

Palliative Care: The World Health Organization's Global Perspective

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Introduction

Tens of millions of people worldwide are affected by life threatening illnesses such as HIV/AIDS and cancer, which cause them and their families great suffering and economic hardship. The majority of the cases occur in the developing world where quite often there is little accessibility to prompt and effective treatment for these diseases. The development of palliative care through effective, low cost approaches is usually the only feasible alternative to respond to the urgent needs of the sick and improve their quality of life.

WHO's Past Contribution to Palliative Care

In the early 1980s, the World Health Organization (WHO) Cancer Unit began the development of a global initiative to advocate for pain relief and opioid availability worldwide. Although at that time a major emphasis was given to cancer pain relief, the management of cancer pain was conceived as the spearhead for a comprehensive and integrated palliative care approach to be developed in the medium term. Various important achievements were obtained.¹ The publication of guidelines in a wide variety of languages, some of which have become best-sellers, has had a great impact in influencing the development of pain and symptom relief

worldwide (Table 1).² It is also important to highlight the progressive expansion of a global network on pain relief and palliative care formed by numerous national and international organizations. WHO's efforts and constant advocacy during many years has certainly played a major role in this global awareness.

Despite the substantial efforts and significant progress made in the development of palliative care worldwide in the last decade, there are still important gaps to be bridged. Many countries have not yet considered palliative care as a public health problem and, therefore, do not include it in their health agenda. Several initiatives have developed as "islands of excellence." These initiatives have not, however, been well integrated into the country's national health policies and, therefore, have not yet had a significant impact in the population of patients in need of palliative care. In many countries, there are serious impediments to opioid availability, a key element to pain control. Morphine consumption is especially low in most developing countries. Important regional and global health initiatives dealing with related issues have not explicitly considered palliative care among their priorities. Consequently, there is no doubt that there is a need to advocate worldwide for adequate policy development and effective program implementation in the area of palliative care. In order for initiatives to achieve sustainability and adequate coverage, it is essential to promote a public health approach in which comprehensive palliative care programs are integrated into the existing health systems and are tailored to the specific cultural and social context of the target populations.

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Table 1
WHO Guidelines on Cancer Pain, Opioid Availability, Symptom Control and Palliative Care

- *Cancer Pain Relief: With a Guide to Opioid Availability* was published in 1996. It is available in 16 languages.
- *Cancer Pain Relief and Palliative Care* is a report of a WHO expert committee which was released in 1990 and is available in 10 languages.
- *Symptom Relief in Terminal Illness* was published in 1998 and is available in 8 languages.
- *Cancer Pain Relief and Palliative Care in Children* was published in 1998 and is available in 6 languages.
- *National Cancer Control Programmes: Policies and Managerial Guidelines, 2nd ed.* was released in June 2002. Although it is currently available only in English, translations into French and Spanish are in progress, and translations into other languages are planned.

Adapted from Colleau and Weis.²⁽¹⁾

WHO's Present Definition of Palliative Care

WHO has broadened its approach to palliative care. Whereas before, a disease-specific approach was used, now the similarities and opportunities for cooperation among those working with different diseases are emphasized. In particular, the need for collaboration between those working with HIV/AIDS patients and those working with patients with other chronic diseases is noted.

The earlier WHO definition of palliative care stressed its relevance to patients not responsive to curative therapy.³ This statement might be interpreted as relegating palliative care to the last stages of care. Today, however, there is wide recognition that the principles of palliative care should be applied as early as possible in the course of any chronic, ultimately fatal illness. This change in thinking emerged from a new understanding that problems at the end of life have their origins at an earlier time in the trajectory of disease. Symptoms not treated at onset become very difficult to manage in the last days of life. People do not "get used to" pain; rather, chronic unrelieved pain changes the status of the neural transmission of the pain message within the nervous system, with reinforcement of pain transmission, and activation of previously silent pathways.

The WHO approach to palliative care has also been extended, such that, while pain relief is still an important component, it is by no means the only consideration. The physical, emotional, and spiritual needs of the patient

are all considered important concerns in palliative care.

In addition, the WHO consideration of palliative care has broadened in that it no longer considers just the patient, but includes considerations of the health and well-being of family members, and of the carers working with the patient. It extends beyond the period of care for the patient, and includes a consideration of the need to support and counsel those who have been bereaved.

These concepts are captured in WHO's most recent definition of palliative care and in the similar definition which is framed to take into account the particular needs of children (Appendix 1 and 2).⁴

WHO's Current Contribution to Palliative Care

At present WHO is developing various activities related to palliative care. A major emphasis is given to advocating for palliative care as a global public health problem. Recommendations are tailored to different resource settings, and priority is given to initiatives that are well integrated into the existing health system and related programs. Policy development, education and training, provision of good quality care (including home-based care), and drug availability are considered key components of a comprehensive palliative care program. Adequate program management includes balanced implementation of these components, while achieving high coverage and improved quality of life among patients and their families.

Palliative care is one of the priority areas of the WHO Program on Cancer Control. Two initiatives are being developed: a palliative care project in Africa for HIV/AIDS and cancer patients, and a European project for improving the performance of cancer control programs.

The ongoing African initiative (Appendix 3) is a joint cancer and HIV/AIDS project. It is being developed with a clear awareness of the need for prevention and the importance of a continuum of care for both diseases. In the case of the cancer problem, palliative care is seen as an entry point to develop, in the near future, a more comprehensive approach to cancer prevention and control. In the case of HIV/AIDS, the development of palliative care, which has until now been neglected in Africa,

is an urgent need, especially considering that around 80% of the patients in need of this type of care are HIV/AIDS patients.

The European initiative is under design. It will involve the development or reinforcement of palliative care activities within the framework of cancer control programs, as well as integrating palliative care into other related programs. A group of countries will be invited to join this initiative that, if successful, will be expanded to other interested countries.

While pain control is not the only issue in palliative care, it remains a key component. Most of the strong analgesics are opioids, which are subject to international control as narcotic drugs. Previous studies indicate that overly stringent regulations can reduce the availability of controlled drugs for medical use. The WHO department of Essential Drugs and Medicines Policy (EDM) deals with the international control of narcotic drugs and psychotropic substances based on the United Nations drug control conventions. To improve access to opioid analgesics, EDM, in close collaboration with the International Narcotics Control Board (INCB) and the WHO Collaborating Center for Policy and Communications in Cancer Care, is promoting balanced regulatory approaches so that control measures may not unduly restrict the accessibility to opioids.

To this end, EDM and collaborators have developed guidelines for the purpose of assisting national authorities in conducting a self-diagnosis of their regulatory systems to identify deficiencies, if any.⁵ They are also promoting a balanced opioids control policy through workshops/seminars (one for China, another for Andean countries, in 2000; two similar seminars are planned for 2002). In addition, they are advocating and promoting the same policy through collaboration with national opinion leaders. For example, support was given to Italian experts in their efforts to modify Italian drug control regulations in 2001.

Another collaborative development and research project coordinated by WHO is titled *Syndromic Practice Guidelines for Common Outpatient Conditions in Adults (SynAps)*. Simplified guidelines for the care of adolescents and adults are being developed. These guidelines describe care that can be given by multipurpose first-level facility health workers in situations where resources are limited and

where there is a high prevalence of HIV infection. The guidelines, *Integrated Management of Adolescent/Adult Illness (IMAAI)*, include a module on palliative care. The palliative care guidelines assume that most care will be provided at home, with health workers providing back-up to home-based care by the family and community-carers. A booklet relying heavily on illustrations is also being developed to prepare families and community-carers to care for patients at home. For each symptom, the guidelines for the health worker include both a summary of non-pharmaceutical recommendations for home care and medications that the health worker might also provide. This would counter tendencies to rely only on medication while providing guidance on what to provide to supplement home care. The IMAAI guidelines use the same format as outpatient materials within *Integrated Management of Childhood Illness (IMCI)*.⁶ The palliative care section is applicable to both adults and children. The guidelines will be accompanied by training materials and materials to support country adaptation.

Priority Actions for Palliative Care According to Resource Levels

At the country level, it is acknowledged that situations differ widely. Traditions and cultural attitudes to palliative care vary. So, too, do the frameworks of the existing health care services into which palliative care services must fit. And, importantly, countries differ in terms of the resources they have available to spend on palliative care. In view of this last consideration, WHO has developed general recommendations for countries according to the level of resources available that can be adapted to each country situation.

Overall, it is recommended that all countries implement comprehensive palliative care programs with the purpose of improving the quality of life of the majority of patients with cancer or other life-threatening conditions, and their families. These programs should provide pain relief, other symptom control, and psychosocial and spiritual support. All countries should promote awareness among the public and health professionals that cancer pain can be avoided, and should ensure the availability of oral morphine in all health care settings.

In low resource settings, it is important to ensure that minimum standards for pain relief and palliative care are progressively adopted at all levels of care in targeted areas, and that there is high coverage of patients through services provided mainly by home-based care. Home-based care is generally the best way of achieving good quality care and coverage in countries with strong family support and poor health infrastructure.

Countries with medium levels of resources should ensure that minimum standards for cancer pain relief and palliative care are progressively adopted at all levels of care, and that, nationwide, there is increasing coverage of patients through services provided by primary health care clinics and home-based care.

Countries with high levels of resources should ensure that national pain relief and palliative care guidelines are adopted by all levels of care and that, nationwide, there is high coverage of patients through a variety of options, including home-based care.

Future Challenges

WHO is committed to the promotion of a public health approach to palliative care, well integrated into existing health care systems, and focusing on a broad definition of palliative care which encompasses the needs of family and caregivers, as well as those of the patient, and which addresses the physical, emotional, and spiritual needs of all those involved. As outlined, a number of initiatives are underway, often targeting the important needs of cancer and HIV/AIDS patients, but applicable to those affected by other diseases in need of palliative care.

Challenges in the near future include the validation of models for implementing effective and efficient palliative care programs in different resource settings. These programs need to be accessible to all patients and their families in need of this care. In this regard, the African project might serve as a model for low resource settings. It is anticipated that it could be expanded to other countries in Africa, in the first instance, and later to other parts of the world, especially to countries with similar characteristics. The European project will provide an opportunity for testing, in high and medium resource countries, appropriate models

for developing effective and efficient cancer control programs that include palliative care as one of the key components, together with prevention, early detection and treatment. WHO, with its partners, will continue to advocate globally for pain relief and opioid availability, within the context of the comprehensive approach to palliative care. Special emphasis will be given to advocating for drug availability within those countries developing projects like the ones described above.

The WHO is seeking to strengthen its collaboration with the numerous governmental and nongovernmental organizations working in the field of palliative care. We share the same goals, and by combining our efforts and creativity we have greater potential to contribute to the well-being of the millions of people that every year are in need of pain relief and palliative care worldwide.

Appendix 1: WHO's Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care⁴:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness

- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

Appendix 2: WHO's Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998):^{4,7}

- 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.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centers and even in children's homes.

Appendix 3: African Project

The WHO Program on Cancer Control is developing an initiative to strengthen the development of palliative care in southern African countries in collaboration with WHO Departments of Care for HIV/AIDS, various relevant governmental and intergovernmental agencies, nongovernmental organizations, and the WHO Regional Office for Africa (AFRO). The project is titled "Community Health Approach to Palliative Care for HIV and Cancer Patients in Africa." Five countries are participating in the project: Ethiopia, Botswana, Uganda, the United Republic of Tanzania, and Zimbabwe.

The main goal of this project is to contribute to the improvement of the quality of life for cancer and HIV/AIDS patients in southern African countries by facilitating and strengthening initiation and development of palliative care programs with a public health approach. These programs will provide pain relief and palliative care to an increasing proportion of patients.

The project has been undertaken after careful consideration of the existing situation in Africa, where thousands of patients suffering from these diseases are diagnosed in late stages or have limited accessibility to treatment. It is acknowledged that important palliative care activities are already ongoing in some of the African countries and involve both government as well as nongovernmental initiatives supported, in many cases, by international organizations. These initiatives have produced a solid knowledge base about the way non-costly, good quality palliative care can be provided in low resource settings. They rely mainly on the community network, educated and supervised by a palliative care team. However, there are still important gaps to be bridged in the region. The level of morphine consumption in the region is one of the lowest worldwide and trends have not changed.

The African project is currently in the early stages of development. Country teams have been established and these team members have undertaken situation analyses and needs assessments in their countries. On the basis of these studies, project proposals have been developed. These proposals were discussed at a meeting held in Botswana in July 2002, with a view to moving onto the next phase—implementation of the projects. Implementation is, of course, dependent on funds, and obtaining these funds is a key challenge for each of the teams involved in the project.

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