
Strengthening of palliative care as a component of integrated treatment throughout the life course

Report by the Secretariat

1. This report describes the current status globally of palliative care and measures that are crucial to its development with a public health approach.

DEFINITION, NEEDS AND BENEFITS

2. WHO defines palliative care as 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.¹ Palliative care also respects the choice of patients, and helps their families to deal with practical issues, including coping with loss and grief throughout the illness and in case of bereavement.

3. With respect to palliative care and the right to health, the Committee on Economic, Social and Cultural Rights, in its General Comment 14, noted that “States are under the obligation to respect the right to health by ... refraining from denying or limiting equal access for all persons ... to preventive, curative and palliative health services.”² The right to health is recognized as a fundamental human right by WHO’s Constitution and several international human rights instruments such as the International Covenant on Economic, Social and Cultural Rights, the Convention on the Elimination of All Forms of Discrimination Against Women, the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, the Convention on the Rights of the Child, and the Convention on the Rights of Persons with Disabilities.

4. WHO estimates that, worldwide, some 20 million people need end-of-life palliative-care services each year,³ and just as many people are believed to need palliative care in the year before death, giving an annual total of about 40 million people. It is estimated that of the 20 million people needing palliative care at the end of their life, around 80% live in low- and middle-income countries; some 67% are elderly (more than 60 years of age), whereas about 6% are children.

¹ National cancer control programmes: policies and managerial guidelines. 2nd ed. Geneva: World Health Organization; 2002.

² Document E/C.12/2000/4.

³ “How many people are in need of palliative care worldwide?” In: Global atlas of palliative care at the end of life. Geneva: World Health Organization and Worldwide Palliative Care Alliance; 2014 (in press).

5. Conditions in which palliative care may be needed include noncommunicable chronic diseases such as cancer, cardiovascular diseases, chronic obstructive pulmonary diseases, kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological diseases, Alzheimer's disease and other dementias, and congenital anomalies and infectious diseases such as HIV/AIDS and drug-resistant tuberculosis. Nearly all adults in need of palliative care die as a result of cardiovascular diseases (38.5%) and cancer (34%), followed by chronic respiratory diseases (10.3%), HIV (5.7%) and diabetes (4.6%).¹ Those in need of palliative care dying from HIV/AIDS, tuberculosis and hepatitis B and C tend to be aged 15 to 59 years, whereas those dying from Alzheimer's disease, Parkinson's disease, chronic respiratory diseases, cardiovascular diseases, diabetes, rheumatoid arthritis and cancer are predominantly older than 60 years.

6. Palliative care improves the quality of life of patients (through for instance a reduction in the burden of symptoms) and of their families, but also benefits health care systems by reducing unnecessary admissions to hospital and use of health care services. Most research on the impact of palliative care emanates from high-income countries, but a growing body of research is reporting similar findings, namely that palliative care, delivered in culturally appropriate models with close community involvement, can achieve similar outcomes in low- and middle-income countries.

7. Pain is one of the most frequent and serious symptoms experienced by patients in need of palliative care. Opioid analgesics are essential for treating moderate-to-severe pain in cancer patients and severe pain in patients with various advanced progressive non-cancerous conditions.² Pain is particularly frequent in the terminal phase of illness. For example, around 80% of both cancer and AIDS patients and 67% of both patients with cardiovascular diseases and those with chronic obstructive pulmonary diseases will experience moderate-or-severe pain at the end of their lives. Palliative care is not limited to management of pain but several other distressing symptoms, such as respiratory distress, which is serious and frequent in patients with life-threatening illnesses. Opioids are effective in reducing the feeling of breathlessness in patients with advanced disease of any cause.

IMPLICATIONS FOR HEALTH SYSTEMS

8. The need for palliative care services will continue to grow, owing in part to the rising prevalence of noncommunicable diseases and the ageing of populations everywhere. For noncommunicable diseases, the need could be reduced through their early detection and timely management to prevent complications. The growing demand for palliative care, coupled with financial constraints, demands a sustainable public health approach (see paragraph 19 below). This is likely to require a reconfiguration of services to integrate palliative care into existing health care services and to engage the wider community in supporting those in need of palliative care, by working in partnership.

9. National health systems need to include palliative care in the continuum of care for people with chronic, life-threatening conditions, strategically linking it to prevention, early detection and treatment programmes.³ It should not be considered as an optional extra. Palliative care services need to be

¹ "How many people are in need of palliative care worldwide?" In: Global atlas of palliative care at the end of life. Geneva: World Health Organization and Worldwide Palliative Care Alliance; 2014 (in press).

² Opioids in palliative care: safe and effective prescribing of strong opioids for pain in palliative care of adults. National Institute of Health and Care Excellence Guidelines 2012 (<http://www.nice.org.uk/nicemedia/live/13745/59287/59287.pdf>, accessed 22 November 2013).

³ Cancer control: knowledge into action. WHO guide for effective programmes. Module 5: palliative care. Geneva: World Health Organization; 2007.

provided alongside potentially curative treatment and need to be adapted to the increased physical, psychosocial and spiritual needs of patients, their families and carers as the disease progresses into the terminal phase.

10. Palliative care services need to be provided in accordance with the principles of universal health coverage. All people, without discrimination, should have access to nationally determined sets of basic health promotion, preventive, curative, rehabilitative and palliative health services and essential, safe, affordable, effective and good-quality medicines and diagnostics. Furthermore, the use of these services must not lead to financial hardship, especially among poor people and populations living in vulnerable situations.

11. Various models for implementing palliative care exist. Success factors are: a multidisciplinary and multisectoral approach; adaptation to the specific cultural, social and economic setting; and integration into existing health systems, with emphasis on primary health care and community- and home-based care. In settings with limited resources, where the number of people needing care is high and the number of nurses and doctors to provide that care is low, a successful approach is the provision of care through trained community carers or volunteers who are supervised by health care professionals.

CHALLENGES IN PROVIDING PALLIATIVE CARE

12. Worldwide, provision of palliative care has to overcome significant barriers: health policies in many countries do not adequately meet the needs for palliative care; research and training are often nonexistent or limited; and access to opioid analgesics is difficult to ensure. A recent study on the status of palliative care in 234 countries, areas or territories found that it was well integrated into health care systems in only 20 of them; 42% have no delivery system for palliative care services, and in 32% service delivery reaches only a small percentage of the population.¹ Some 80% of the world's population lack adequate access to medication needed for palliative care. In 2010, the International Narcotics Control Board estimated that the levels of consumption of opioid analgesics were "inadequate" in 21 countries and "very inadequate" in more than 100 countries.² In 2011, WHO estimated that annually 5.5 million late-stage cancer patients and 1 million patients with end-stage HIV/AIDS experience moderate-to-severe pain but have no access to adequate pain treatment.³ Research and evaluation processes are needed to ensure the quality of palliative care and the safe use of medications such as opioids.

13. Other barriers include a lack of awareness of the great need for palliative care; insufficient or unimplemented government policies for improving the provision of palliative care; a lack of knowledge of palliative care among health care workers; limited availability and accessibility of opioid analgesics (especially in oral form) and other essential palliative care medications in many countries; misconceptions about palliative care; and financial and health system constraints. Social and

¹ Lynch T, Connor S, Clark D. Mapping levels of palliative care development: a global update. *Journal of Pain and Symptom Management* 2013;**45**(6):1094–106.

² International Narcotics Control Board. Report of the International Narcotics Control Board on the availability of internationally controlled drugs: ensuring adequate access for medical and scientific purposes. New York: United Nations; 2011.

³ World Health Organization Briefing Note. Access to Controlled Medicines Programme: improving access to medications controlled under international drug conventions. Geneva: World Health Organization; 2012.

cultural barriers (such as beliefs about death and dying) and the difficulty in ensuring ethical decision processes in life-threatening conditions also have an important impact on access to palliative care.

RESPONSE OF WHO AND OTHER ORGANIZATIONS IN THE UNITED NATIONS SYSTEM

14. The United Nations conventions on international drug control¹ recognize the need to use some substances under international control for medical and scientific purposes. In its preamble, the Single Convention on Narcotic Drugs, 1961 explicitly recognizes that “the medical use of narcotic drugs continues to be indispensable for the relief of pain and suffering and that adequate provision must be made to ensure the availability of narcotic drugs for such purposes”. WHO works with the Commission on Narcotic Drugs of the United Nations Economic and Social Council and International Narcotics Control Board, which monitors and supports Member States’ compliance with the provisions of the Conventions, to improve access to these medications for medical purposes.

15. The Health Assembly in resolution WHA55.14 (Ensuring accessibility of essential medicines) urged greater access to medicines and in resolution WHA58.22 (Cancer prevention and control) made that explicit for palliative care. In addition, in 2010 the Commission on Narcotic Drugs, in resolution 53/4 (Promoting adequate availability of internationally controlled licit drugs for medical and scientific purposes while preventing their diversion and abuse), inter alia supported International Narcotics Control Board’s recommendation to governments to promote access to and rational use of narcotic drugs and psychotropic substances, while preventing their diversion and abuse. The Control Board has repeatedly voiced its concern about the disparate and inadequate access worldwide to controlled substances for medical and scientific purposes, and has made a series of recommendations to countries for rectifying this situation.

16. In 2011, WHO published the revised edition of its guidance for assessing the availability of and access to controlled medications in Member States.² In 2012 the United Nations issued the guidance prepared by the International Narcotics Control Board and WHO to countries on how to calculate amounts of controlled medicines that they need to meet realistic needs, in order to obtain relevant licenses.³ After studying the feasibility of providing support to countries for improving access to opioid analgesics, WHO established the Access to Controlled Medications Programme in consultation with the Control Board, with the aim of expanding legitimate medical access to all medications controlled under the drug conventions. In order to increase the responsible use of medications for pain, in 2012 WHO published guidelines on the pharmacological treatment of persisting pain in children with medical illnesses, which include pain relief in palliative care.⁴

¹ For instance, the Single Convention on Narcotic Drugs, 1961, as amended by the 1972 Protocol amending the Single Convention on Narcotic Drugs, 1961, and United Nations Conventions on Psychotropic Substances, 1971.

² Ensuring balance in national policies on controlled substances. Guidance for availability and accessibility of controlled medicines. Geneva: World Health Organization; 2011.

³ Guide on estimating requirements for substances under international control. Developed by the International Narcotics Control Board and the World Health Organization for use by competent national authorities. New York: United Nations; 2012.

⁴ World Health Organization. Persisting pain in children package: WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses. Geneva: World Health Organization; 2012.

17. Both the 18th edition of the WHO Model List of Essential Medicines and the 4th WHO Model List of Essential Medicines for Children (both issued in 2013) include sections on medicines for pain and palliative care in order to emphasize that application and to ensure that all the medicines needed for optimal palliative care are available and affordable to those in need, in accordance with the essential medicines concept. These lists include medicines for various common symptoms such as anorexia, nausea, constipation and diarrhoea in addition to pain, for which opioid and non-opioid medicines are listed.

18. WHO's global action plan for the prevention and control of noncommunicable diseases 2013–2020, which was endorsed by the Health Assembly in resolution WHA66.10 in May 2013, includes palliative care among the policy options proposed to Member States and in its global monitoring framework.¹

PUBLIC HEALTH APPROACH

19. The Secretariat has identified the formulation and implementation of the following policies as essential for expanding palliative care within a public health approach:

- health system policies to ensure the integration of palliative care services into the structure and financing of national health care systems at all levels of care
- policies for strengthening and expanding human resources, including education and training of health care professionals, in order to ensure adequate responses to the palliative care needs, together with training of volunteers and education of the public
- a medicines policy in order to ensure the availability of essential medicines for the management of symptoms, including pain and psychological distress, and, in particular, opioid analgesics for relief of pain and respiratory distress
- a policy for research into assessing the needs for palliative care and identifying standards and models of service that work, particularly in limited resource settings.

ACTION AT COUNTRY LEVEL TO STRENGTHEN PALLIATIVE CARE

20. Many of the services and interventions for providing palliative care are already within the reach of countries, including those in the low- and middle-income range. Actions that can support the extension and strengthening of services for palliative care at the country level include the following:

- (i) formulating and implementing national policies that integrate evidence-based palliative services into the continuum of care, at all levels, of chronic life-threatening conditions, with an emphasis on primary care, and community- and home-based care;
- (ii) advocating for palliative care in efforts to promote universal health coverage and essential medicines policies, on the basis of the results of assessment and improvement of the quality and safety of palliative care;

¹ Document WHA66/2013/REC/1, Annex 4.

- (iii) implementing and monitoring the recommendations in the global action plan for the prevention and control of noncommunicable diseases 2013–2020 and ensuring its integration into universal coverage and essential medicines schemes;
- (iv) ensuring that education about palliative care (including ethical aspects) is offered to students in undergraduate medical and nursing schools and to health care providers at all levels, in accordance with their roles and responsibilities and as part of human resource development;
- (v) ensuring adequate access to controlled medicines while minimizing opportunities for their diversion and abuse by aligning national and local regulations with WHO’s guidance in national policies for controlled substances;
- (vi) ensuring access to all aspects of palliative care (basic medical support and psychosocial and spiritual support to patients and families), under the supervision of trained health care professionals, as appropriate;
- (vii) establishing ethical guidance related to the provision of palliative care, in areas such as equitable access, respectful care and community involvement in policies and programmes;
- (viii) working in partnership with different sectors to foster operational research in palliative care, including the development of cost-effective models of such care.

All these measures, combined with committed leadership, are considered necessary for effective and efficient palliative care.^{1,2}

ACTION BY THE EXECUTIVE BOARD

21. The Board is invited to note this report.

= = =

¹ National cancer control programmes: policies and managerial guidelines. Geneva: World Health Organization; 2002.

² Cancer control knowledge into action. WHO guide for effective programmes: palliative care. Geneva: World Health Organization; 2007.