training to be paid for practising palliative care;
- lack of insurance coverage for palliative home care; and
- excessive fear of opioid side-effects, addiction and diversion (opiophobia), resulting in excessively restrictive opioid prescribing regulations.

Throughout the world, but especially in LMICs, most people in need of palliative care are at home and cannot easily travel beyond their communities; also, most people prefer to die at home. Therefore, it is important that palliative care be accessible in the community and in patients' homes. Further, most suffering due to serious or life-threatening health problems can be relieved with inexpensive, safe and effective medicines and equipment prescribed by any primary care physician, clinical officer, assistant doctor or nurse practitioner with basic palliative care training (6,7). It is neither feasible nor necessary for most palliative care in LMICs to be provided by palliative care specialist physicians. Accordingly, the WHO framework on integrated, people-centred health services, adopted by the World Health Assembly in 2016, asserts that palliative care is an essential function of primary health care (PHC) (5).















## Overlapping principles of PHC<sup>1</sup> and palliative care

The inseparability of PHC and palliative care is evident from recent international documents on PHC (8,9,10). In 2009, World Health Assembly resolution WHA62.12 reaffirmed the principles of PHC – including equity, solidarity, social justice, universal access to services, multisectoral action, decentralization and community participation – as the basis for strengthening health systems (11). All of those principles of PHC are also principles of palliative care. This resolution also emphasized putting people at the centre of health care by implementing comprehensive PHC services – including health promotion, disease prevention, curative care and palliative care – coordinated with secondary and tertiary care to assure easy and rapid referral whenever necessary. PHC, like palliative care, benefits from the participation of civil society and the community in policy formulation and accountability mechanisms to ensure that the health system is socially acceptable, universally accessible and affordable, and scientifically sound (12). In addition, PHC and palliative care have in common an emphasis on providing continuity of care and solidarity (accompaniment), respecting patients' values, responding to social suffering, and paying attention not only to patients but also to their families (6,13).

<sup>1</sup> PHC is a whole-of-society approach to maximize the level and distribution of health and well-being by acting simultaneously on three components: primary care and essential public health functions as the core of integrated health services; multisectoral policy and action; and empowering people and communities. PHC is the most equitable, effective, and cost-effective way to enhance the health of populations.



# Integrating palliative care into PHC services

WHO recommends a stepwise approach to integrating palliative care into health services in general, and into primary care in particular, in a cost-effective manner, to reach all those in need (1, 14, 16).<sup>2</sup> This strategy includes:

- updating existing policies on palliative care and creating new ones where none exist;
- assuring safe accessibility of essential palliative medicines, including oral fast-acting morphine;
- initiating required training in palliative care for all clinicians who treat people with palliative care needs, including training in basic palliative care for all primary care workers (15);
- implementing palliative care services that are integrated into all health care systems at all levels, including palliative home care as part of primary care.

In settings where primary care is underdeveloped, primary care and palliative care can be developed and expanded at the same time. The same infrastructure and human resources that provide primary care both can and should provide basic palliative care; similarly, efforts to implement community-based palliative care both can and should strengthen primary care.

WHO recommends an essential package of palliative care for primary health care (EP PHC) that is designed to assist health care and primary care policy-makers, planners, implementers and managers to integrate palliative care into community-oriented primary care (16). The EP PHC is the minimum package that should be accessible in primary care clinics, and it is designed to address the palliative care needs of both adults and children. The package comprises:

- safe, effective, inexpensive, off-patent and widely available medicines;
- simple and inexpensive equipment;
- basic intersectoral social supports; and
- human resources needed to apply each element of the EP PHC effectively and safely.

Together, these elements can prevent and relieve suffering of all types – physical, psychological, social and spiritual – and thereby improve patient outcomes (16).

Morphine, in oral fast-acting and injectable preparations, is the most clinically important of the essential palliative care medicines (17). It must be accessible in the proper form and dose by any patient in the hospital or in the community with a clinical indication. All doctors who provide primary care should be adequately trained and legally empowered to prescribe oral and injectable morphine for inpatients and outpatients in any dose necessary to provide adequate relief, as determined by the patients. There is evidence that specially trained nurses also can prescribe opioids safely and effectively. Legally capacitated health workers who are inexperienced at prescribing morphine can be trained adequately with a basic course in palliative care (16). Reasonable precautions should be taken to prevent diversion and non-medical use of morphine and other controlled medicines. Model guidelines for this purpose are available (18).

<sup>2</sup> WHO differentiates PHC, a whole-of-society approach to health, from primary care, the first level of contact for health services that are continuous, comprehensive and coordinated.











A basic model for integrating palliative care into health care systems, and the palliative care interventions that should be available at each level, is shown in Table 1.

**Table 1. Palliative care interventions, delivery platforms and providers**

| Intervention                                                                                                                                                 | Delivery platform                                                                                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                                                                      |                                                                                                                                                                                                                                                                                                                                                                                                                                        |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                                                                                                                              | Mobile outreach or home care                                                                                                                                                                                                                                                                     | Facility-based primary care                                                                                                                                                                                                                                                            | First-referral level                                                                                                                                                                                                                                                                                                 | Second- and third-referral level                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b><i>Ongoing care for patients with well-controlled symptoms related to serious or life-limiting health problems</i></b>                                    | <ul style="list-style-type: none"> <li>• CHWs, supervised by a nurse or social worker at the primary care facility, provide surveillance and emotional support as often as daily</li> <li>• Visits as needed by a palliative care trained primary care nurse, doctor or social worker</li> </ul> | <ul style="list-style-type: none"> <li>• Nurses and ideally an interdisciplinary team consisting also of a doctor or social worker with basic training in palliative care provide outpatient care and home visits as needed</li> <li>• Inpatient hospice care in some cases</li> </ul> | <ul style="list-style-type: none"> <li>• Small palliative care team led by one or more doctors with basic or intermediate training in palliative care</li> <li>• Inpatient palliative care</li> <li>• Outpatient palliative care clinic</li> </ul>                                                                   |                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b><i>Initial control of moderate or severe symptoms related to serious, complex or life-limiting health problems or control of refractory suffering</i></b> |                                                                                                                                                                                                                                                                                                  |                                                                                                                                                                                                                                                                                        | <ul style="list-style-type: none"> <li>• Small palliative care team led by one or more doctors with basic or intermediate training in palliative care</li> <li>• Inpatient palliative care</li> <li>• Outpatient palliative care clinic</li> <li>• Coordination with and counter referral to primary care</li> </ul> | <ul style="list-style-type: none"> <li>• Palliative care team led by full- or part-time doctors with intermediate training in palliative care</li> <li>• A palliative care specialist physician should lead the team at major cancer centres and general hospitals</li> <li>• Inpatient palliative care ward</li> <li>• Outpatient palliative care clinic</li> <li>• Coordination with and counter referral to primary care</li> </ul> |

CHW: community health worker.

Source: Adapted from Krakauer et al. 2018 (6).



People who can be involved in palliative care at the PHC level include doctors, assistant doctors, clinical officers and nurse practitioners; nurses; social workers, psychologists and trained lay counsellors; pharmacists; community health workers (CHWs); chaplains and faith leaders; and volunteers and family caregivers.

When integrating palliative care into PHC there is a risk of overwhelming already overburdened primary care clinicians with yet another responsibility and set of tasks. To avoid this, adequate funding is required to employ an adequate number of primary care staff, and thereby to strengthen primary care. However, integration of palliative care, including home care, into PHC appears to not only improve access to palliative care and patient well-being, but also reduce costs for health-care systems and provide financial risk protection for patients' families, by reducing dependency on hospital inpatient and outpatient services (4, 19-21). Thus, any additional investment in human resources may result in cost savings (4).

Many countries already have CHWs who live in the same community as patients and can visit them at home, daily if necessary. Existing, supervised CHWs can be trained in as little as a few hours to provide emotional support; to observe for uncontrolled symptoms, unmet social needs and improper use of medicines; and to report their observations to supervisors at primary care facilities (22). Where necessary, a nurse can then speak with and provide instructions to the patient or family caregiver by mobile phone. The nurse also may make a home visit and/or speak with a supervising primary care physician or a physician at the referral level for advice.

## Conclusion

Palliative care is essential care for people in the community with serious or life-threatening illnesses. For ethical, public health and financial reasons, palliative care must be considered an essential integrated service within PHC.









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