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Palliative Care Indicators



Asociación Latinoamericana
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Palliative Care Indicators

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TABLE OF CONTENTS

Title	Page
Section 1 – Description and Background	
Rationale	6
Background	7
Palliative Care Indicators	7
Objectives	8
Methodology	8
Results	9
Section 2 – Palliative Care Indicators	
Health Care Policy	11
Education	12
Service provision: Infrastructure	14
Medications	15
Conclusions	16
Acknowledgments	16
References	17

SECTION 1

PROJECT DESCRIPTION AND BACKGROUND

Rationale

Non-communicable diseases (NCDs) are currently the main cause of mortality worldwide. An estimated 36 million deaths, or 63% of the 57 million deaths that occurred globally in 2008, were due to NCDs, comprising mainly cardiovascular diseases (48%), cancers (21%), chronic respiratory diseases (12%) and diabetes (3.5%) (1). Currently, NCDs are the main cause of death and disability in Latin America and the Caribbean. In 2002, they were responsible for 44% of deaths of men and women less than 70 years old and were the main cause of death in one out of two in the total population (2). NCDs contributed to almost 50% of the lost Disability Adjusted Life Years in the Region.

In 2008, around 80% of all NCD deaths (29 million) occurred in low- and middle-income countries. A higher proportion (48%) of NCD deaths in low- and middle-income countries is premature (under the age of 70), compared to high-income countries (26%). The probability of dying from an NCD between the ages of 30 and 70 is highest in Sub-Saharan Africa, Eastern Europe and parts of Asia. According to World Health Organization (WHO) projections, the total number of annual NCD deaths will increase to 55 million by 2030, if the present trend continues (3).

A large percentage of NCDs are preventable. They have in modifiable behavioral risk factors such as tobacco consumption, unhealthy diet, physical inactivity and excessive use of the alcohol. Viable and cost effective interventions, and the adoption of maintained measures to prevent risk factors and improve health care, can avoid million premature deaths (4).

Palliative care aims to attain to the best quality of possible life for the patients with advanced, progressive conditions and life threatening diseases and the relief of pain and suffering and other symptoms; the provision of psycho-social, spiritual and social support and the support to caregivers and relatives during the course of the disease and the bereavement process. Palliative care can be provided in specialized institutions, community centers and in homes.

The control of the NCDs requires an integration of services by means of the strengthening the referral systems and integration among the first one, second and third levels of care provision. An appropriate control must include prevention, screening and early detection, as well as diagnosis, treatment, rehabilitation and palliative care. The importance of palliative care as an essential component of care is being recognized by health providers, government representatives and legislators.

Pain relief is one of the basic components of the palliative care and in order to accomplish it is necessary for opioid analgesics to be available and accessible. Morphine is recognized as essential analgesic in the WHO Model List of Essential Medicines (5) and the preamble of the Single Convention on Narcotic Drugs (6) establishes that these medications are indispensable for the relief of pain and suffering and gives instructions to the member states to take the necessary provisions to assure their availability. With adequate treatment of pain and palliative care, it is possible to alleviate the suffering of most of the patients and their families.

Access to pain treatment and to palliative care services is limited, even in developed countries, as a result of lack of political will, insufficient education and information, and excessive regulations on the use of opioid medications. Many national health programs and strategies for life threatening conditions such as cancer and HIV do not have provisions to ensure access to palliative care and to pain treatment. The developing countries, which constitute for about 80 percent of the global population, represent only 6% of the world-wide morphine consumption (7), resulting in tens of millions of people suffering with moderate to severe pain, including 5,5 million patients with advanced cancer and 1 million patients with HIV (8).

Background

In 2008, the World Health Assembly endorsed the Action Plan for the Global Strategy for the Prevention and Control of NCDs covering the period 2008-2013. It comprised a set of actions which, when performed collectively by Member States and other stakeholders, would tackle the growing public-health burden imposed by NCDs. In order for the plan to be implemented successfully, high-level political commitment and the concerted involvement of governments, communities and health-care providers were required.

- The High-level Meeting of the United Nations General Assembly on the Prevention and Control of NCDs and the adoption of the Political Declaration represented a breakthrough in the global struggle against NCDs. For the first time, all Member States of the United Nations agreed that NCDs constitute a major challenge to socioeconomic development, environmental sustainability and poverty alleviation. The UN Political Declaration on NCDs makes a clear call for including NCDs in health-planning processes and the development agenda of each Member State. It also commits governments to a series of multi sector actions and to explore the provision of adequate, predictable and sustained resources through domestic, bilateral, regional and multilateral channels, including traditional and voluntary innovative financing mechanisms;
- Recognizing the leading role of WHO as the primary specialized agency for health, and reaffirming the leadership role of WHO in promoting global action against NCDs, the World Health Assembly in the resulting resolution (9) requested the WHO Secretariat to prepare before the end of 2012, a follow-up plan for the outcomes of the High-level Meeting consistent with existing WHO strategies and prepare recommendations to establish a set of global objectives and goal to prevent and control NCDs.

The Political Declaration also called on Member States to consider the possibility of establishing national objectives and indicators based on each country's condition, following WHO's guidance. The WHO, in consultation with Member States, has prepared a draft for the Action Plan for the Global Strategy and Prevention and Control of NCDs covering the period 2013-2020 (10).

In September 2012, the Pan American Sanitary Conference approved a Regional Strategy for the prevention and control of NCDs (2012-2025). The Action Plan 2006-2013 is still kept current until a new regional plan is developed in consonance with the country priorities as well as the action plan and framework developed by WHO (11).

The WHO action plan for the prevention and control of NCDs covers the following components: monitoring, prevention and health care provision. In the Regional Strategy by the Pan American Health Organization (PAHO) (12), four areas were defined which are: prioritize NCDs in political and public health programs; consider monitoring as an critical component; accept the need to reorient health systems so that they respond to the needs of the population suffering with NCDs and take note of the essential function of health promotion and prevention of NCDs.

Palliative Care Indicators

For many years, the palliative care community has advocated for systematic monitoring of palliative care at national and global levels. Although several palliative care organizations have developed reports on the status of palliative care development, (13,14,15) and more recently, the ALCP published the ALCP Atlas of Palliative Care (16), Member States have no obligation to monitor or report palliative care, and the available reports have had limited impact on the provision of care.

Several of the described objectives in the PAHO Regional Strategy for Non Communicable Diseases, include palliative care and access to medications:

1. Provide by the PAHO Secretariat, technical assistance to developing countries in the strengthening, implementation and evaluation of their programs to control NCDs, including palliative care (page 29)
2. Facilitate the strengthening and reorientation of health care systems to control in optimal conditions, NCDs and their risk factors. The described activities include determine the quality of health care services for NCDs, including palliative care (page 30).
3. Guarantee better access to technology and essential medications for the treatment of NCDs and their risk factors and promote and monitor their rational use (page 34).

The PAHO document does not describe indicators specific to palliative care which may be helpful to Member States in monitoring this discipline. On the other hand, the new WHO plan provides a comprehensive global monitoring framework and includes indicators and a set of voluntary global targets for the prevention and control of NCDs. One of these is a palliative care indicator, a step forward which is welcomed by the international palliative care community. The proposed indicator is:

“Access to palliative care assessed by morphine-equivalent consumption of strong opioid analgesics (excluding methadone) per death from cancer.”

The international palliative care community supports the inclusion of a palliative care indicator, as this will contribute to the development of the field. However, given that palliative care covers other aspects in addition to pain treatment in patients with advanced cancer, the palliative care associations consider it necessary to develop additional indicators which could be used to monitor palliative care globally (17). Based on the above, the ALCP requested support from the International Association for Hospice and Palliative Care (IAHPC) to help develop a project to develop palliative care indicators.

Objectives

The goal of this project is to develop a set of indicators that could contribute to the monitoring of palliative care.

The specific objectives of this project are:

1. To develop a framework and a tool for the monitoring of palliative care within the NCDs framework.
2. To develop indicators applicable in all countries of the world.
3. To evaluate the efficacy, applicability of the tool and the developed indicators.

Methodology

The ALCP convened a meeting in Lima, Peru in November 11 and 12, 2012 to identify the palliative care indicators applicable to all countries of the Region.

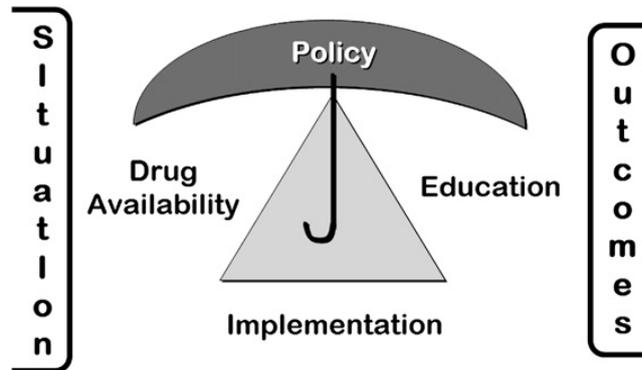
Several experts in epidemiology, palliative care, health care administration and health care systems were identified and invited, including representatives of PAHO, the WHO Regional Office for the Americas. Additional members of the ALCP board were also invited.

For the purpose of this project, the underlying discussions and recommendations were based on the WHO definition of palliative care (18):

“Palliative Care is an approach that improves the quality of life of patients and their families facing the problem 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.”

The palliative care public health strategy represented in Figure 1 and its components were adopted as a framework for the discussion: 1) Adequate health care policies, 2) education of health providers, legislators and the public in general, 3) availability of medications and 4) implementation of services in all levels of care (19).

Figure 1



The discussions centered on indicators to monitor palliative care within the context of national health care provision and national policies, and not at the organizational or local level.

Results

During the meeting in Lima, the discussions centered on indicators to monitor and evaluate palliative care within the context of health care at the national public level and not at the organizational level. Other indicators appropriate for reduced geographical or for organizational levels may be developed in the future.

Ten indicators for palliative care were developed by the ALCP and IAHPC group: one for public health, three for education, three for structure and three for medications.

Section 2 defines each one of the indicators, sources of information, units of measure and corresponding formulas.

SECTION 2

PALLIATIVE CARE INDICATORS

Health Care Policy Indicator

Objective: To monitor the provision of palliative care through a public health strategy.

P0.1 – Existence of a current national palliative care plan/program

Definition: Existence of a current national palliative care plan or program as a result of policy/actions defined with the objective of implementing and/or improving care of palliative care patients.

The national plan/program should:

- Have national scope
- Be designed to integrate palliative care in health care services
- Have a budget assigned
- Have a responsible person assigned

A national plan or program is defined as a specific palliative care plan or program or a palliative care component within a broader program, such as prevention and control of NCDs, a national cancer control or HIV program

Technical data:

Source: Data provided by the health care authority.

Type: Structure

Unit of measure: Dichotomic (Yes/No)

Frequency: Annual

Education Indicators

Objective: To monitor palliative care education for health care professionals.

ED.1 – Proportion of medical schools which include palliative care education in undergraduate curricula

Definition: Number of medical schools which include palliative care education in undergraduate curricula, expressed as a percentage of the total number of medical schools, in a determined country, territory or geographical area.

For the purpose of this project, undergraduate education is defined as course or specific module within a course which includes the basic aspects of palliative care. Basic aspects of palliative care include:

- The identification, evaluation and treatment of the most frequent symptoms
- The physical, psychological and social aspects of care
- Communication issues with the patient, relatives and caregivers.

Technical Note:

Source: Data provided by the health care and the education authorities.

Type: Result

Unit of measure: Percentage

Formula:

$$\left(\frac{\text{Number of medical schools which include palliative care education at undergraduate level}}{\text{Total number of medical schools}} \right) \times 100$$

Frequency: Annual

Ed.2 – Proportion of nursing schools which include palliative care education in undergraduate curricula

Definition: Number of nursing schools which include palliative care education in undergraduate curricula, expressed as a percentage of the total number of nursing schools in a determined country, territory or geographical area.

For the purpose of this project, undergraduate education is defined as course or specific module within a course which includes the basic aspects of palliative care. Basic aspects of palliative care include:

- The identification, evaluation and treatment of the most frequent symptoms
- The physical, psychological and social aspects of care
- Communication issues with the patient, relatives and caregivers.

Technical Note:

Source: Data provided by the health care and the education authorities.

Type: Result

Unit of measure: Percentage

Formula:

$$\left(\frac{\text{Number of nursing schools which include palliative care education at undergraduate level}}{\text{Total number of nursing schools}} \right) \times 100$$

Frequency: Annual

Ed.3 – Number of specialized palliative care educational programs for physicians, accredited by the national competent authority.

Definition: Number of specialized palliative care educational programs for physicians, accredited by the national competent authority.

For the purpose of this project, specialized palliative care education is defined as specialty, sub-specialty, master degree or diploma, as defined by the respective competent authority.

Technical Note:

Source: Data provided by the health care and the education authorities.

Type: Structure

Unit of measure: Absolute number or absolute magnitude of programs

Frequency: Annual

Service Provision: Infrastructure Indicators

Objective: To monitor access to palliative care in the primary care level.

PS.1 – Inclusion of palliative care in the list of services provided in the primary care level

Definition: There is palliative care provision in the primary care level.

Technical Note:

Source: Data provided by the health care authority.

Type: Structure

Unit of measure: Dichotomic (Yes/No)

Frequency: Annual

PS.2 – Number of palliative care services per million inhabitants

Definition: Number of available palliative care services per million inhabitants in a defined population.

For the purpose of this project, palliative care service is defined as a service which provides care to patients with advanced, incurable and progressive conditions. Care is provided for acute problems and complex symptoms. Services include minimum a physician and a nurse with specialized training in palliative care.

Defined population is the population living in the geographical area in which the indicator is applied (national, state, province, etc.)

Technical Note:

Source: Data provided by the health care authority.

Type: Structure

Unit of measure: Number of palliative care services per million inhabitants

Formula:

$$\frac{\text{Number of palliative care services of } \times 1,000.000}{\text{Total number of inhabitants}}$$

Frequency: Annual

PS.3 – Number of physicians working in palliative care per million inhabitants

Definition: Number of physicians available who work in palliative care services per million inhabitants in a defined population.

For the purpose of this project, palliative care service is defined as a service which provides care to patients with advanced, incurable and progressive conditions. Care is provided for acute problems and complex symptoms. Services include minimum a physician and a nurse with specialized training in palliative care.

Defined population is the population living in the geographical area in which the indicator is applied (national, state, province, etc.)

Technical Note:

Source: Data provided by the health care authority.

Type: Structure

Unit of measure: Number of physicians working in palliative care per million inhabitants

Formula:

$$\frac{\text{Number of physicians working in palliative care services } \times 1,000.000}{\text{Total number of inhabitants}}$$

Frequency: Annual

Medications Indicators

Objective: To monitor access to strong opioids for the treatment of pain and other symptoms.

ME.1 – Consumption of strong opioids per cancer deaths

Definition: Morphine-equivalent consumption of strong opioid analgesics (excluding methadone) per death from cancer.

Note: This indicator was adopted by WHO as an indicator of access to palliative care in the Global NCD Action Plan framework in November 2012.

Technical Note:

Source: International Narcotics Control Board and health care authority

Type: Process

Unit of measure: Milligrams per cancer death

Formula:

$$\frac{\text{Consumption of strong opioids (*) in eq. morphine (excl. methadone)/year}}{\text{Number total cancer deaths}}$$

(*) morphine, oxycodone, hydromorphone, pethidine, fentanyl

Frequency: Annual

Note: in addition to ME.1, the group considered important to develop an additional indicator on the consumption of opioids with some variations:

ME.2 – Consumption of strong opioids per capita

Definition: Morphine-equivalent consumption of strong opioid analgesics (excluding pethidine) per capita in a defined population per year.

Defined population is the population living in the geographical area in which the indicator is applied (national, state, province, etc.)

The variations with respect ME.1 are:

1. Include methadone in the group of selected medications. In Latin America, methadone is used in palliative care as first line analgesic and in opioid rotation (20 21 22 23). Not including it would negatively affect the perception of the real consumption of opioids in palliative care.
2. Exclude pethidine: Pethidine is an analgesic widely used for acute pain, but it is not recommended for chronic long term use and therefore not suitable for palliative care. Including it would affect the perception of the actual use of analgesics in palliative care.
3. The denominator is per capita. The population denominator would provide more accurate measure of the availability of opioids for all patients with palliative care needs, not only for terminal cancer patients.

Technical Note:

Source: International Narcotics Control Board and health care authority.

Type: Process

Unit of measure: Milligrams per capita.

Formula:

$$\frac{\text{Consumption of strong opioids (*) in eq. morphine (excl. pethidine)/year}}{\text{Total number of inhabitants}}$$

(*) morphine, oxycodone, hydromorphone, fentanyl, methadone

Frequency: Annual

ME.3 – Number of pharmaceutical establishments that dispense strong opioids per million inhabitants

Definition: Number of public and private authorized pharmaceutical establishments that dispense strong opioids to ambulatory patients.

Technical Note:

Source: Data provided by the health care authority.

Type: Structure

Unit of measure: Number of pharmaceutical establishments that dispense opioids per million inhabitants

Formula:

$$\frac{\text{Number of pharmaceutical establishments that dispense opioids} \times 1,000,000}{\text{Total number of inhabitants}}$$

Frequency: Annual

Conclusions

The indicators are intended to be useful to monitor and supervise the progress of palliative care and to promote the development of the discipline: the indicators proposed in this paper are modeled on WHO public health and may result in changes in health policy and education and improve access to medicines for the relief of suffering

The indicators are designed taking into account the social and health systems of countries and resources. We hope the hospice and palliative care community uses these indicators and assist governments in the task of keeping relevant information available to monitor the progress of palliative care.

These indicators were developed for the countries of Latin America, but can be applied in countries of other continents and regions. The ALCP invites other regional and national associations to use these indicators for the existence of a global monitoring system as a basis for comparative studies between countries.

The ALCP will develop studies in the future to measure the use and application of indicators and hopes to collaborate with other national organizations and governments in this effort.

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