

NATIONAL PROGRAMME OF PALLIATIVE CARE



DIRECTORATE-GENERAL OF HEALTH

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INTRODUCTION

The dominant culture of society has considered treatment of disease as the main aim of the health services. Within this context, the incurable and the inevitable reality of death are almost regarded as a failure in medicine.

In effect, the approach to the final stage of life has been viewed, in the health services, as a strange and disturbing practice with which it is difficult to deal with.

The hospital, as known to us, adapted itself and structured itself, with high technological sophistication, so that the disease should be treated in using all resources. However, when one faces the failure of the usual means of treatment and the patient is, undoubtedly, treading towards death, the hospital is seldom prepared to treat and care the patient's suffering.

The health centre, which is essentially dedicated to health promotion and to disease prevention, has difficulty in responding to the multiple demands of these patients.

As a matter of fact, in an environment in which both the pressing character of the cure and of disease prevention prevail, the treatment and follow up of patients with intensive suffering in the final life stage becomes difficult. As does the help they need to continue to live with dignity and quality.

The National Network of Continuous Care, established by Decree-Law N. ° 281 of November 8, 2003, provides specific answers to patients in need of medium and long term care, either on an in-patient basis, at home or at day units.

Although, without doubt, the provision of palliative care practices is contemplated in the National Network for Continuous Care, the delivery of differentiated palliative care for patients in an advance stage of incurable situations and enormous suffering is not yet foreseen in that Network.

The practice of palliative care requires proper organisation and specific approach, provided by technical teams prepared for that effect.

We must overcome this situation. The ageing population, the increase of cancer and AIDS cause the patients, with lack of palliative care, to have a strong social and public health impact.

The solution for this problem is not simply based on the maintenance of hybrid responses in which they are, simultaneously, curative and palliative aspects. Nor do they fit within the Network of Continuous Care, which is essentially intended for overall recovery and maintenance of the chronic patients. Nor do they fit within the National Plan for the Fight Against Pain. This Plan is intended for physical pain and not for overall suffering.

The solution is based, rather, on the proposal made by the international movement of palliative care, which has, in the last decades, previously recognised an attitude of overall effort in valuing suffering and health quality, as a treatment goal as well as active and organised care.

In fact, the complexity of suffering and the combination of physical, and psychological factors in the final stage of life, make it necessary that the approach to such matters, with the value of health care remain, always, a multiple-disciplinary task. Such task, which congregates, not only the patient's family, the trained and differentiated professionals, the prepared and dedicated volunteers but also the community.

For that reason, the World Health Organisation considers palliative care as a priority health policy. It recommends a programmed and planned approach, within a perspective of overall support to the multiple problems of the patients who are in a more advanced disease stage and those in their final life stage.

Also, the European Council, acknowledging the existence of deficiencies and threats to the fundamental right human beings have to support and assistance in the final life stage, recommends more attention to the patients' life conditions. Namely, in what respects the prevention of their loneliness and suffering, providing the patient with the possibility of receiving care, in an appropriate environment, which may promote the protection of the incurable patient's dignity in the end-of-life stage. This being based on three fundamental principles:

- a) To defend the rights of the incurable and final-life-stage patient to a complete range of palliative care;
- b) To protect the rights of the incurable and final-life-stage patient providing them with freedom of choice;
- c) To maintain the absolute interdiction of, intentionally, putting an end to the life of the incurable and final-life-stage patient.

The Resolution of the Council of Ministers N. ° 129/2001 approves the National Oncological Plan 2001 – 2005. On one hand, it determines the delivery of palliative care, which is defined as one of its strategic goals in order to give continuity to palliative care in the final disease stage, planning its geographic distribution throughout the national territory. This, bearing in mind all possible means to get as close as possible the patients' homeground.

On the other hand, the National Health Plan of Health 2004 – 2010 identifies the palliative care as a priority scope of intervention.

Therefore, having taken into consideration that palliative care is recognised as a fundamental feature of health care, which requires qualified support as a necessity, in terms of public health, as an ethic imperative that promotes the fundamental rights and as a social obligation, the National Programme of Palliative Care is put in place.

The current Programme, created by a group of experts within the Directorate-General of Health, counts upon the scientific avail of the National Council of Oncology and it is designed to be put into practice in the care delivery networks contemplated in the Health System.

I – CHARACTERISATION

Palliative care constitutes an organised response to the need of treating, caring and actively supporting the patients in their final life stage.

The goal of palliative care is to ensure the best possible quality of life to the patients and to their families.

The family should be actively incorporated in the care delivered to the patients and on the other hand, they ought to be the object of care, either during illness, or mourning.

In order that the next of kin may, in a concerted and constructive manner, understand and collaborate with the adjustments, which the disease and the patient determine, they need to get support, information and instruction from the palliative care teams.

Palliative care has the following fundamental components: symptom relief, psychological, spiritual and emotional support to the families during mourning as well as interdisciplinary approach.

In the current Programme, palliative care embodies both principles and rights that universally constitute their basis and their specific character:

1. PRINCIPLES

The practice of palliative care is based on the following principles:

- a) asserting life and facing death as a natural process;
- b) facing disease as a cause of suffering to be decreased;
- c) considering that the patient is worthy of what he stands for and worthy of it up to the very end;
- d) recognising and accepting in each patient their own values and priorities;
- e) considering that both suffering and fear when facing death are human scenarios, which may be clinically and humanly supported;

- f) considering that the final life stage may contemplate moments of reconciliation and personal growth;
- g) based on the central conception that one cannot make use of a human being's life. Therefore, neither anticipating nor delaying death, repudiating euthanasia, assisted suicide and the therapeutic and diagnosis futility;
- h) embracing in an integrated manner the patient's physical, psychological, social and spiritual suffering;
- i) being based on the continuity of care, humanity, compassion, availability and scientific rigor;
- j) being centred in seeking the patient's wellbeing, helping the patient to live with quality, as much as possible, until the very end;
- k) being only delivered when the patient and the family accept it;
- l) respecting the patient's right to choose the place where he wishes to live and be looked after in the final life stage;
- m) being based on differentiation and on interdisciplinary.

2. RIGHTS

The practice of palliative care respect the patient's rights:

- a) To receive care;
- b) To have autonomy, identity and dignity;
- c) To have personalised support;
- d) To get relief from suffering;
- e) To be informed;
- f) To refuse treatments.

3. DEFINITIONS

In the scope of the current Programme, it is acknowledged by:

Palliative

Patient's relief from suffering.

Palliative Action

Whatever therapeutic resources bearing no curing intention, which aim at decreasing, either in terms of in-patient or domicile, the negative repercussions of the disease on the patient's overall wellbeing. The palliative actions are an integrated part of the professional practice, whatever the type of disease is or the stage of its evolution. These actions may be delivered either at the Hospital Network, or at the Continuous Care Network, namely in situations of irreversible condition or in progressive chronic disease.

Palliative Care

Care delivered to patients with intensive suffering situations, deriving from incurable disease in an advanced stage and rapidly progressing, with the principal objective of promoting, as much as possible and up to the end, their wellbeing and life quality. Palliative care is active care, co-ordinated and holistic, which comprise support to the family, delivered by teams and specific palliative care units, in terms of in-patient or at home, according to levels of differentiation.

Diagnosis and Therapeutic Futility

The diagnosis and therapeutic procedures, which are not adequate and useless regarding the evolving and irreversible disease situation and bringing about additional suffering to the patient and family.

II – RECEIVERS

Palliative care, exactly defined within the scope of the current Programme, is designed for the patients:

- a) Do not have any perspective of a healing treatment;
- b) Have a rapid progressive disease, and with limited life expectation;
- c) Have enormous suffering;
- d) Have problems and needs of difficult resolution that demand specific organized and multidisciplinary support.

Palliative care is not directed, within the scope of the current Programme, at patients in an acute clinical situation, either in recovery, in convalescence or with long term impairments, even if they are faced with an irreversible condition.

Palliative care is not determined by the diagnosis but by the patient's situation and needs. Nevertheless, the diseases that often require more organised palliative care are cancer, AIDS and some neurological diseases that are severe and progress rapidly. The characteristics of these diseases make the existence of symptoms and of needs more frequent due to their intensity, mutability and complexity. The individual and family impact are very difficult to solve, either within hospital services in general, or at a Network of Continuous Care level.

Palliative care is directed, in priority, to the final life stage but they are not only aimed at the dying patients. Lots of patients need to be looked after for many weeks, months or, exceptionally, before death.

III – MODEL

1. SITUATIONAL DIAGNOSIS

The organisation of palliative care is, still, incipient in the Country; existing no data, at a national level, which might enable to estimate the needs, which have so far not been met within this area. Nevertheless, taking into account the international experience, in Countries where Palliative Care was developed in the last decades, one could estimate about 1 000 patients per 1 000 000 of inhabitants and per year who are in need of palliative care¹.

2. FUNDAMENTALS

The current Programme is based on:

- a) the lack of palliative care matters;
- b) the principles and values defined by the palliative care pioneers by the World Health Organisation and by the European Council;
- c) the importance of the delivery of a complete range of differentiated palliative care within the Country's various regions and as near as possible to the users' domiciles;
- d) the initial character of the development of the palliative care in Portugal;
- e) the fact that the majority of patients in need of palliative care are those who suffer from cancer, AIDS, advanced organ insufficiency or degenerative neurological diseases;
- f) the importance and the need of implementing the strategic goals in matters of palliative care, defined by the National Oncological Plan 2001-2005;
- g) the importance and need of implementing the necessary interventions, in terms of management on suffering, consigned in the National health Plan 2004-2010;
- h) the advantage and the need of articulating the palliative care with that of the Hospital Network, the Health Centres and the Continuous Care Networks.

¹ To be outlined, as an example that, there currently exists in the United Kingdom, per million of inhabitants, about 50 in-patient beds and six teams of domicile palliative care.

3. DIFFERENTIATION LEVELS

The setting up of palliative care units, within the scope of the current Programme, should be, progressively, carried out and co-ordinated by the *Administrações Regionais de Saúde (ARS)*, in order to satisfy the needs that were not locally met with and to ensure the existence of differentiated training.

Palliative care units may deliver care on an in-patient or domicile basis covering a wide range of situations, ages and diseases.

In order to ensure a complete range of palliative care and to respect the principle of continuous care, each *ARS* should be ensured by an effective articulation between the different types and levels of palliative care, which exist within its geographic scope. This articulation requires the definition of criteria and respective protocols of articulation and reference.

Cancer patients represent a significant group in the palliative care users. In view of this, hospitals with oncological medical services or units should be regarded as number one priority to establish the means and structural models for the delivery of palliative care.

Palliative care should be planned, within the current Programme, according to the following levels of differentiation:

Palliative Action

1. It represents the basic level of palliative care and corresponds to the delivery of palliative actions without the resource to teams or differentiated structures.
2. It can and must be delivered either on an in-patient or domicile basis, in the scope of the Hospital Network, the Health Centres Network or in the Continuous Care Network.

Palliative Care - Level I

1. Delivered by teams with differentiated training within palliative care.
2. Structured by means of mobile teams that do not have at their disposal an inpatient basis but, in fact, have a physical facility available in order to organize their activity.

3. May be delivered either on an inpatient or domicile basis.
4. May be limited to a differentiated counselling performance.

Palliative Care - Level II

1. Are only delivered to self inpatient units or at home, by differentiated teams, which directly deliver palliative care and ensure supportive availability on a 24 hours basis.
2. Delivered by multidisciplinary teams holding differentiated training in palliative care. Besides medical doctors and nursing personnel, there are professional technicians who are indispensable for the delivery of an overall support, namely within the social, psychological and spiritual scopes.

Palliative Care - Level III

They meet with the conditions and adequate capabilities comprising Palliative Care - Level II added by the following characteristics:

- a) Development of structural and regular specialised training programmes in palliative care;
- b) Development of regular research activity for palliative care;
- c) Enlarged multidisciplinary teams with the capability of responding to highly demanding and complex situations regarding palliative care matters, assuming them as referral units.

IV – GOALS

1. GENERAL GOALS

The current Programme aims at obtaining the following general goals:

1. To respond, progressively, to the needs of the community, promoting the patients' easy access to palliative care in the scope of the various regions of the Country and as close as possible to the patient's domicile.
2. To respond to the patients' needs and preferences, providing them with a complete range of differentiated palliative care, either on an inpatient or domicile basis.
3. To promote the articulation between palliative care and other kinds of health care provisions.
4. To ensure the quality of the organisation and the delivery of palliative care, in terms of assessment and qualitative continuous promotion.
5. To set up conditions for differentiated training in palliative care.

2. SPECIFIC GOALS

1. To establish movable teams for palliative care of Level - I.
2. To establish and develop units for palliative care of Level II and Level III, with priority for the university and oncological hospitals.
3. To establish and develop units for palliative care of Level III with the capability of differentiating technical professionals in the scope of palliative care of Level III.

V – TEMPORAL HORIZON

The current Programme will develop gradually until 2010.

VI – TARGETS

The current Programme aims at obtaining the following goals:

1. On December 31, 2008 the below-cited units should be in operation.
 - a) 8 units of Level - I;
 - b) 3 units of Level - II;
 - c) 2 units of Level - III.
2. On December 31, 2010 the below cited units will be in operation:
 - a) 12 units of Level I;
 - b) 8 units of Level II;
 - c) 5 units of Level III.

VII – TRAINING

In Portugal, palliative care still does not require medical specialisation or individualised nursing. However, the complexity of the clinical situations, the variety of pathologies, the complexity of a wide therapeutic spectrum and the management of enormous suffering, naturally, need a solid and differentiated preparation. This must either involve the pre-graduate professionals' training demanding technical preparation, theoretical training and effective practical experience.

The differentiated training within the scope of the palliative care is a fundamental and indispensable aspect of the organisation and quality of this type of care. It should be directed at all the professionals involved therewith. Its technical content should be defined by the Directorate-General of Health, after the audition carried out by the Professional Associations and Scientific Societies.

The palliative care units of Level III have a particular role and responsibility in the training of the various professionals who will be part of multidisciplinary teams concerning palliative care. When implementing the current Programme, this aspect should be taken into consideration.

VIII – QUALITY

The values and principles, which inspire and guide the palliative care, are the first and foremost important qualitative criteria that should contemplate the overall organisation and provider of this type of care and, therefore, its continuous improvement.

The *Instituto da Qualidade em Saúde* will define the qualitative criteria that are specific within the scope of palliative care. They are to be divulged throughout by a Normative Circular of the Directorate-General of Health. These criteria, in which the definition of the professional health ratio/patient will have levels of demand or of variable applicability. This according to the type and level of the units of differentiation.

However, it is deemed important to enunciate beforehand within the scope of the current Programme, some of the general quality principles, which ought to be taken into mind when one considers both the organisation as well as the performance of the palliative care units.

From the outset, each palliative care unit should consider:

- a) its adaptation to the needs;
- b) its effectiveness and its efficiency;
- c) its equity and access assurance;
- d) its structures and its minimum performing resources;
- e) its good criteria practices;
- f) its achieved results;
- g) the patients, families and professionals' satisfaction;
- h) the mechanisms of internal assessment.

The structures and resources necessary for the performance of the palliative care units, naturally, depend upon the type, level of differential and the movement of assistance that derives from the communities' needs.

The movable teams, which may also act as consultants in palliative care, providing support to more complexity situations, are multidisciplinary. They should be set up, to say the least, by medical doctors, nursing personnel, social assistants and secretaries. They should count on the structural spiritual support of the volunteers.

These teams consist of technical professionals with differentiated training in palliative care. They can dedicate themselves to the practice of this type of care, on a part time basis.

In general terms, one considers, within the scope of the current Programme, that each module of inpatient Level II palliative care may have an average allocation ranging between 10 and 15 beds. And that each domicile team may provide palliative care to 10 – 15 patients. For this extension, one should consider a multidisciplinary team that will, at least, include:

- a) medical doctors, nurses and aid workers who should ensure the daily and effective visit during each day of the week, including calls and emergency visits at night;
- b) nurses who will ensure, on an inpatient basis, their effective stay on a 24 hours basis;
- c) aid workers who will ensure, on an inpatient level, their effective stay on a 24 hours basis;
- d) daily psychological aid for patients and with support to both families and professionals;
- e) physiotherapists who will ensure the individual therapeutic plans;
- f) professional social service workers;
- g) structural spiritual support;
- h) secretariat;
- i) unit management;
- j) technical co-ordination of the unit.

The domicile teams for palliative care should ensure telephone support on a 24 hours basis, emergency visits and an effective articulation with in-patient units. This procedure will enable an easy and quick access, whenever deemed necessary, to in-patient in a palliative care unit.

The palliative care units with a more differentiated level should be allocated with resources, which will enable the development of training and research activities, which are inherent to them.

The integration of volunteers in the palliative care units is an important feature for the quality of care. The volunteers, supervised by a technical team, can become a fundamental liaison link between the community, the patient, the family and the

health professionals. They can, also, introduce a particular human richness in what respects the welcoming, being present and in listening. This is extremely vital in the final life stage. Nevertheless, it is necessary to have written criteria for its selection, its integration and its assessment. This task will be defined by the Directorate-General of Health.

For the palliative care, minimum requisites of instalment and performance should be put into practice. They will be established in a Circular Normative of the Directorate-General of Health. However, the quality of the palliative care makes it necessary that its provision takes place in a particularly welcoming environment.

IX – FINANCING

The setting up of palliative care units is susceptible of co-financing through the structural funding of the Operational Programme, Health “Health XXI”, 3rd. Community Cadre of Support, in what refers to:

- a) works of adapting or remodelling installations and equipment – Measure 1.2 “Areas of Strategic Acting”;
- b) training to be carried out in Portugal or abroad – Measure 2.4 “ Training Support to Projects concerning Health Modernisation”.

The setting up of palliative care units by the social, private and co-operative sectors is susceptible of co-financing through structural funds contemplated in Measure 3.1 “Creation and Adaptation of Health Care Providing Units” pertaining to the Operational Programme, “Health XXI”, 3rd. Community Cadre of Support.

X – FOLLOW UP AND ASSESSMENT

The execution of the current Programme is followed up and assessed by the *Administrações Regionais de Saúde* at the regional level and by a Commission to be set up and to be functioning under the direct dependency of the Directorate-General of Health at the national level.

