The National Health System Palliative Care Strategy

2007 HEALTHCARE
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National Health System

Palliative Care Strategy

Strategy approved
by the National Health System
Interterritorial Council
on March 14, 2007



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Prologue

This Palliative Care Strategy is encompassed within the National Health System Quality Plan, one of the objectives of which is to improve the care provided to those patients with prevalent diseases entailing a major social and economic burden.

It is estimated that more than half of those who die each year in Spain go through an advanced and terminal stage. Providing an appropriate response to the many physical, emotional, social and spiritual needs of each one of these patients and their loved ones supposes a major challenge for the Healthcare System. One of the aspects most highly emphasized when planning this Strategy was precisely that it be based on the system's integral, coordinated response to all of the patients who were to be in need this care, wherever and whenever they were to need it.

As the World Health Organization has emphasized, palliative care is one of the cornerstones of the care provided for patients with cancer and other advanced and terminal-stage chronic processes.

Palliative care has developed increasingly in Spain over the past few years. We have some models of excellence which have contributed to a better knowledge of the needs of these patients and their family members and how to deal with these needs. There is, however, a considerable degree of heterogeneity in the distribution of the resources and in the care models. It is therefore advisable to advance toward more equitable access and a more highly effective, efficient and ethical use of the resources.

Improving the quality of palliative care also requires the continuing incorporation of scientific evidence and the regular, systematic evaluation of the care-providing process.

This Strategy sets out a collaborative, interdisciplinary model based on the coordination among levels of care and among specific, conventional palliative care resources. It is also recommended that the training at all care-providing levels be optimized.

One outstanding aspect is the incorporation of an evaluation system based on a set of indicators and reports of a qualitative type in order to keep track of what has been achieved and set out a continuing improvement of the strategy.

I would like to emphasize the wide-ranging consensus existing among the different players involved in the Strategy, both the Technical Committee as well as the Institutional Committee, who have most generously enriched this document at the successive working meetings held. My acknowledgment and gratitude to all involved, as I am certain that their work will indeed contribute to relieving the suffering of many.

Elena Salgado Méndez
Minister of Health and Consumer Affairs

Introduction

Despite the major medical advances over the past few years, providing suitable care for the growing number of elderly individuals, patients with chronic degenerative diseases and cancer still continues to be a major public health challenge. Many of these patients will evolve into a terminal stage, characterized by intense suffering and a high demand for care.

In Spain 380,000 persons die annually, it being possible to estimate that 50%-60% of these individuals die after going through an advanced and terminal stage[1]. These large numbers should not overshadow the unique, transcendental end-of-life experience of each individual human being.

The main objective of palliative care is to relieve the suffering and enhance the quality of life of these patients to the farthest extent possible. This necessarily involves the healthcare professionals and Administrations taking up the challenge of delivering integral care which will take into account not only the physical, emotional, social and spiritual aspects, but which is also provided in the ideal location[2], placing special emphasis on the dying process and taking the family members into account in the bereavement process whenever necessary.

In 1990, the World Health Organization emphasized the development of palliative care programs, facilitating the availability of opioids and improving the training of professionals in palliative care as being the cornerstones of relieving suffering[3].

European Council of Ministers recommendation 1418 (1999) emphasizes the need of recognizing and safeguarding the rights of citizens to palliative care[4]. Recommendation 24 (2003) similarly underlines that it is the responsibility of the governments to guarantee that palliative care will be accessible to all those in need thereof[5]. This recommendation stresses the need of developing a coherent, integral national policymaking framework for palliative care which includes nine sections: guideline principles, structures and services, care policy and organization, quality improvement and research, education and training, family, communication, teamwork and bereavement. Palliative care must be an integral part of the countries' healthcare systems and, as such, must be an element of the general health plans and of the relevant specific programs (i.e. cancer, AIDS or geriatrics).

In response to these recommendations, the Ministry of Health and Consumer Affairs published the Bases for the development of the National Palliative Care Plan in 2001, these Bases having been approved by the Interterritorial Council on December 18, 2000. These Bases called for integral care integrated into the healthcare network and broken down by healthcare districts with a suitable coordination of levels and the participation of interdisciplinary teams[6].

In May 2005, the Health and Consumer Affairs Commission of the Congress of Deputies passed a non-Law proposal on palliative care[7]. The Government was urged therein to promote an analysis of the current status of palliative care in Spain in the Interterritorial Council and to develop a Palliative Care Plan for the National Health System (NHS) to include organizational, structural, training, awareness-heightening and information-related aspects.

In December 2005, the Directorate General of the Quality Agency organized the "Palliative Care in the NHS: Present and Future" Meeting, during which the current status of palliative care in Spain was reviewed in depth, the conclusions (Annex II) served, in conjunction with the prior references, to initiate the process of drafting this Palliative Care Strategy for the National Health System.

The National Health System Cancer Strategy, which was approved by the Interterritorial Council on March 29, 2006 and was integrated into the Ministry of Health Quality Plan, devotes an extensive section to palliative care, emphasizing as top-priority objectives the integral care of patients and their family members and the assurance of a coordinated response among the levels of care in each district, including the specific palliative care provided in hospital and on a homecare basis[8].

Antonio Pascual López
Scientific Coordinator of the Strategy

Technical note

This document is comprised of three parts:

1. General aspects – detailing the Strategy justification and purposes and the current status of palliative care in Spain (p. 19-44).
2. The NHS Palliative Care Strategy objectives approved by the National Health System Interterritorial Council on March 17, 2007 – detailing the Strategy objectives and recommendations prioritized and generally agreed upon by the Technical Drafting Committee and the Autonomous Community Institutional Committee (p. 45-109).
3. The Strategy evaluation and information system making it possible to effectively follow-up on the actions in order to achieve the Strategy objectives (p. 111-123).

1. General aspects

1.1 Justification

Advanced and terminal-stage patients have a great need and demand for being provided with care involving all levels of care in the healthcare system. Twenty-five percent of all hospitalizations are of patients in their last year of life, additionally entailing very high costs[9]. For different reasons, one of the most important of which is the current predominantly cure-oriented Medicine and the limited degree of training in palliative care, the standard care received by terminal-stage patients has not as yet been developed to the necessary degree. Situations of both hard-fought struggles and abandonment of treatment have been found to coexist with one another[10].

There is a widespread demand for quality, human being-focused care at reasonable costs affording the possibility of living and dying with dignity. The priorities of the patients are: having their symptoms relieved, avoiding undue prolonging of their situation, having a feeling of control over the decision-making, not being a burden and tightening the bonds with their loved ones[11].

Palliative care is aimed at providing a professional, scientific and humane response to the needs of advanced and terminal-stage patients and their family members. The main objectives of palliative care are[12] :

1) Taking care of the pain, physical symptoms and the emotional, social and spiritual needs and practical aspects of the care of patients and their family members.
2) Information, communication and emotional support, assuring the patients that their voices will be heard, taking part in the decisions made, being given clear, honest answers and expressing their emotions.
3) Assuring care continuity throughout their entire evolution by setting up coordination mechanisms among all of the levels and resources involved.

All healthcare professionals must provide the patients they are caring for with palliative care at both the hospital care and homecare level.

The primary level of care plays a core role in integral care at the community level[13, 14, 15, 16, 17]. In those patients with more highly complex

needs, evidence exists supporting the benefits of coordination with the palliative care teams [18, 19, 20].

In Spain, there has been a rapid growth in the palliative care programs and services in response to the major demand and the growing interest on the part of the healthcare system in meeting this demand[21]. Nevertheless, improving the accessibility to palliative care on the part of all of the patients who need this care and the quality of the care received still as yet continues to be one of the current challenges in healthcare.

One of the most outstanding critical points is the heterogeneity of resources among the different Autonomous Communities, a small degree of specific palliative coverage in cancer patients and even less in non-oncology patients and therefore sometimes delayed interventions on the part of palliative care teams. In regard to pediatric, oncology and non-oncology patients, specific palliative homecare coverage is practically nonexistent.

The term “palliative care” makes reference to an entire warm, humanistic philosophy of caring for patients and their family members. Additionally, a modern palliative care concept implies sound organizational, training and research bases.

The National Health System Palliative Care Strategy is aimed at contributing to guaranteeing the right to the relief from suffering through an equitable, effective response on the part of the healthcare systems.

The reaching of generally-accepted agreements and shared implementation of experiences and good palliative care practices in the different Autonomous Communities (AC) stands as a guarantee of achieving the objectives set.

1.2 Strategy purposes

Mission

To enhance the quality of the care provided to advanced and terminal-stage patients and their family members by promoting the integral coordinated response of the healthcare system to their needs and respecting their autonomy and values.

Objectives

To set out appropriate feasible, measurable commitments on the part of the Autonomous Communities (AC) in order to contribute to the homogeneity and enhancement of the palliative care provided in the National Health System.

Values

- Right to relief from suffering
- Intrinsic value of each person as a unique, autonomous individual
- Quality of life defined by the patient
- Expectations of the patient and family as to the response to be provided by the healthcare system and their end-of-life needs.
- Solidarity toward suffering

Principles

- Accompaniment of the patient and family based on their needs
- Equitable, accessible, integral care
- Care continuity and coordination of levels of care
- Straightforward, open communication
- Ethical reflection and participation of the patient and family in the decision-making process
- Continuing professional development and skill enhancement to suitable respond to the needs of patients and their family members.
- Interdisciplinary teamwork
- Treatment measures based on the best available evidence
- Non-discrimination in terms of age, gender or any other personal aspect.

1.3 Target population

This strategy is addressed to patients of any age who have cancer or chronic degenerative diseases who are in the advanced / terminal stage. The palliative interventions shall be based mainly on the needs of the patient and their family members more than on a specific set expected survival timeframe.

The criteria proposed for defining a patient with an advanced / terminal-stage disease has been[22]:

- Progressive, advanced, incurable disease
- Prognosis of limited life expectancy
- Highly unlikely response to specific treatments

- Fluctuating evolution and frequent crisis of needs
- Intense emotional impact on family
- Repercussions on the care-providing structure
- High demand for and use of resources

Annex I includes the characteristics of the advanced / terminal-stage situation in different patient subgroups:

— Patients with cancer
— Patients with degenerative chronic diseases
— Small children

1.4 Palliative care definition

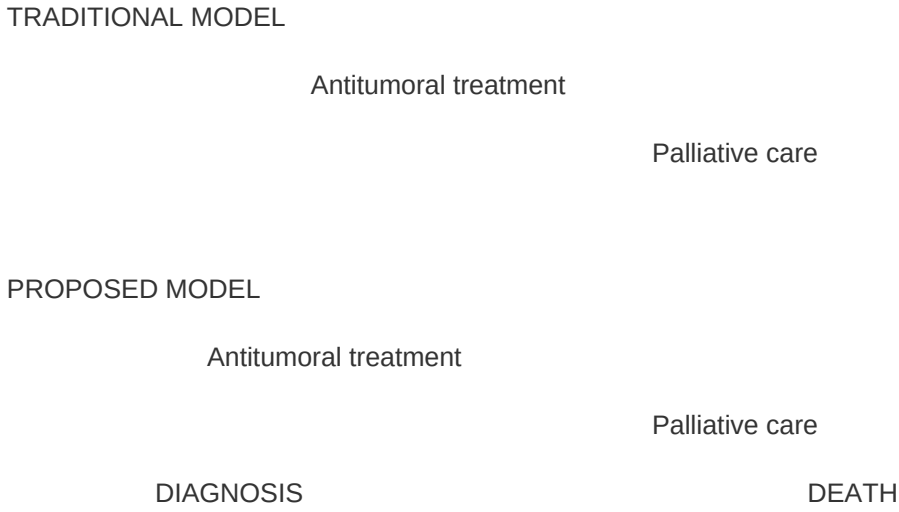
In a key document for the development of palliative care published in 1990, the World Health Organization (WHO) adopted the definition proposed by the European Palliative Care Association as the "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount." It stressed that palliative care must not be limited to the final days of life but rather be implemented progressively as the disease advances in terms of the needs of patients and family members (Fig. 1)[23].

Later, the WHO broadened the definition of palliative care to: "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"[24].

This definition is completed by way of the following palliative care-related principles:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor 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

Fig. 1 Organizational models proposed by the World Health Organization for the care of oncology patients and palliative care



Source: World Health Organization. Cancer pain relief and palliative care. Geneva: WHO, 1994. Technical Report Series: 804.

- Offers a support system to help the family cope during the patients illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, 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.

1.5 Current status of palliative care in Spain

1.5.1 Past development of palliative care in Spain

The modern development of palliative care has its origins in hospice care, spearheaded in the United Kingdom by Cicely Saunders in the late seventies. Her book "The Management of Terminal Malignant Disease"[25] includes the full experience of the team at St. Christopher's Hospice throughout their first years of work. Afterward, homecare teams, day centers and hospital support teams were progressively developed[26]. In 1987, Palliative Medicine was established as a specialty in the United Kingdom.

In the rest of Europe, palliative care was developed as of the late seventies. The works of Vittorio Ventafridda in Milan on pain treatment in cancer, the setting up of the European Palliative Care Association and the development of institutional policies by some governments have been some determining milestones in its development.

The concept of palliative care units in acute hospitals came into being in Canada at the Royal Victoria Hospital in Montreal. The term "palliative care" seems more appropriate for describing the philosophy of the care given to terminal-stage patients, the "hospice" concept referring more to the physical structure of an institution.

In Spain, numerous professionals at both the community and hospital level have contributed to developing palliative care in their everyday work of accompanying patients and families. In 1985, a pioneering article was published dealing with the topic of terminal-stage patients titled "Medicine's untouchables"[27], based on the palliative experiences of the Oncology Department at the Marqués de Valdecilla Hospital in Santander. The Palliative Care Unit began functioning at the Santa Creu de Vic Hospital (Barcelona) in December 1987, and in 1989 at the Red Cross Hospital in Lleida.

In 1989 a Palliative Care Unit was created at the El Sabinal Hospital in Las Palmas on the Grand Canary Island. The symptom control manual published by this team has served as a point of reference for the large majority of Spanish professionals[28].

In 1991, the largest and most active Palliative Care Unit in Spain was promoted at the Gregorio Marañón Hospital in Madrid, which maintains major connections with different Latin American countries.

Similarly, two pioneering initiatives in palliative care were carried out in Madrid that same year. In District 4, a palliative care unit was gotten under way in primary care[29], and a specific continuing care program for terminal patients was developed in District 11 based on the coordination and collaboration between primary and specialized care.

Following these more personal, individual initiatives, some others began being carried out through the healthcare Administration. The most important was the *Pilot Programs for the Planning and Implementation of Palliative Care in Catalonia 1990-1995*[30] within the "Vida als Anys" (Life to Years) Program. This Program has been a determining factor in the development of palliative care not only in Catalonia, but also throughout Spain and Europe, as a result of its being a WHO pilot program which successfully globally resolved the incorporation of palliative care into the Public Health System both in homecare and at the hospitals in the public healthcare network. Afterward, another eight Autonomous Communities have developed Palliative Care Plans or Programs.

In 1991, the Primary Care Services Portfolio was created for the end purpose of explicitly setting out, standardizing and homogenizing the different services provided in the health programs and responding to the health needs (impact) and the demands of the consumers (satisfaction) nationwide managed by the "INSALUD" National Institute of Public Health Care[31].

Homecare for bedridden and terminal patients was included in the services portfolio as of 1991. In its fifth version, in 1995, terminal patient care is listed as a separate service.

As of 1995, terminal patient care coverage has increased from 44.5% to 51.3% in 2001 within the territory managed by the National Institute of Public Health Care[32].

In 1998, three health districts in the Autonomous Community of Madrid, in conjunction with the Subdirectorate General of Primary Care (National Institute of Public Health Care – INSALUD), started up the project "Homecare Support Team" Program (ESAD) for the purpose of enhancing the quality of the homecare provided within the scope of primary care to those patients with degenerative chronic diseases, with functional limitations and/or complex bedridden and terminal patients[33].

The Homecare Support Teams play the main role of supporting, training and counseling the primary care professionals for the purpose of providing good-quality Homecare. Similarly, to facilitate the coordination with the specialized level and the social services. One of the main aspects of this Program is care focused on the patient's home.

The results of an evaluation study conducted in 1998-1999 revealed that pain control in 83% of the patients with terminal cancer was being achieved, these being results similar to those described by other authors who were achieving 70%-90% control with the intervention of specific pain control or palliative care units[34, 35]. When exitus is at home, this was used as an indicator of the quality of the care provided, this having been achieved in 55.2% of the patients (65% in the case of terminal cancer patients and 87% in the patients cared for by Homecare Support Teams)[29]. In view of the results achieved in the pilot test, the Directorate General of Primary and Specialized Care decided to implement this model and program progressively throughout the rest of the National Institute of Public Health Care (INSALUD) territory.

In Catalonia, the Homecare support teams are known as the "PADES" (Homecare and Support Team Program. The precedents in Catalonia were the Homecare Program of the Santa Creu de Vic Hospital in 1984-1986 and the experience carried out at the Red Cross Hospital in Barcelona. The types of patients for whom this care is provided include the elderly and cancer patients.

Another of the community figures created for particularly complex homecare is that of the Liaison Nurse, which is encompassed within the set of measures which was started up following the publication of the Andalusian Government decree "Plan for the Support of Andalusian Families" of May 4, 2002 for the purpose of guaranteeing integral, continuing care to meet the care needs of patients and their lay caregivers at home. This figure meant a boost and an enhancement of the care of those patients having a great need for care and their family members, the target population of thereof placing priority on the terminally ill.

The Spanish Association Against Cancer (AECC) got its first Mobile Homecare Unit under way in 1991 for terminal patients in Madrid, having later expanded throughout the entire country. In 1991, the Order of San Juan de Dios expressed a special interest on the part of patients with chronic degenerative diseases and by terminal-stage patients, as a result of which the first Palliative Care Unit was gotten under way at the San Juan de Dios Hospital in Pamplona.

In 1992, the Spanish Palliative Care Society (SEC-PAL) was founded, encompassing the different professionals involved in palliative care on a multidisciplinary basis. This Society brings together nine federated autonomous community societies, the last to having joined having been the AEC-PAL (Spanish Palliative Nursing Care Association).

The official Spanish Palliative Care Society publication, the *Palliative Medicine* Journal and its website (www.secpal.com) are reference points in Spain and Latin America. The Spanish Palliative Care Society organizes a National Palliative Care Congress and scientific meetings annually.

Over the past few years, different scientific societies, such as the Spanish Family and Community Medicine Society (SemFyC), the Spanish Society of Medical Oncology (SEOM), the Spanish Radiation Oncology Society (SEOR) and the Spanish Geriatrics and Gerontology Society (SEGG) have contributed significantly to furthering palliative care in Spain.

The Spanish Family and Community Medicine Society (SemFyC) formed a Palliative Care Task force in 1988, which prepared some palliative care-related recommendations[36]. In 2001, an important document generally agreed upon between the Spanish Family and Community Medicine Society (SemFyC) and the Spanish Palliative Care Society (SEC-PAL) on homecare for terminal cancer patients[37]. A care organization framework was set out, specially focused on the responsibility of family physicians in homecare and the coordination among levels of care. Recently, the Spanish Family and Community Medicine Society has devoted a monographic issue of its Primary Care Journal to addressing integral care of advanced-stage oncology patients[38].

The scientific oncology societies have always devoted special attention to palliative care. In 2000, the Spanish Society of Medical Oncology (SEOM) created a Palliative Care Group, the objectives of which were to conduct an analysis of the palliative activity of the Medical Oncology services and to plan, develop and foster continuing care within regular clinical practice by encouraging communication, coordination and training with other specialties. In 203, the Continuing Care Section was created, which includes three areas of work: teaching, research and provision of care, coordinating a group of members of the Spanish Society of Medical Oncology (SEOM) who are actively involved in these areas[39, 40, 41, 42, 43, 44]. The publications of the Continuing Care Section include a reference manual[45] and different clinical practice guides[46, 47, 48, 49]. It also organizes a yearly Continuing Care course for residents and a Continuing Care Congress on Medical Oncology.

Apart from the above, the Spanish Society of Radiation Oncology (SEOR) created the Continuing Care and Support Section in 2005. One of the most outstanding objectives of this Section is the actual analysis of the activity in palliative care, setting out joint work with the European Society for Therapeutic Radiation and Oncology (ESTRO) and the American Society for Therapeutic Radiation and Oncology (ASTRO), promoting the training, care and research in continuing care within the specialty and training, information, dissemination and coordination with other specialties to aid in eliminating the existing differences among the different levels of care. The Spanish Society of Radiation Oncology (SEOR) devotes different activities to continuing care at its national biennial Congress and highlights some publications on support-palliation[50, 51, 52].

The Spanish Geriatrics and Gerontology Society (SEGG) has set up the End-of-Life Care Group, which is preparing technical documents on geriatrics and end-of-life care and on end-of-life advance planning among the elderly. This Society has published a monograph on palliative care in the elderly[53] and a monographic issue of the Spanish Geriatrics and Gerontology Journal on palliative care[54]. The upcoming Congress of the SEGG will be revolving around end-of-life care.

1.5.2 Regulatory framework

Care for terminal-stage patients is a right recognized by international organizations and a healthcare benefit clearly detailed under Spanish law.

The World Health Organization has drafted technical reports on several occasions urging the member States to set out measures to control cancer-related pain by means of providing palliative care, recommending the use and the availability of opioids[55], proposing strategies for symptom control[56] or reviewing cancer-related pain treatment in children[57].

On its part, the WHO Regional Office for Europe has contributed reviews in recent publications of the evidence in support of starting up terminal-stage patient care programs, mainly by way of abstracts of the best available evidence in different fields[58, 59]. Two of these publications (*Palliative care – the solid facts*[60] and *Better palliative care for older people* [61]) have been translated into Spanish and distributed by the Ministry of Health and Consumer Affairs[62, 63].

Although starting up health programs does not come under the authority of the Council of Europe but rather of the member States, this organization does set out recommendations which are customarily taken into account by the States. Hence, the right to receive end-of-life care has been in some way been approached in European resolutions and recommendations[64].

One thereof, Resolution 613 (1976)[65] on the rights of patients and the dying revindicates the right of terminal-stage patients to die peacefully with dignity; Recommendation 779(1976)[66] considering that physicians must make every effort to relieve suffering; and the Resolution on the respect for human rights (1995)[67] having requested the States to grant preference to the creation of palliative care establishments.

In most of our neighboring countries, the philosophy and values reported by the health systems revolve mainly around the ethical theories of distributive justice and health being considered a right of citizens which the public powers are under the obligation to safeguard, forming part of and being a cornerstone of the Welfare State.

Royal Decree 63/1995 of January 20th on the ordering of the National Health System Health Benefits defined the rights of the health system consumers to the safeguarding of their health on generally regulating the benefits provided by the public healthcare system.

It is set forth under Article 7.1 of the National Health System Cohesion and Quality Law 16/2002 of May 28th that the National Health System catalogue of benefits is for the purpose of guaranteeing the basic common conditions for continuing integral care at the appropriate level. This law considers the National Health System healthcare benefits to be the preventive, diagnostic, treatment, rehabilitation and health promotion and maintenance services or set of services addressed to citizens, lastly stating the benefits to be encompassed in this catalogue.

Article 8 of the aforesaid law sets forth that the healthcare benefits in the catalogue shall be provided by means of a portfolio of common services which, as stipulated under Article 20, shall be agreed upon within the National Health System Interterritorial Council and shall be approved by Royal Decree.

Royal Decree 1030/2006 of September 15th setting out the portfolio of common services of the National Health System and the procedure for their updating, undertake to update the benefits set forth under the prior Decree of 1995 and details the same, including both in the portfolio of primary care and specialized care services a specific section describing the benefits to be offered to the population (Table 1).

Over the past few years, the Council of Europe has published two specific recommendations on palliative care. Recommendation 1418 (1999)[4] on the protection of those patients in the final stage of their lives, advocated palliative care being defined as a right and as one further healthcare benefit. Lastly, Recommendation 24 (2003)[5] on the organization of palliative care recognized that this benefit should be developed more in Europe and recommended to the State the adoption of policies, legislation and other measures necessary to set out a coherent framework for the national palliative care policies.

There has been a rapid response to the European recommendations in Spain. In 1999, the Senate Plenary Session of September 14th passed a motion urging the Government to prepare a National Palliative Care Plan[68].

Table 1. National Health System Palliative Care Services Portfolio

Primary Care

Palliative care of terminal patients

This care encompasses integral, individualized continuing care of persons with diseases in the advanced stage which are not subject to undergoing treatments for curative purposes and whose life expectancy is limited (generally, less than 6 months) as well as of the persons close to these patients. The treatment objective is to enhance their quality of life with respect for their systems of beliefs, preferences and values.

This especially humanized and personalized care is proved at the patients' homes or at the healthcare center, if necessary, by setting up the necessary mechanisms to guarantee the continuity of the care and the coordination with other resources, all in accordance with the protocols established for the corresponding healthcare service.

This care includes:

1. Identification of the patients in the terminal stage according to the diagnostic criteria and the natural history of the disease.
2. Integral assessment of the needs of patients and caregivers and setting out a written care plan including preventive measures, hygiene-diet recommendations, symptom control and general care.
3. Frequent evaluation and check of physical and psychological symptoms, indicating the pharmacological and non-pharmacological treatment of the pain and of other symptoms. Information and support for the patients throughout the different stages of the process.
4. Information, health advice, counseling and support to those close to the patient, especially the main caregiver.
5. In the situations which so require, particularly in complex cases, the care is provided by healthcare and/or social support structures or by specialized services, both in the physician's office and at the patient's home or by way of hospitalization, were the case to be.

Specialized care

Palliative care for terminal patients

This care encompasses integral, individualized continuing care of persons with diseases in the advanced stage which are not subject to undergoing treatments for curative purposes and whose life expectancy is limited (generally, less than 6 months) as well as of the persons close to these patients. The treatment objective is to enhance their quality of life with respect for their systems of beliefs, preferences and values.

This especially humanized and personalized care is proved at the patients' homes or at the healthcare center, if necessary, by setting up the necessary mechanisms to guarantee the continuity of the care and the coordination with other resources, all in accordance with the protocols established for the corresponding healthcare service.

This care includes:

1. Identification of the patients in the terminal stage according to the diagnostic criteria and the natural history of the disease.
2. Integral assessment of the needs of patients and caregivers and setting out a written care plan including preventive measures, hygiene-diet recommendations, symptom control and general care.
3. Frequent evaluation and check of physical and psychological symptoms, indicating the pharmacological and non-pharmacological treatment of the pain and of other symptoms. Information and support for the patients throughout the different stages of the process.
4. Information, health advice, counseling and support to those close to the patient, especially the main caregiver.

In 2001, following its approval by the National Health System Interterritorial Council Plenary Session of December 18, 2000, the document *Bases for development, National Palliative Care Plan*[6, 69, 70] was published, the purpose of which was "to guarantee the individual legal right of terminal-stage patients to care anywhere under any circumstance or in any situation", the general objective of which was "to enhance the quality of life of terminal-stage patients and their family members in a rational, planned and efficient manner by guaranteeing palliative care according to the governing principles of the National Health System". This Plan included in its annexes a document on end-of-life situations generally agreed upon among the General Council of the Judiciary and the Ministry of Health and Consumer Affairs (of May 3, 1999) and the aforementioned Council of Europe Recommendation 1418 (1999).

This plan also included a number of bases for further expansion thereon and urged the Autonomous Communities to develop the recommendations set out thereunder. Despite this plan having been approved by wide-ranging agreement, the measures were gotten under way to widely differing degrees, no major advances having been made until 2003.

In May 2003, the Government enacted the "National Health System Cohesion and Quality Law"[71] for the purpose of guaranteeing equity, quality and social involvement. This law defined the National Health System benefits corresponding to public healthcare, primary care, specialized care, sociosanitary care, emergency care, drug benefits, orthoprostheses benefits, dietetic product benefits and healthcare transportation benefits. Terminal patient care was considered as being one of the basic benefits in primary and specialized care and was guaranteed as of that point in time for all Spanish citizens.

As a complement to the Cohesion and Quality Law, for the purpose of further expanding upon the contents of the basic benefits, the "Royal Decree by virtue of which the portfolio of common services of the National Health System and the procedure for the updating thereof"[72] was enacted in 2006. Once again, the minimum content requirable for the care of terminal patients everywhere nationwide was set out in this regulation and the provision thereof guaranteed. One of the benefits described under this Decree was the identification, frequent integral assessment of the symptoms, information and referral to specialized mechanisms in cases of complexity.

On May 10, 2005, the Healthcare Commission of the Congress of Deputies passed a non-Law proposal urging the Government to evaluate the current status of palliative care in Spain, to enforce the document *Bases for development. National Palliative Care Plan* and to foster the creation of palliative care units on the part of the Autonomous Communities, among other actions[7].

1.5.3 Epidemiology

Need for palliative care among the population

The majority of the deaths which occur in Europe and in the developed countries are of persons over 65 years of age, showing a progressive upward trend, which is changing the patterns of end-of-life illness. Despite this, there is very little healthcare policy related to their needs during the last years of their lives.

A total of 21% of the population in Spain was over 60 years of age in 2000, this figure being anticipated to rise to 27% in 2020[73]. The segment of this age range which will proportionally be increasing to the greatest degree will be those over 85 years of age. It is anticipated that, by the year 2020, due to this aging of the population, the three leading causes of death in Spain will be: ischemic cardiac disease, cerebrovascular disease and chronic obstructive pulmonary disease. Lung/tracheal/bronchial cancer will be ranked as the fifth cause of death.

Due to all of the above, it is of major importance to approximate the figure for the population subject to receiving palliative care, methodological and recordkeeping problems however existing so as to define this population. In the literature reviewed[74, 75, 76, 77], they use records of mortality by cause or specific pathology records.

In our country, although specific cancer registries exist in the different Autonomous Communities, the information is not accessible or comparable in all cases.

The method which is proposed for estimating the palliative care target population has been similar to that described in the McNamara study[1].

- A review of bibliography has been made so as to ascertain the experiences in estimating palliative care coverage, the articles of McNamara[1], Murray[78] and Dy[79] having been chosen due to the degree to which they are in keeping with the objectives set out. The ten pathologies proposed by McNamara in his estimate of minimums have been selected: cancer, cardiac insufficiency, hepatic insufficiency, renal insufficiency, COPD, ALS and motor neuron diseases, Parkinson's, Huntington's, Alzheimer's and AIDS.
- The causes of death and the number of deaths due to these causes have been selected from the Spanish National Institute of Statistics (INE)[80] database. In some cases, pathologies have been associated in order to adapt them to the pathologies detailed by McNamara. The correspondence between the IDC-10 and National Institute of Statistics taxonomies is shown in Table 2.

The Spanish National Institute of Statistics (INE) has published the mortality figures and their classification by causes. From these figures, the number of deaths due to cancer and due to all of the other nine non-oncological causes selected by McNamara have been obtained. The results, broken down by Autonomous Communities, are provided in Table 3.

From 1997 to 2001, the average death rate in Spain was of 8,950 deaths/1,000,000 inhabitants/year. The cancer death rates range from 1,800 to 2,250 deaths/1,000,000 inhabitants/year. While the death rates taking into account the nine non-oncological causes all together range from 2,700 to 3,600 deaths / 1,000,000 inhabitants/year.

Just as in the McNamara study, the final population has been estimated taking into account the rate corresponding to the minimum of the range for oncology (1,800) and non-oncology (2,700) patients.

These calculations refer to average rates for the entire country, without going into specific aspects such as the dispersion of the population, age pyramid, etc. A closer calculation could be made for each geographical area (Autonomous Community, Health District …), attempting to come up with a figure generally-agreed upon for each scope[81].

Table 2. IDC-10 and Spanish National Institute of Statistics (INE) pathology taxonomy correspondence			
	Pathology	IDC-10* correspondence	Spanish Institute of Statistics Codes
Oncological	**Cancer**	COO-D48	0090-41 Tumors
Non-oncological	**Cardiac insufficiency**	150 100-102, 126-149, 151, 152	057 Cardiac insufficiency 058 Other heart diseases
	Renal insufficiency	N00-N29	077 Kidney and urethra diseases
	Hepatic insufficiency	K70, K72.1, K73, K74, K76.1.9	071 Cirrhosis and other chronic liver diseases
	COPD	J40-J44, J47 J00-J99	064 Chronic lower respiratory tract diseases (except asthma) 067 Other respiratory system diseases
	ALS and motor neuron diseases, Parkinson's, Huntington's	G00-H95	052 Other nervous system and sensory organ diseases
	Alzheimer's	F00-F09	**046, 051 and 060** 046 Organic, senile and pre-senile mental disorders
	AIDS	B20-B24	066 ADS

*** IDC-9 is currently used, IDC-10 being in the updating stage**
Source: IDC-10; International Disease Classification. INE: Spanish National Institute of Statistics

Table 3. Mortality by cause and Autonomous Community (2004)

Autonomous Community	Population	Deaths oncological pathology	Deaths 9 non-oncological pathologies	TOTAL deaths oncological + non-oncological
Andalusia	7,687,518	16,028	21,910	37,938
Aragón	1,249,584	3,534	4,529	8,063
Asturias	1,073,761	3,427	4,203	7,630
Balearic Islands	955,045	1,905	2,470	4,375
Basque Country	2,115,279	5,482	6,430	11,912
Canary Islands	1,915,540	3,450	3,819	7,269
Cantabria	554,784	1,492	1,891	3,383
Castile-La Mancha	1,848,881	4,430	6,139	10,569
Castile and Leon	2,493,918	7,397	9,282	16,679
Catalonia	6,813,319	16,182	20,794	36,976
C. Valencia	4,543,304	10,026	13,356	23,382
Extremadura	1,075,286	2,769	3,566	6,335
Galicia	2,750,985	7,848	10,597	18,445
Madrid	5,804,829	11,436	14,653	26,089
Murcia	1,294,694	2,485	3,524	6,009
Navarre	584,734	1,378	1,727	3,105
Rioja	293,553	763	981	1,744
Ceuta	74,654	110	145	255
Melilla	68,016	102	134	236
TOTAL SPAIN	**43,197,684**	**100,244**	**130,150**	**230,394**

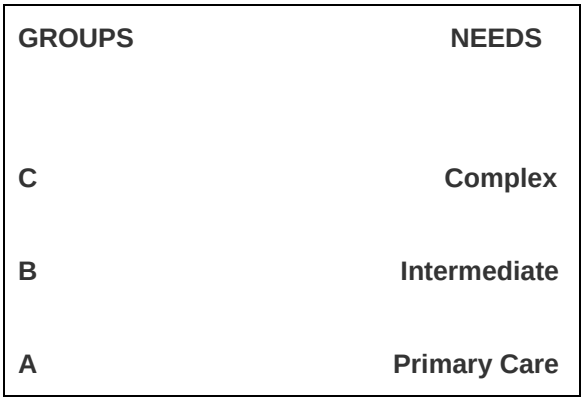
Source: Spanish National Institute of Statistics (INE) 2007.

Need of specific palliative care

Studies conducted in Australia estimate that 37.5% of the patients in need of palliative care are in intermediate or complex situations which may require the intervention of a specific palliative care team (Fig. 2)[82].

By additionally combining the calculations of other authors[83, 84, 85, 86], an appropriate palliative care coverage of 60% could be established on the part of the specific teams for oncology patients and a 30% coverage for non-oncology patients (always taking into account solely the 9 causes selected by McNamara).

Fig. 2. Conceptual model of level of needs of patients with terminal or advanced-stage diseases



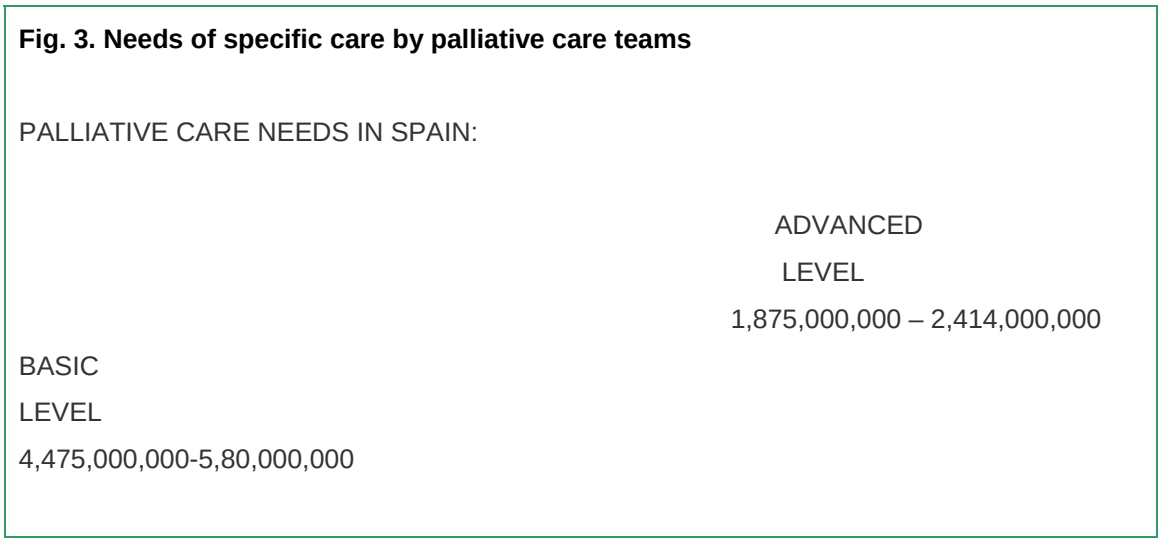
Source: Palliative Care Australia. A guide to palliative care Service development: a population based approach.2003, *www.pallcare.org*

According to these calculations and the palliative care need estimates described hereinabove, the anticipated care rates on the part of specific teams would be 1,875 to 2,415 /1,000,000 inhabitants/ year, as is shown in Fig. 3.

In regard to the number of specific mechanisms, in the United Kingdom, the European standard in providing palliative care, the rate is 1 per every 81,000 inhabitants[87]. In Australia, the recommended rate is 1 per every 100,000 inhabitants[88], and in two Spanish programs (Catalonia and Extremadura) rates of 1 per 100,000 - 200,000 inhabitants[86] and 1 per 135,000 inhabitants[75] have been respectively described.

The latest information on human resources and materials (structure, type of activity, patients for which care has been provided by pathologies, professionals and teaching activity) is available in the 2004 SECPAL Directory (see *http://www.secpal.com/directorio/)* which has been conducting a nationwide survey annually since 1997 which served as a reference for the Ministry of Health and Consumer Affairs document *Bases for development. National Palliative Care Plan.* Nevertheless, it must be taken into account that numerous Autonomous Communities have enhanced and expanded their resources as of 2004.

Fig. 3. Needs of specific care by palliative care teams



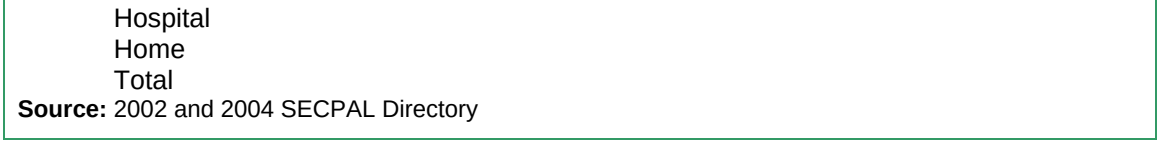
As is shown in Fig. 4, palliative care has developed in Spain maintaining a constant trend in regard to the number of resources since the early nineties, a growth of around 18 programs per year having been maintained. The ratio between hospital and homecare resources has remained constant, with minimal variations among Autonomous Communities.

The European Palliative Care Society's "Palliative Care Development in Europe" Task Force conducted a comparative study in 2005 and 2006 on different aspects of the development of palliative care in 42 European Countries[89, 90, 91]. Data is provided from any national study conducted in the countries analyzed or, were the countries not to have conducted any study or the studies conducted were outdated, from the best estimate based on the prior studies and the knowledge of the environment on the part of key individuals in palliative care chosen for this work precisely for their publications on national palliative development. Despite the possible biases, this data has been upheld by the executive committees of the national scientific societies and by the Task Force by drawing a comparison thereof with other international comparative studies[92, 93, 94].

The findings of this study are being disseminated in specialized journals[95, 96] and have been compiled in a monograph[97] titled *EAPC Atlas of Palliative Care in Europe*.

The Reports on the current status of palliative care in the 42 countries studied are available in the Internet institutional section of the aforementioned Society[98] .

Fig. 4. 1982-2004 trend in the number of specific palliative care resources



Source: 2002 and 2004 SECPAL Directory

Table 4 shows the number of specific palliative care resources in 22 Western European countries.

The country having the greatest allotment of palliative care resources in adult population is the United Kingdom, with more than 15 services /million inhabitants; Spain being ranked in an intermediate position, in 11th place of the 22 countries with regard to the resources available per million inhabitants. Spain avails of one third of the resources existing in the United Kingdom and one half of those available or existing in Belgium, Ireland or Sweden.

In the most highly developed countries, the number of beds specifically for palliative care totals around 5 / 100,000 inhabitants (United Kingdom, Iceland, Poland, Holland, Luxembourg and Norway). Solely specific Palliative Care Unit beds are taken into account. Beds devoted to advanced-stage patients in assisted living facilities, sociosanitary structures or Palliative Unit structures are not included. In France, Austria, Spain, Armenia, Germany, Italy, Denmark, Cyprus and Ireland, 2-3 palliative care beds/ 100,000 inhabitants are estimated. This data is provided in Table 5.

Table 4. Specific provision of palliative care resources in 22 European countries

Country	Unit admissions	Residences	Hospital support team	Homecare	Total specific resources	Population per million inhabitants	Service per million inhabitants
Iceland	2	0	1	3	6	0.3	20
United Kingdom	63	158	305	356	882	60	15
Sweden	40	5	10	50	105	9	12
Belgium	29	0	77	15	121	10	12
Ireland	8	0	22	14	44	4	11
Luxembourg	1	0	1	2	4	0	9
Holland	4	84	50	NK	138	16	8
France	78	0	309	84	471	61	8
Norway	12	2	16	1	31	5	7
Austria	18	7	10	17	52	8	6
Spain	95	1	27	139	262	43	6
Switzerland	12	5	7	14	38	7	5
Finland	2	4	10	10	26	5	5
Germany	116	129	56	30	331	83	4
Italy	5	90	-	153	248	59	4
Israel	5	4	3	14	26	7	4
Denmark	1	6	6	5	18	5	3
Cyprus	0	1	0	2	3	1	3
Greece	0	0	20	9	29	11	3
Malta	0	0	1	0	1	0	3
Portugal	3	1	1	3	8	10	1
Turkey	10	1	10	0	21	74	0.3

Source: Centeno C, Clark D, Rocafort J, Flores LA, EAPC Task Force on the Development of Palliative Care in Europe: 2004, EurJ Pall Care 2004; 11: 257-9.

Table 5. Provision of palliative care beds, totals and per million inhabitants

Country	Total specific beds	Ratio of specific beds for the population
Luxembourg	39	86
Sweden	650	72
Iceland	17	58
United Kingdom	3,180	53
Norway	220	48
Holland	716	44
Ireland	147	37
France	1,615	27
Austria	209	26
Spain	1,098	25
Germany	2,034	25
Belgium	216	21
Cyprus	18	19
Italy	1,095	19
Denmark	90	17
Finland	75	14
Israel	78	11
Portugal	53	5
Turkey	241	3

Source: Centeno C, Clark D, Rocafort J, Flores LA. EAPC Task Force on the Development of Palliative Care in Europe: 2004. Eur J Pall Care 2004; 11:257-9.

1.5.4 Critical points

A list of the critical points, prioritized and grouped according to the lines of the palliative care strategy is provided in following (1).

(1) The analysis of the critical points has been made by means of an open, participative discussion among the Technical Committee experts concerning a proposal to the Institutional Committee, followed by a prioritization by means of the adapted nominal group technique.

General aspects

- Need of palliative care universalization
- Inequities in accessibility
- Difficulties in defining terminality, particularly in non-oncology patients
- Very few programs devoted to non-oncology patients
- Very few programs devoted to pediatric oncology and non-oncology patients
- Late start of the palliative measures and lack of continuity therein

Integral care

- Identification and notification of the advanced and terminal status
- Need of a biopsychosocial approach, integrally assessing the needs of patients and families
- Insufficient support for the family environment
- Insufficient care provided for emotional problems and bereavement
- Need of clinical practice guides and protocols generally agreed upon and based on scientific evidence
- Insufficient psychological care for pediatric patients and their family members

Organization and coordination

- Lack of coordination of the care resources
- Deficit of human resources and palliative care structures
- Lack of implementation of interdisciplinary model and teamwork
- Needs of psychological support of the professionals
- Lack of definition of degrees of complexity and of inclusion and referral criteria
- Need for development of share care models with greater involvement of primary care
- 24-hour care continuity
- Very few social resources

Patient autonomy

- Very little emphasis on ethical and legal aspects of palliative care
- Need of fostering patient autonomy and involvement in decision-making
- Very little impact of the regulations on living wills
- Insufficient knowledge of palliative care on the part of society at large

Training

- Widespread demand for palliative care training
- Need of specific training of the palliative care team professionals
- Need of training in emotional aspects

Research

- Small number of projects funded
- Very little evaluation and few unified standards

Table 6. Top-priority areas stressed by the Institutional Committee

- Advanced training
- Basic training
- Specific palliative care resources
- Palliative care in non-oncology patients
- Coordination of levels of care
- Degrees of complexity
- Organizational model
- Target population
- Social coordination

1.6 Methodology

Just as for the Strategies already approved in 2006 by the National Health System Interterritorial Council (NHSIC), this Strategy has been drafted starting from the basis of three elements:

1) The conclusions of the NHS Palliative Care Meeting organized by the Ministry of Health and Consumer Affairs in December 2005, marking the start of the drafting process.

2) An exhaustive analysis of the current status of palliative care in Spain and on the international plane for the purpose of identifying the background information, the current status of the

healthcare organization, the critical points and the available evidence on better practices. For this purpose, the palliative care plans currently in effect in the Autonomous Communities have been taken into account.

3) The election of the Scientific Coordinator and the setting up of the Strategy Drafting Committees.

Two committees were formed:

A Technical Committee comprised of the palliative care medical and nursing societies (SECPAL and AECPAL), medical oncology, radiation therapy, pediatric and nursing societies (SEOM, SEOR, SEOP and SEEO), geriatric societies (SEGG, SEEG) and nursing societies (FAECAP and AEC) and the Spanish Patient Forum, as well as by social workers and clinical psychologists.

An Institutional Committee bringing together the representatives appointed by the Autonomous Community Health Councils, one of the main duties of which has been to evaluate the suitability and feasibility of the objectives proposed, given that the Autonomous Communities proper and their Health Services are the ones responsible for organizing and providing the services.

On the part of the Ministry of Health and Consumer Affairs, the Directorate General of the Quality Agency, through the Health Planning Office has been in charge, in conjunction with the Technical Coordinator, of heading this work with the support of the Health Information Institute and an external consultants' office.

These two Committees have worked jointly and interactively both by means of attending meeting, by e-mail and through the use of other computer tools.

In a first stage, the critical points of the National Health System in providing care for advanced and terminal-stage persons were identified. To this end, the Autonomous Communities set out what were, in their judgment, the priorities to be dealt with and, based thereon and on its own experience, the Technical Committee pointed out those critical points in the care-providing process which displayed the greatest deficiencies or inequalities.

Based on these deficiencies and in order to achieve the greater quality and equity of the system, the objectives and recommendations were set out and presented to the Interterritorial Council on March 14, 2007.

For all of the lines of strategy as a whole, indicators were identified with the help of the Health Information Institute which will make a continuing, systematic evaluation possible in order to afford the possibility of following up on and evaluating the Strategy throughout the process of its being

carried out by means of an information system feasible for the entire National Health System and all of the palliative care plans and programs as a whole currently in existence in the Autonomous Communities.

The document structure

The document is structured into three parts:

Part One – General aspects – which includes the justification, the purposes of the Strategy (mission, principles, values on which it is inspired), the definition of palliative care and the current status of palliative care in Spain, then taking up the development thereof in the past and epidemiological situation and, lastly the drafting methodology.

Part Two – Development of the strategy lines – in which the objectives and recommendations are detailed.

The general agreement of those taking part in the preparation of the Strategy resulted in the following lines of strategy having been defined based on a framework of values and principles discussed in the preceding section hereinabove:

- Strategy line 1: Integral care
- Strategy line 2: Organization and coordination
- Strategy line 3: Patient autonomy
- Strategy line 4: Training
- Strategy line 5: Research in palliative care

The strategy lines are set out in overall and specific objectives along with the corresponding technical recommendations. Additionally, a section of examples of good practices carried out in Spain which have shown themselves to be of proven efficacy and effectiveness is included. Lastly, it must be explained that the order in which the strategy lines are presented is dictated by the theoretical pertinence of the health planning focus and the internal coherence of the Strategy.

Part Three – The Strategy evaluation and information system – which includes descriptive information, indicators and a qualitative report.

In conclusion, this document is aimed at setting out a set of objectives and recommendations, based on the available information /evidence, to realistically be achieved in terms of the resources available and the scope of the Autonomous Community authorities which will contribute to enhancing the quality of the interventions and results of the palliative care provided.

2. Development of the lines of strategy

2.1 Integral care

2.1.1 Analysis of the current status

The main objective of palliative care is to relieve suffering and to enhance the quality of life of these patients to the extent possible. Each treatment meeting among the healthcare professionals and these patients at any level of care must deal with the physical symptoms, the emotional, social and spiritual problems as well as practical aspects such as situating the care in the ideal location[99]. Similarly, exquisite care will be required during the dying process in addition to accompanying the family members in the bereavement process whenever necessary.

End-of-life needs

Palliative treatment is for the purpose of maintaining or enhancing the quality of life of those patients who are suffering from an incurable disease. This care must be based on need[100] and focused on relieving suffering.

One of the characteristics of the care model proposed in the document *Bases for development. National Palliative Care Plan* is that of "integrality", which is understood as that which covers all of the patient's needs, including the healthcare, psychological, social and spiritual needs. The multidimensional approach was initially defined in the sixties by Cicely Saunders[101] on describing the concept of total pain and was later adopted in the WHO reports, being considered the best model for integral care, given that it stresses the patient's own perception concerning their disease process.

Within this context, the immediate family and social environment have been considered from the start as being part of the whole to be treated. In fact, the home is the place where terminal-stage patients spend most of their time and where the family members provide up to 80%-90% of the care. It is probably for this reasons that the lay caregivers have a higher morbimortality and must be on both the giving and receiving ends of care[102].

According to the study "Effectiveness of a case management model in homecare in bedridden terminal patients, hospital admissions and lay caregivers"[103] conducted during the 2003-2005 period in the Primary Care Health Districts of Malaga, Almeria, Granada and Costa del Sol, the homecare model implemented revealed itself to reliably identify those patients who are most vulnerable and to have a positive bearing on the functionality of the hospital admissions, the overload of the caregivers and the use of healthcare services, generating a smaller number of visits to the home by the intervention group, the obtaining of a greater number of social aids, of interventions on the part of the social worker, of physiotherapy and fewer visits of the caregiver to the health center. To the contrary, it does not seem to have any effects of the functionality, mortality, institutionalizing or readmissions of the most deteriorated patients.

Table 7 describes the dimensions of caring for terminal-stage patients, the elements thereof being classified into major groups: assessment; physical, psychological, social, transcendental-spiritual needs; practical matters; needs during the dying process; care during the dying process or bereavement care[104].

Table 7. Dimensions of terminal patient care

Handling the disease (disease assessment)	— Oncology/non-oncology history (previous admissions) — Main diagnosis — Prognosis — Comorbidity: secondary diagnoses — Patient's degree of knowledge of the disease. Information/ knowledge — Allergies, drug side effects, adverse effects — Toxic habits (smoking, drinking, others) — Mediation: regular/specific/symptomatic
Physical needs	— Functional repercussion of the symptoms — Cognitive condition, degree of consciousness — Autonomous /dependent function (motor→mobility, excretion, intake / senses→hearing, sight, sense of taste, touch, smell /psychological → rest / sexual — Food and fluid intake — Pain and other symptoms (cardiorespiratory /gastrointestinal (nausea, vomiting, food intolerances, constipation) / mouth conditions (dryness, mucositis) / skin conditions (dryness, itching, rash, nodules) / general conditions → agitation, lack of appetite, cachexia, asthenia, weakness, hemorrhage, sleepiness, pleural discharge, ascitis, fever, chills-dysthermia, incontinence, insomnia, lymphedema, myoclonia, prolapses, sweating, syncope, vertigo. — Ulcers — Toxic habits: smoking, drinking

Table 7. Dimensions of terminal patient care (cont'd)	
Psychological	— Experiences, prior personality — Information: what the patient knows and wants to know — Adaptation: mood, how the patient responded to the diagnosis and to the terminality situation, need of communication, self-image, guilt feelings — Expectations: concerning the disease, concerning the quality of life. Motivation. — How the patient perceives the family / social support (suffering, scarce …). — Easy of accessing specialized psychological care
Social	— Values, beliefs — Evaluation by specific personnel (social work) for all patients following protocol — Affective relations: social role, isolation, family and/or community conflicts, family dynamic — Material/practical: resources, housing, comfortable environment, testament — Socioeconomic: employment needs (work-unemployment), assure resources for the patient/family — Sociocultural: leisure time, social activities, continue with their regular life, recognize values and beliefs — Care: current and foresee future needs (assure care continuity) — Family: leaves from work for performing the care of the patient, social aid for performing the care — Security, comfortable environment — Privacy, private life — Routines, rituals, recreations — Economic resources, expenses — Legal matters (i.e. delegation of powers for finances, for health expenses, advance directives, living wills, beneficiaries — Protection of lay caregivers — Guardianship, custody needs
Spiritual or transcendental	— Existential, transcendence — Values, beliefs, practices, affiliations — Search for the meaning of their disease — Need of valuing oneself for what one is — Need of their religious beliefs being respected — Knowing that their symbols and rites are respected — Giving meaning to their life (reconciliation, guilt, soul-searching — Sharing their spiritual concerns — Need of transcendence, through legacy or beliefs concerning life after death — Hope→matrix — Feeling of being alive, values — Spiritual counselors, rites and rituals — Symbols, icons

Table 7. Dimensions of terminal patient care (cont'd)	
Practical aspects	— Need of preserving their autonomy in the support in their basic and instrumental daily living activities — Need of having their personal care and business covered — Accessibility to the treatment team — Education on the care — Caregiver — Telephone access, transportation — Need of improving the access to resources and facilitating transportation — Need of economic coverage
Patient needs in the dying process	— Symptom control: difficulty breathing, anxiety, pain, delirium, fear, weakness — Comfort care — Communication, talk, be listened to — Take into account where the patient wants the care and accompaniment to be carried out, need of knowing the possibilities — Knowing who is going to accompany and care for them, the caregivers' need of also being cared for — Ending life (i.e. winding up business, ending relations, saying goodbye) — Donations (i.e. objects, money, organs, remembrances, ideas) — Covenant / adaptation in the decisions, resources — Knowing the seriousness — Providing a solution to pending legal, economic matters, legacies-inheritances, prior conflicts (personal-spiritual) — Last wills: treatments, sedation, what to do with the body, spiritual assistance — Religious and funeral rites
Patient's family's needs during the dying process	— Perception of the control of the situation by the healthcare personnel — Continuity in care and in the decisions — Accessibility to the appropriate resource — Foreseeing problems/situations: onset of symptoms/decisions/exhaustion-bereavement — Feeling of control-security and training: in caregivers/in handling symptoms-medication/written information — Explaining the reasons why and causes and possible outcomes — How to know one is dying. Following the dying process — Facilitating goodbyes: spaces for emotional expression = specific time — Training in death-related red tape — Foreseeing and handling psychological changes during the final hours of life — Inheritances — Funeral and religious rites

Table 7. Dimensions of terminal patient care (cont'd)	
Bereavement and losses	**Patient** — Recover physical, emotional losses, role… — Support: space for being heard — Solutions and alternatives — Adaptation to the physical, emotional losses, rele… **Family** — Accessibility of professionals — Emotional support (listening, company) — Knowing if what they are going through is normal — Orientation for overcoming, getting over the loss — Time / "taking leave" occupational aspects — Legal aspects (inheritances, guardianships…) — Review the final days and the decisions that were made — Prevention of pathological bereavement

Symptoms of the advanced/terminal stage of the disease

Different studies conducted in our environment have revealed the presence of many, multifactor and changing symptoms during the advanced and terminal stage[105, 106], sometimes lacking in assessment and control[107].

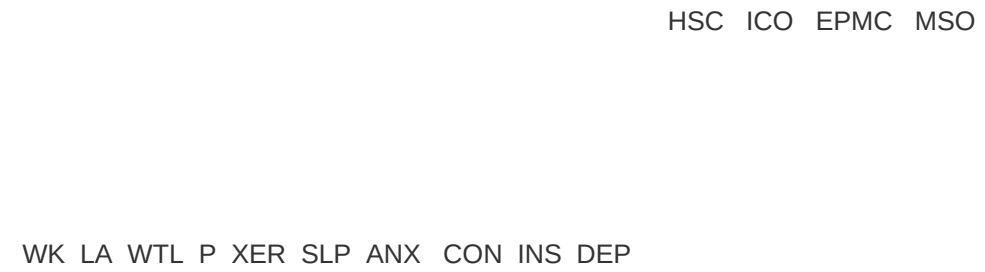
As conventionally defined in the past, terminal-stage patients have numerous problems or many, multifactor, intense, changing symptoms[108]. Although asthenia is generally the most frequent symptom[109], and pain is that which is considered paradigm, terminal-stage patients have on the average of 8-10 symptoms[110].

Different studies conducted in our environment have revealed the presence thereof during the advanced terminal stage[105, 106, 110], sometimes insufficiently controlled[107]. It must be explained that the frequency of the symptoms which is described in the different studies depends, in part, on where they are recorded (hospital, community, specific palliative care services), the stage of evolution in which they are measured (onset, dying process)[111] and by whom they are assessed (patient, caregivers or professionals)[112]. These factors make it difficult to compare different series.

Fig. 5 shows the frequency of symptoms in different environments: from the population-based study conducted in Catalonia in palliative care units at the Santa Creu I Sant Pau Hospital (HSC), the Catalonian Oncology Institute Service (ICO), and the population-based study "Dying of cancer in Catalonia" (EPMC) and the Multi-center Oncology Service (MSO) study[112].

The frequency of the symptoms also depends on the oncology cases, on the localization of the primary tumor, natural history and on the metastasis, it being known that these symptoms tend to gradually "cluster" in the most advanced situations, very particularly during the final days[113,114,115].

Fig. 5. Prevalence of symptoms in the population with oncological disease in different palliative care environments



Symptoms: Weakness (WK), Loss of appetite (LA), Weight loss (WTL), Pain (P), Xerostomy (XER), Sleepiness (SLP), Anxiety (ANX), Constipation (CON), Insomnia (INS), Depression (DEP).

Source: Espaulella J, Gómez X, Lozano A, Codorniu N, Moreno F, Argimón J. General principles of symptom control in advanced, terminal cancer patients. Jano 1997; 52 (1209): 1588-90.

Some authors have identified symptom clusters in the form of syndromes. This affords an overall handling of these symptoms and foreseeing complications. Recently, one study has identified 7 of these symptoms: tiredness, loss of appetite- cachexia, neuro-psychological, upper gastrointestinal tract, nausea and vomiting, aero-digestive symptoms, weakness and pain[116].

The symptoms are additionally multifactor. The precise diagnosis of the causes makes it possible to set out a more precise etiological treatment. Except in those cases in which means out of the ordinary are required beyond common sense or in the few cost-effective ones, it is important not to lose sight of the ability to set out a correct causal diagnosis. “Attention to detail” with a precise methodology, rationally employed, have a bearing on the treatment outcome.

The fact of the evolution of the symptoms usually being changing, in outbreaks or in crisis, due, in turn to the patient's weakness and the progression of the disease, makes it necessary for the assessments to be made frequently. This fluctuating evolution, with its major emotional impact and problems of adapting to the situation, explains in part the care pattern being based on demand and of quite particular characteristics, both at the hospital and in the home. The mechanisms involved in appropriately caring for advanced terminal patients must anticipate the evolution and adapt the organization to this type of needs.

Emotional aspects

The emotional impact, the worry and/or suffering of the patient are also clearly distinguishing elements of the situation and often undergo a seesawing. changing evolution[117]. These patients customarily display major degrees of emotional distress, which may be difficult to recognize and treat[118].

Coping with a diagnosis of cancer, the disease process, a prognosis of "incurable" and the fact of dying are undoubtedly events hard to deal with and usually cause a major psychological impact and tremendous suffering. In these situations, an intense flow of emotions and feelings emerges, which, due to their being difficult to handle, may give rise to an emotional breakdown not only in the patient but also in the family[119].

The intensity of the emotional suffering or the complexity of its handling makes suitable psychological care necessary for both the patient and the family members. In a recent study, it was found that the two most frequent reasons for referring patients were depressive (21.6%) and anxiety-related (14.9%) symptomatology, the most frequent reasons for family member referrals having been the problem of communication or conspiracy of silence 19.77%)[120].

Family care

One of the main principles of palliative care is that of considering the patient and family members as one single whole for which care is to be provided. The family and the patient's surrounding environment have many different needs and, at the same time, are actively involved in the care of their loved ones, particularly in the home[62, 121,122]. European Council Recommendation (2003) 24 states as one of its guiding principles that of helping those closest to the patients by fostering their ability to provide practical and emotional support, to adapt to the process and to deal with bereavement and absence[5].

Advanced, terminal disease causes intense suffering for family members. One of most outstanding of the many contributing factors are the emotional problems, such as existential fear, anxiety and depression, empathetic suffering, conflicts and deficient healthcare[123, 124].

Evidence exists as to many of these problems being cared for inappropriately with insufficient information and communication, emotional support and practical help[125].

The WHO report "*Better palliative care for older people*" highlights the importance of caregivers becoming increasingly older, with greater morbidity, particularly of the women, on whom this care has traditionally been based[62]. This same report also points out that some families with elderly members who need full-time care will find the financial cost and burden to be unmanageable and may become unbearable for elderly women taking care of their husbands whom they will outlive. More than 75% of the main lay caregivers are women, predominantly the wife in the case of male patients and the daughter in the case of female patients.

The usual profile of the main lay caregiver in our environment is a female – wife or daughter – who lives in the patient's home, often displaying physical and emotional problems and sleep disorders[126,127, 107, 128]. A total of 2%-5% of the persons over 65 years of age live in residences for the elderly and the chronically infirm requiring palliative care[129].

In the case of pediatric patients, the minor's adaptation to their disease depends to a great extent on how well their family is able to adapt to the situation.

At the same time that the family needs care, it has a major share in providing this care. The SECPAL-SemFYC document on caring for terminal cancer patients at home stresses the key role of the family, especially of the main caregiver, and states that without the support of the family, proper homecare would be impossible[37]. The counseling and reinforcement of the caregiving capacity form part of the palliative care objectives[130]. Some experiences exist of guides for caregivers of terminal-stage patients[131], and tools are being developed for evaluating the capacity for homecare[132].

Caring for a family member is often a source of gratification and recognition[133], taking into account also that one of the priorities of these patients is to tighten the bonds with their loved ones[134]. Nevertheless, the family may reach a situation in which they burn out, defined as an implicit or explicit manifestation of the family's having lost the ability to provide an adequate response to the patient's

demands and needs due to exhaustion or overburdening[135]. Once identified, this situation requires action being taken by a multidisciplinary professional, avoiding negative or blame-placing connotations for the family. It is recommended that multicenter research be carried out in order to delve deeper into the causes, precipitating factors and preventive and therapeutic strategies. Tools are currently being readied for evaluating caregiver burn-out[136]. One of the strategies proposed for the prevention and treatment of this burn-out is the temporary admission of the patient to give the family some rest[137].

Although there be a widespread impression of effectiveness of the palliative measures on the caregivers, some systematic, detailed evaluations are necessary[138]. Proposals exist of questionnaires for measuring the quality of life (QL) of these lay caregivers[139,140]. Some studies in our environment emphasize a high degree of satisfaction in caregivers of patients for whom care is provided in palliative care units[141,142].

The evaluation of the needs of bereaved family members and the development of care programs whenever necessary is one area where there is clearly room for improvement in palliative care. Accompanying bereavement is for the purpose of helping the patients and their family members to deal with the many feelings of loss experienced during the patient's illness and following their death[143].

Pioneering studies concluded in 1980 that the bereavement accompaniment programs were capable of reducing the risk of psychiatric and psychosomatic disorders[144]. Some studies have evaluated the effectiveness of interventions in bereavement groups in our environment[145,146]. Help documents exist for the family members[147]. A multicenter study on 160 Spanish palliative care groups has revealed that 88.6% of these groups included some type of bereavement support, although without any systematic planning and with little involvement of psychologists and social workers[148]. The diagnostic criteria of complicated bereavement were guilt (12.5%) and depression (11.4%).

Care complexity in palliative care

The document "*Bases for development. Palliative Care Plan*" defined in 2000 that all of the patients subject to receiving palliative care were under the care-providing responsibility of the entire conventional healthcare network as a whole and that, in situations of complexity, the intervention of specific services was required[6].

In terms of this complexity, the Plan set out some patient-related (difficulty of controlling symptoms, little response to conventional treatment, need of complex treatments, (difficulties in adapting emotionally) or family-related (difficulties in providing care or in adapting, risk of

pathological bereavement, caregiver burn-out) intervention criteria. Some authors have proposed more specific criteria for referral from the primary care teams such as the presence of intense symptoms (6/10) with an associated emotional impact without any solution following two visits[149]. In Australia, progress is being made in constructing a patient referral tool in the form of a grid of individually-accepted criteria[150,151].

In our environment, at an outpatient clinic located in a university hospital, some complexity-related descriptors have been described, such as the pain of poor prognosis or the intense symptoms measuring above 5 on the Analog Visual Scale (AVS) [152].

In the sociosanitary field, one attempt at describing a combination of criteria is the recent version of the Resident Assessment Instrument (RAI) for palliative care[153].

In any case, no method which is valid or associated to the costs of the intervention has as yet been described for the time being.

Complexity is actually a concept and a value which is multifactor in nature, and the degree of complexity will depend on all of the related factors as a whole and not on one certain individual characteristic in particular. Of all these factors, those associated with the patient (age, past history), those depending on the clinical situation (pain and other symptoms, dying process, presence of certain syndromes), the related to the emotional situation, those depending on the evolution of the disease (limited prognosis), those related to the family (burn-out or absence of a caregiver) and the ethical dilemmas are of particular importance.

The specific needs for the care of advanced or terminal-stage patients in terms of their age or characteristics of the disease are detailed in Annex I.

Protocols and guides

The Ministry of Health published a Palliative Care Recommendations Document in 1993 which was a widely-consulted starting reference[154]. Afterward, different guides and protocols – both general ones on palliative care as well as monographic ones on certain specific symptomatic, emotional and socio-family aspects have been drafted.

Within the framework of the development of the Ministry of Health and Consumer Affairs Quality Plan through the National Health System Quality Agency, the Program for the Preparation of Clinical Practice Guides is being carried out based on the evidence for the entire National Health System as a whole. To carry out this Program, in which the preparation of thirteen Clinical Practice

Guides has been prioritized, an agreement has been reached between the Carlos III Health Institute and Health Technologies Evaluation Agencies and Divisions of the Health Councils of several Autonomous Communities and the Latin American Cochrane Center. Within this Program, the Health Technology Evaluation Service of the Basque Government Department of Health (OSTEBA) is coordinating the preparation of the Palliative Care Clinical Practice Guide with the collaboration of the scientific societies and experts.

2.1.2 Objectives and recommendations

General objective 1

To provide those patients who have an advanced terminal disease and their family members with an evaluation and integral care in keeping with their condition to each point in time at any level of care throughout the entire evolutive process.

Specific objectives

1.1 Identify those patients in an advanced-terminal stage and record this identification on their medical record.

Recommendations

- The identification will normally be made by the physician responsible for the patient. In any case, an interconsultation with the corresponding specialists is advisable for the purpose of adequately defining the advanced/terminal condition and optimizing the palliative treatment plan.
- Define the criteria by which the situation of terminality is specified.

1.2 Avail of a treatment and care plan coordinated with the different primary and specialized healthcare professionals involved based on an integral evaluation adapted to the physical, emotional, socio-family, spiritual and cultural needs of the patients who have been identified as advanced/terminal-stage patients.

Recommendations

- A definite evaluation model including all of the needs and a system of classifying the care problems encountered shall be available within the individualized care plan.
- This model will include at least pain-related aspects and other symptoms, the functional capacity and the degree of dependency, the cognitive evaluation, the degree of knowledge of the situation, the psychosocial history and the treatment strategy, including a care plan.
- In primary care, regularly-scheduled appointments will be set according to the established treatment plan and the minimum criteria set in the palliative care process procedures. The appointment schedule for a patient in the final stage of life shall be set at least every 1-2 weeks in terms of the needs.
- The Primary Care Teams will avail of the instrumental and pharmacotherapeutic means necessary for providing care for the palliative patients.

1.3 Make an integral evaluation of the patient's family, placing particular emphasis on the main lay caregiver for the purpose of preventing their fatigue in carrying out their role, encouraging their taking good care of themselves and setting out the care they require.

Recommendations

- Following the death of the patient, the need for psychosocial support in the bereavement process shall be evaluated.

1.4 Make an evaluation of the care-providing capacity and provide educational support to the lay caregivers.

Recommendations

- The patient's main lay caregiver and the specific socio-family support network must be stated in a readily visible place on the patient's medical record.
- Implementation of a protocol for identifying the risk of the family burn-out.
- Implementation of a protocol for identifying the risk of pathological bereavement.
- In these protocols, special emphasis shall be placed on the case of small children, adolescents, elderly spouses and persons with very little social support.
- Set out mechanisms for referring patients to specialized professionals in situations of complicated bereavement.

1.5 Set out a monitoring system making it possible to evaluate the good control of the pain and other symptoms with a minimum regularity of every 1 or 2 weeks, depending on the needs.

Recommendations

- Set out a system for measuring and categorizing the pain and other symptoms with validated instruments.
- Especially monitor, in the case of older persons in the terminal-stage, pressure ulcers, falls, confusional syndromes and incontinence.
- Explicitly in the case of patients who have difficulty orally expressing themselves, get the pain assessment on the part of the caregivers and by way of direct observation.
- Systematically evaluate patient and family satisfaction with the process and results of the care provided.

1.6 Revise the care objectives following the identification of the dying stage or of "final days" at any care level, intensifying the comfort measures and the evaluation of their outcomes, taking the final wishes especially into account.

Recommendations

- Implement a dying stage clinical practice protocol.
- Make an evaluation of the family's capacity to assume the final moments and the situations of complexity which may arise as a result thereof, providing them with reflexive elements and decision-making support if necessary.

General objective 2

To provide those patients in the advanced/terminal stage of a disease with care based on the best practices and scientific evidence available.

Specific objectives

2.1 Procedures for taking action and evaluating the palliative care process to be set out by the Autonomous Communities.

Recommendations

- The criteria and circuits for referral among the different care resources shall be included in these procedures, including those specific to palliative care.
- The professional teams involved shall take part in drafting these procedures.

2.2 **A**vail of a system in each Autonomous Community for keeping records and systematically evaluating clinical outcomes in patients in an advanced/terminal-stage situation.

Recommendations

- Evaluate at least the degree to which the pain and symptoms are controlled, the number of home and emergency visits, the number, length and place of hospitalizations and the place of exitus.
- Incorporate mechanisms into the manual or computerized Medical Record systems at all levels of care which will make it possible and facilitate proper "palliative patient" clinical registration as well as the main process giving rise thereto (IDE 9/10, IPCC, etc.)

- Habilitate, within the bounds of each territory, the tools making the single "palliative patient" registration, as well as the main process giving rise thereto.
- Avail of a unified, generally-agreed minimum system of indicators at the national level.

2.3 Implementation on the part of the Autonomous Communities of guides integrated into clinical practice in accordance with the quality criteria set out by the National Health System.

Recommendations

- The Autonomous Communities will set out the ideal clinical practice guides with the collaboration and general agreement of the professionals involved.
- Set out a plan for disseminating the guides to all of the professionals.

2.4 Set out specific intervention guidelines based on the available scientific evidence in those patients with degenerative chronic diseases of any age in the advanced/terminal stage.

Recommendations

- Avail of specific recommendations in highly prevalent pathologies and also those of low prevalence involving a major need of care.
- Include in these recommendations integral evaluations on the part of the reference specialized resources (geriatrics or others).
- Promote pilot palliative intervention projects in certain subgroups of these patients.

Examples of good practices

1.1 Guide for the integrated management of cancer-related care processes: palliative care in oncology patients

Objectives

- Promote the management of processes as a strategy aimed at achieving the enhancement of the care quality to the satisfaction of the consumers using the healthcare system in relation to this health problem.

- Guarantee the provision and coordinated management of healthcare and social services which will make it possible to achieve the optimum level of physical, emotional, social and spiritual well-being for those persons in the terminal stage of an oncological disease and their families, regardless of where they live.

  In accordance with the following principles:

  — Integral orientation for the person and their family.

  — Provision of professionalized, coordinated services, each team contributing their specific added value within an individualized plan for action.

  — Promote a standardized care model with a first level of care corresponding to the Primary Care Teams which may require the support of specialized teams for optimizing the homecare or the specialized care – outpatient or hospital – so as to provided specific services throughout the process.

- Develop an interconsultation care network which will provide specific support to the standardized resources in providing palliative care.

- Guarantee the functional integration of healthcare services among one another and the integration thereof with the social services.

- Reduce care variability.

Target population: Oncology patients who are subsidiaries of palliative care and their families.

Scope: Autonomous Community of Castile and Leon.

Description: The guide includes all of the subprocesses, activities and tasks provided by different professional teams acting in a coordinated manner and aimed at obtaining the most efficient response.

For each level of intervention, blocks of activities-subprocesses which can occur simultaneously, jointly and/or successively are set out.

The subprocesses or blocks of activity are as follows:

1. Initial recruitment and evaluation: Identification of oncology patients who may be subsidiaries of palliative care and an initial evaluation being made by each team responsible.

2. Set out an individualized primary care intervention plan: Making a joint multiprofessional evaluation, identification of problems and intervention plan.

3. Specific provision of care services:

    a) Within the community scope: Primary Care teams and homecare teams

    b) Within the hospital scope: Palliative care units, medical oncology and other specialized services.

4. Evaluation of the individualized plan: Analysis of the evolution of the situation and of the effectiveness of the interventions.

5. Monitoring the process: Supervision of the situation once the anticipated results have been achieved in order to keep the situation stable.

Evaluation: Three pilot areas have been designated for the implementation of the oncoguide: Salamanca, Burgos and Avila. In each one of these locations, a task force has been set up including oncology, palliative care and primary care professionals.

In a first stage, an evaluation has been made of the coverage achieved, which was 35% of the terminal patients in Salamanca, 20% in Burgos and 22% in Avila, taking a 0.3% terminality index as the basis.

Institution and center responsible for the intervention: Castile and Leon Health Council and Regional Health Administration.

Bibliographic references:

Planning and Development Administration. Guides for integrated care of cancer-related processes: “oncoguide project”. Palliative Care of oncology patients. Valladolid: Health Council, 2005.

Examples of good practices

1.2 Bereavement support groups: 5 years of evolution

Objectives

- Facilitate a space for helping those family members in a situation of bereavement due to the death of a family member for whom care was being provided in the Palliative Care Unit.
- Promote the resilience of the family and accompany them. By means of the conveyance of feelings and experiences, the persons in the group can identify in themselves and in other members their own capacities to cope with the new situation.
- Gather from their experience of the care received those care-providing indicators which it will be necessary to modify
- Detect those situations of pathological bereavement for making an appropriate referral to the corresponding mental health team.

Target population: Family members in bereavement due to the death of a family member for whom care was being provided in the Palliative Care Unit who need or seek support to cope with the process.

Scope: Palliative Care Unit

Description: The bereavement groups are sociotherapeutic groups. These groups meet once a month for an hour and a half, the maximum length of care planned being for nine months. The dissemination of the groups is done individually and/or by means of condolence letters which are sent to the family through the Unit following the death of the patient.

This group is coordinated by a nurse and a specially-trained social worker from the service. The sessions are recorded and supervised by a psychiatrist specialized in supervising group dynamics and family therapy.

Evaluation: A total of 147 persons have taken part. These group sessions have been attended by an average of 12 people. A total of 55 sessions have been held. The participants have been mostly women (87%) (widows, mothers, daughters) have taken part.

The groups have afforded their participants with the possibility of sharing different experiences, discovering the abilities to communicate and to heighten or at least not lower their self-esteem.

The complementarity of different disciplines (nursing and social work) is values as highly enriching by both the coordinators and the group.

Institution and center responsible for the intervention: Palliative Care unit of the Duran i Reynals Hospital. Catalonia Institute of Oncology.

Bibliographic references:

Novellas A, Bleda M. Bereavement support group: 5 years of evolution. Med Pal 2005, 12: 17-23.

2.2 Organization and coordination

2.2.1 Current status analysis

Organizational models

The large number of patients who go through advanced and terminal stage of many different diseases, in conjunction with the great need and demand for care, make it necessary for all of the healthcare professionals to contribute to guaranteeing the right to relief from suffering.

As has been mentioned in the justification, Primary Care (PC) plays a core role in integral care at the community level. In Specialized Care (SC) at the hospital level, the services which provide care for a large number of advanced-stage patients, such as Medical Oncology and Radiation Therapy, Internal Medicine and Geriatrics, customarily take part in the identification and direct provision of care of these patients.

The portfolio of services includes at both the primary care and specialized care levels, the identification, integral evaluation, treatment, information and connection with support structures if necessary[155].

The development and quality of the services with which the homecare of these persons is approached are sometimes limited and insufficient. Some factors explaining this situation may include: deficiencies in the training of the professionals, organizational problems and different degrees of motivation regarding homecare among the professionals.

The two care models which base their measures on the homecare of the patients are Homecare and Home Hospitalization.

The Homecare model is generally characterized by providing care for chronic, terminal and bedridden patients. The organization often operates under the Primary Care Administrations with resources inherent to these Administrations. The care of patients needing palliative care is provided within this scope through the Primary Care Teams (PCT) and specific support teams when the complexity of the care or the primary care team proper so requires. Within this community scope, the Primary Care professionals become ultimate reference points of the care. The appropriate communication among the hospital, support teams and Primary Care Teams (PCT) is necessary in order to guarantee a community organizational mode which will provide the patients with the maximum benefits in their care[156].

Home Hospitalization generally provides care for acute processes or early releases (medical or surgical), operating in organizational terms under the Hospital Administration with resources inherent

to this Administration. The hospital professionals are the ones in charge of providing the basis of the care. A homecare program can only be set out on the basis of an underlying premise: “a patient for whom care is provided in their home must never be in a situation of receiving any less care than a patient of similar characteristics for whom care is provided in a hospital”.

At both the homecare and hospital care levels, evidence exists as to the benefits of the coordination with the palliative care teams in those patients with more complex needs[157,158].

A recent multi-center study which has included 395 terminal-stage cancer patients for whom care was provided by 171 Spanish palliative care teams has revealed, in addition to a lower number of hospital stays and emergency room care, a significant lowering of the costs of the care[158].

A prior study conducted within the community scope, in which 217 terminal-stage cancer patients were included, found better results in symptom control and quality of life in patients for whom care was provided by Homecare Support Teams in comparison to patients under the care of Primary Care Teams, although, due to the number of losses, these differences were not maintained throughout the full length of the study[159].

For organizational purposes, the large majority of strategies and programs take in different levels of care[160,161,82,162].

The level of basic, primary, general palliative care or palliative focus refers to the care which must be provided to all patients who are in need thereof in both primary and specialized care[163,164].

The level of specific, secondary, specialized or advanced palliative care takes in different types of interventions on the part of the palliative care teams in situations of complexity.

Some authors term hospital care in Palliative Care Units as “third level”[164].

During the drafting of the Strategy, it was generally agreed to define the palliative care teams according to the Council of Europe Recommendation Rec(2003) 24: “Specialised palliative care services are those services whose core activity is limited to the provision of palliative care. These services are typically involved in the care of patients with more complex and demanding care needs,

and consequently, require a greater degree of training, staff and other resources." They are accessible, identifiable interdisciplinary teams integrated by professionals with training, experience and dedication for responding to situations of complexity. These teams also perform teaching and research duties to differing degrees. They are comprised of physicians and nurses, with the necessary cooperation of a psychologist and social workers and the collaboration of other professionals. The composition of these teams will depend on the demographic and geographic characteristics and on the degrees of need of the territorial healthcare structures in question.

A certain degree of heterogeneity exists in the provision of these services among the different Autonomous Communities. The most usual organizational formulas are[165]:

- Palliative care support teams: The interventions of these teams may be at the homecare or hospital care level, with different patterns, ranging from counseling to timely, intermittent interventions or sharing responsibility in the direct care. The priority areas of intervention are symptom relief, emotional support and communication, support of ethical decisions and connection among different models such as, for example, the Homecare and Support Team Program (PADES), the Homecare Support Teams (ESAD) and the Spanish Association Against Cancer (AECC) homecare teams. Approaches combining team interventions at both the homecare and hospital care levels may also be chosen.
- Palliative Care units: These are specific palliative care hospital units manned by an interdisciplinary team. These units may be located in acute or sociosanitary hospitals, being recommended in both (30%-40% in acute hospitals)[86]. These units often perform hospital support team and outpatient consultation tasks.

In the survey conducted within the framework of the Strategy, practically all of the Autonomous Communities recognize palliative care as being a top-priority area of health intervention. Within the primary care context, all of the Communities report including palliative care in the evaluation of their portfolio of services.

In the survey conducted within the framework of drafting this Strategy, eight Autonomous Communities (Andalusia, Catalonia, the Basque Country, Extremadura, Galicia, Madrid, Murcia and Navarra), in addition to Ceuta and Melilla, report having some type of Palliative Care Plan or Program. Additionally, three Communities report having at least one agency responsible for the Planning. A brief explanation is provided in following as to the situation by Autonomous Communities.

Asturias: In 1992, the first Palliative Care homecare team was started. Guides and Protocols for taking Action have been drafted in different Health Districts, the Autonomous Community Palliative Care Strategy currently being in the process of being designed.

Andalusia: The 2002-2006 Integral Oncology Plan[166] marked the beginning of a reorganization of the provision of palliative care, including the setting up of new specific teams for the purpose of completing the geographic coverage. In November 2006, the Andalusian Government Health Council began getting a specific palliative care program under way, which could be completed during the second half of 2007[167].

Aragón: Measures are being taken in 7 of the 8 health districts into which the regional Health System is organizationally structured, each of which has Homecare Support Teams (ESAD). An oncology patient palliative care program was published.

Balearic Islands: Palliative care is included in this Autonomous Community's portfolio of services, and they avail of specific resources in primary care and in the hospital care area.

Canary Islands: This Autonomous Community has specific palliative care resources in the hospital care area. A framework document on palliative care, defining the regional care model, is currently in the process of being drafted, headed by the Canary Island Health Service Care Program Administration.

Cantabria: One of the pioneering Communities in PC in Spain[168], for providing care for these patients Cantabria has the Medical Oncology Service of the Marqués de Valdecilla Hospital (HMV) since 1984, in conjunction with the Primary Care Teams, which include the "Terminal patient care protocol" in their portfolio of services. In 1993, a terminal oncology patient homecare team was created, operating under the Spanish Association Against Cancer (AECC), which works in coordination with the Marqués de Valdecilla Hospital (HMV) Oncology Service; a Homecare Support Team (ESAD) having been created by the Cantabrian Health Service toward the end of 2000. Both of these teams provide specific partial coverage. The regional palliative care plan is currently in the process of being drafted, and some relevant measures, such as getting support teams under way in all of the health districts, the advanced training of the professionals of the specific teams or the designation of a coordinator of the regional program have already been set up.

Castile-La Mancha: This Autonomous Community avails of specific homecare teams in palliative care for providing primary care and hospital care. This care is included in this Autonomous Community's portfolio of services.

Castile and Leon: Palliative care was included as a top-priority objective in the 1998 Sociosanitary Care Plan[169]. This Plan favored, for one part, the creation of palliative care units, with a reference regional unit in Salamanca, also having established the training of the healthcare professions

in palliative care[170,171], greater involvement of primary care and the fostering of home hospitalization. Currently, palliative care is being included, in addition to in the II Sociosanitary Plan, also in the Geriatric Healthcare Plans and in the Plans for the Care of the Disabled, as well as in the Regional Cancer and Mental Health Strategies. Apart from the above, within the "Oncoguides" project (guides for the integrated management of cancer-related care-providing processes) a document has been drafted on *Palliative care of oncology patients*[172], which is currently in the process of being implemented.

Catalonia: In 1990, a WHO Demonstration Program on Palliative Care[173] was gotten under way within the context of a broader-ranging sociosanitary program titled "Vida als Anys" (Life to Years), which was addressed to ill older people, the chronically ill and those persons in a terminal stage. Currently, the palliative care measures are framed within the "Pla Director Sociosanitari" (sociosanitary Master Plan) drafted by the Planning and Evaluation Administration of the Department of Health, the objectives of which include – with a 2005-2007 time horizon – enhancing the care provided to terminal-stage patients, introducing aspects of equity, early coverage, continuing care and accessibility[174].

Community of Valencia: In 1995, the PALET program was gotten under way for providing care for frail, chronic and terminal elderly patients[175], with some objectives such as providing integral care, fostering homecare and outpatient care, optimizing the healthcare resources for this purpose and coordinating the actions of the healthcare and social systems.

The Home Hospitalization Units were gotten under way in the Autonomous Community of Valencia in 1991. From the very beginning, it was defined that the group for which care was to be provided on the part of the Units would be terminal patients, along with elderly and highly advances chronic patients.

In 2007, A Healthcare Plan for Caring for Older Persons and the Chronically Ill was drafted in 2007, including the setting up of palliative care hospital support groups included in the evaluation and care-providing teams defined under the new Plan. The nurse-liaison figure has also been cared both in primary care and hospital care, although as a pilot experience, whose duties are to include being the manager of the cases of these types of patients. This Plan rounds out the oncology Plan section devoted to palliative care.

Extremadura: A Framework Palliative Care Plan was published in 2002[176], in which the guidelines for providing care for terminal-stage patients were set out. The responsibility for the management and evaluation of the Program falls to the Program coordinator, reporting to the Sociosanitary Care and Health Administration of the Extremadura Health Service. The Framework

Sociosanitary Care Plan in Extremadura[177], in effect throughout the 2005-2010 period, includes an analysis of the needs and a description of care options for terminal-stage patients. In 2007, the 2007-2011 Integral Cancer Plan was published, palliative care being one of the seven areas of intervention set out thereunder[178].

Galicia: This Autonomous Community published the Galician Palliative Care Plan[179] in 2006, in which a description is set out of the organizational recommendations in primary care, specialized care and in palliative care units. Some of the measures are aimed at guaranteeing appropriate coverage of palliative care. Lastly, a catalogue of indicators is provided for the evaluation of the Plan. A coordinator of the Plan was appointed in 2006.

Madrid: This Autonomous Community of Madrid Integral Palliative Care Plan[180] was published in 2005 to remain in effect throughout the 2005-2008 period. A description is provided therein of the different types of mechanisms, and the coverage is planned, making provision for a homecare support team in each health district, three acute hospital units and hospital support teams in all of the districts where no acute units were located. This planning is rounded out with six medium-long stay units.

Murcia: The Autonomous Community of the Region of Murcia Integral Palliative Care Plan[181] was published in 2006 to remain in effect throughout the 2006-2009 period. This Plan proposes the existence of a support team in each health district, with Homecare Support Team (ESD) and Hospital Support Team (ESAH) duties. This Plan exhaustively details the composition and duties of each care mechanism.

Navarra: The Health Department and the Primary Care and Mental Health Administration of the Navarra Health Service published a Protocol in 2000 for providing care for terminal-stage patients and their families in Primary Care[182]. In 2005, this Protocol was further broadened with some measures for Primary and Specialized Care by means of the publication of a new document titled "*Oncology patient care in palliative care in Navarra*".

Basque Country: A Palliative Care-End-of-Life Patient Care Plan is in place to remain in effect throughout the 2006-2009 period, drafted by the Health Department Planning Administration. A "Plan for consolidating the development of Palliative Care in the Autonomous Community of the Basque Country " had previously been developed to remain in effect throughout the 1998-2002 period[183].

Rioja: Ample coverage exists thanks to a complete Rioja Health Foundation palliative care network.

Ceuta and Melilla: Palliative care programs have been in place in these two cities since 2001, with a Working Agreement among INGESA, the Autonomous Cities of Ceuta and Melilla and the Spanish Association Against Cancer.

2.2.2 Objectives and recommendations

General objective 3

To avail of an explicit organization model in order for the patients to received palliative care according to their needs at the appropriate point in time, adapted to the different situations and regional boundaries.

Specific objectives

3.1 **I**mplement a regional palliative care model in each Autonomous Community in the form of a specific plan or program with bodies responsible for their coordination and management.

Recommendations

- Set out the levels of care in palliative care within the portfolio of services of each regional health service.
- Define a model, on the part of each Autonomous Community, which explicitly sets out under which organizational divisions the palliative care teams report and their duties.
- Add further palliative care objectives annually into the program contracts and in the management contracts.

3.2 The primary care teams shall be responsible for the palliative care of the advanced/terminal-stage patients in their homes in coordination with specialized care.

Recommendations

- At the level of each Autonomous Community or geographic area in question in each case, there is to be a palliative care Committee in which the healthcare professionals and social workers from the two levels of care and from the specific resources take part.
- The palliative care Committee shall ensure the dissemination and reaching of generally-accepted agreements among the professionals concerning the different protocols, guides and existing routes of clinical practice.

- The fitting standards shall be regulated for facilitating the home use of all those drugs and instruments necessary for providing proper care.

3.3 The Primary Care Teams shall avail of a reference palliative care team for homecare aid and/or support in cases of complexity.

Recommendations

- The professionals will avail of the map of reference resources and their accessing criteria.
- This information will be accessible and will be disseminated among the population.
- The palliative care teams will collaborate with specialized care for the joint evaluation of patients and will perform tasks of liasioning with the Primary Care Teams (PCT), reporting on the outcome of the interventions.

3.4 Avail, for all of the patients who so require, of a specific reference hospital palliative care team and/or a palliative care unit.

Recommendations

- The professionals will avail of the specific reference resources map and the criteria for accessing the same.
- This information will be accessible and will be disseminated among the population.
- The hospital palliative care units may be located in acute hospitals or in medium-long stay hospitals.
- The palliative care units will place special emphasis on the comfort ability of the advanced/terminal-stage person, such as individual rooms, permanent accompaniment, comfort care and free mealtimes without any schedules.
- It is recommended that a system for accrediting reference palliative care units be set out on the part of the Autonomous Communities.

3.5 Provide palliative care coverage for those patients admitted to special homes under the same conditions as for the general population.

Recommendations

- A map of specific and/or shared resources adapted to populations at special risk or in particular need shall be set out.
- The professionals shall know the reference map of resources and their accessing criteria.
- Measures shall be set out to permit the accessibility of those patients admitted in institutions closed to palliative care teams.
- Training courses in palliative care for caregivers and employees of these centers shall be set out.

3.6 The professionals who provide the direct care to the patient will avail, from the point in time at which the advanced/terminal situation is identified, of the duly updated clinical information, the assessment of needs and the treatment and care plan, especially in regard to any change of location for the care to be provided to the patient.

Recommendations

- When the applications of information technology so allow, the primary and specialized care professionals shall have access to the clinical information, it being necessary to move toward the shared medical record.
- The patient and/or family member shall avail of a document which includes a minimum record of data on their follow-up, which must include at least the basic clinical information and a list of problems and updated treatments.

- The care levels (PC and SC) will be coordinated and will work on shared care models, guaranteeing the continuity of the healthcare provided. There will be joint protocols for interdisciplinary measures.
- There will be coordination protocols generally agreed among the levels of care with regard to the hospital admission and release, assuring confidentiality.
- There will be an intrahospital action protocol which, by means of transfer to palliative care units, shortens the stays of the patients in the emergency services; and, similarly, another extrahospital protocol which will allow the direct referral of patients from Primary Care to the palliative care units.

3.7 Provide care coverage to the patients round-the-clock, every day of the week.

Recommendations

- This coverage will be carried out by means of the coordination among the different care mechanisms responsible for the patient and the continuing care and emergency services.
- Include the use of common action protocols and systems for accessing the patient's updated clinical information.
- An expert telephone support system will be available round-the-clock to the care mechanisms to avoid care in hospital emergency rooms and unnecessary hospitalizations.
- There will be procedures established among the continuing, primary and specialized care services to provide information, protocolize actions and provide a coordinated response to emergency situations.
- The patient's entering into the dying process shall be notified to the professionals responsible for the patient by means of the method which each Autonomous Community sets out for this purpose, especially to the regular emergency services and mechanisms

designated for the coverage outside of regular hours for providing care of the primary care teams or specific palliative care resources. This notification is to include detailed information on the clinical situation and treatments performed especially at the patient's home.

3.8 Progressively implement, for the patients and family members, a specific access system for receiving support and psychological and specialized socio-family intervention adapted to their needs.

Recommendations

- The professionals of each district shall know the reference resources map and their accessing criteria.
- This information will be accessible and will be disseminated among the population.
- There will be evaluation, problem detection, intervention and referral protocols at different levels of complexity for properly taking care of the psychosocial aspects of the patient and their family members.

3.9 Progressively implement a support and/or supervision (2) system in the emotional and group-relations aspects of the professionals who work with advanced/terminal-stage patients.

Recommendations

- The professionals will avail of updated information on the support and/or supervision resources.
- The National Health System services, especially those which have a high degree of activity in this field, will avail of specific protocols and measures for identifying the risk of and providing care for stress and professional burn-out.

(2) The term "supervision" is understood as an external system of reflection and analysis of situations connected to the emotional and care-providing relationship with patients and family members, as well as the relational dynamic of the professional teams.

General objective 4

To set out an organizational system which will guarantee the coordination among the different healthcare and social resources and promote integrated actions.

Specific objectives

4.1 Set up a system of coordination among the different institutions with authorities and social and healthcare resources in order to organize the providing of support to the patients and their caregivers.

Recommendations

- Those patients without family support and/or to give the caregiver some rest shall avail of centers with the capacity to provide palliative care services accessible to the reference population and the information on the resources and their accessing criteria.
- The criteria for referral to support centers taking in the emotional, social and family aspects related to the change of location shall be set out.
- The development of volunteer programs for accompanying patients and families shall be fostered.
- There will be action protocols which specify the appropriate selection, instruction, training, supervision, recognition and evaluation of the volunteers.

4.2 Set out caregiver support programs which will provide information on services, resources and materials for this care and which facilitate and expedite red tape.

Recommendations

- A set of measures shall be set out in each district for caregiver support, such as:
- Formulas which facilitate the administrative processes for the caregivers, such as obtaining their own prescriptions or those of the patient in addition to other processes.

- Implementation of telephone consultations for rapidly dispelling doubts concerning the care.
- Concise, basic information pamphlets for the caregivers for managing the most frequent, most readily foreseeable problems and situations.
- Programs for the loan of recoverable orthprostheses material, such as wheelchairs, walkers, etc.
- The Social Work professionals will set out whatever actions are necessary for the adoption of whatever social and family services may be required.
- The setting up of systems for providing a response to emergency situations in need of social care (burn-out or absence of caregiver, etc.) shall be fostered.
- Programs will be created aimed at promoting caregiver well-being: support, sociotherapeutic, health education groups.

Examples of good practices

2.1 Catalonia WHO Palliative Care Demonstration Project. Autonomous Community of Catalonia Palliative Care Model.

Objectives

- Develop the palliative care services in Catalonia for oncology and non-oncology patients.
- Serve as a model for other programs.

Target population: Subsidiary palliative care patients.

Scope: Homecare and hospital care.

Description: This project was gotten underway in 1990 as collaboration between the Catalonian Health Department and the WHO. This collaboration has given rise to a transversal model taking action on conventional general services (basic training in palliative care) and development of specific services: homecare support (PADES), hospital support (UFISS) and separate units with beds (PCU). These units are organized according to the population in the district for which they provide care: metropolitan, intermediate and small-sized districts. Their implementation includes: legislative changes (access to opioids, funding of services), training and qualification of the professionals, development of the palliative care standards, as well as getting lines of research underway.

Evaluation: The Catalonia WHO Palliative Care Demonstration Project has been evaluated regularly. The first findings were published at 5 years and then at 10 and 15 years into the project.

There are 183 centers specialized in palliative care (70 PADES, 34 palliative care units, 63 UFISS, for a total of 552 beds) and a geographic accessibility of 95% of Catalonia. In 2005, a total of 21,400 patients received palliative care, 59% of whom were oncology patients (79.4% of the patients who died from cancer) and 41% due to non-cancerous chronic diseases (25%-56.5% of these patients).

The homecare teams provided care to a total of 12,000 patients, for an average of 171 patients per team. Sixty percent of these patients died at home.

Institution and center responsible for the intervention: Autonomous Community of Catalonia Health Council.

Bibliographic references:

Gómez-Batiste X, Porta-Sales J, Pascual A, Nabal M., Espinosa J, Paz S, Minguell C, Rodríguez D, Esperalaba J, Stjernswärd J, Geli M. Catalonia WHO Palliative Care Demonstration Project at 15 years (2005). J. Pain Symptom Manage 2007; 33: 584-590.

Examples of good practices

2.2 Regional Palliative Care Central Coordination Office in Extremadura

Objective: To provide the program with a central office and a coordinator responsible for organizing and managing the planned actions.

Target population: Subsidiary oncology and non-oncology patients of palliative care.

Scope: Autonomous Community

Description: Identification of a coordinating position. Centralized, unified model. Provision of appropriate management tools (management contracts, objectives, quality system, cost analysis, etc.) in order to carry out palliative care at all levels of care.

Evaluation: A set of structure, process and outcome indicators were evaluated throughout the 2003-2005 period.

The professionals number 1/26,436 inhabitants, the patients numbering 1,635/million inhabitants/year, the activities/million inhabitants/year numbering 6,183 hospital admissions, 3,869 home visits, 11,539 coordinating interconsultations and 483 teaching sessions. Opioid consumption totaled 494,654 defined daily doses (DDD)/year.

Institution and center responsible for the intervention: Autonomous Community of Extremadura.

Bibliographic references:

Herrera E, Rocafort J, De lima L, Bruera E, García-Peña, F, Fernández-Vara G. Regional Palliative Care Program in Extremadura: An Effective Public Health Care Model in a Sparsely Populated Region. J. Pain Symptom Manage. 2007; 33 (5); 591-598.

Examples of good practices

2.3 Continuing care in an Integral Palliative Care Program.

The experience of the Dr. Negrin Grand Canary Hospital

Objective: To reduce the use of the emergency care service on the part of advanced / terminal-stage patients.

Target population: Patients for who care is provided under the homecare program.

Scope: Health district.

Description: Permanent telephone service, with a physician on call who can be called from the patients homes. The problem can mostly be solved over the phone (adjusting a dose, dispelling a doubt, emotional support, etc.) without any need of mobilizing the patient or other healthcare resources. When hospitalizing the patient is considered to be indicated, the patient is admitted directly to the floor without any need of consulting the emergency services.

Evaluation: This program may have had a major bearing on the number of emergencies for which care was provided at the hospital having dropped by 21,743 emergencies (27.95%) in five years. The yearly average is of 4,348 fewer emergencies. The cost of providing care for an emergency was set at 100 euros at that time, as a result of which this would mean a saving of 435,000 euros every year, in addition to the main of objective which is enhancing the quality of life of patients and their family members.

Institution and center responsible for the intervention: Dr. Negrin Grand Canary Hospital.

Bibliographic references:

Gómez Sancho M. Integral high-coverage systems: the experience of Las Palmas, Grand Canary Island. In Gómez Sancho M (ed.) Palliative Medicine in the Latin Culture. Madrid: Arán, 1999, p. 1243-1256.

Examples of good practices

2.4 Coordinated Program for Advanced Oncology Patient Care. Health District XI. Madrid.

Objectives:

- Guarantee continuing care at all levels of care in Madrid Health District 11. Integrate the healthcare and social services.
- Respect the patient's and family's decision as to where to undergo care and die.
- Reinforce those existing structures which so require.
- Guarantee the suitable, specific and continuing training of all those involved in providing the care for these patients by means of training courses and regular rotation by the Homecare Support Teams (ESAD).

Target population: Oncology patients.

Scope: Health district.

Description: The health district has specific multidisciplinary support teams and units: two Homecare Support Teams (ESAD) of the Madrid Health Service and one Homecare Support Team (ESAD) of the Spanish Association Against Cancer. Both are in Primary Care, with medical and nursing staff and a psychologist.

At the Health District 11 Reference Hospital ("12 de Octubre" University Hospital), there is a Functional Continuing Care Unit (Support-Palliation) coordinated by a Medical Oncologists and availing of a specific Hospitalization Unit (San Rafael Hospital) with 15 beds assigned to the program, guaranteeing rapid admission without going through the emergency service, with select personnel trained and instructed for this care. Its functioning scheme and priorities differ from the conventional healthcare network hospital structure.

Evaluation: The overall results of the program in 10 years of analysis reveal care having been provided for a total of 8,537 patients up to 2003. In the external services portfolio evaluation, the existence of a coordinated program ranks high regarding achieving the care objectives, a decrease in the number of patients coming into the emergency room and a large number of terminal patients having died at home (72%).

Institution and center responsible for the intervention: "12 de Octubre" Hospital. Area 11 Primary Care Administration. Madrid Health Service.

Bibliographic references:

Valentín V, Murillo M and Royo D. Alternatives in the terminal-stage patient care model. Revista de Administración Sanitaria, Vol. 3, No. 9, January/March 1999, p. 147-162.

2.3 Patient autonomy

2.3.1 Current status analysis

Patient autonomy is traditionally one of the four main principles of bioethics, the basis of medical deontology and a key issue within the context of good healthcare practice. According to a document signed by the Spanish Medical Association, the main principles and objectives of care in terminal stages are those of promoting the maximum quality of life, dignity and autonomy of the patients[184].

The term "autonomy" is understood as meaning the ability to perform acts with full knowledge of the facts, sufficient information and without any internal or external coercion[185].

As of 1986, when the General Health Law was enacted as a basic law, many of the principles conforming "patient autonomy" became rights of all citizens, including the respect for personal individuality, human dignity and privacy, information on the process of the disease, free choice among options, refusal of treatment or participation[186].

It was however not until 2002 that the bounds of the right to personal autonomy were clearly set by means of the enactment of basic Law 41/2002 of November 14th regulating patient autonomy and clinical documentation and information-related rights and obligations[187].

In the final stage of life, particularly when the nearing of death is foreseeable as a result of being in the terminal-stage of a disease, the respect for a patient's personal dignity and autonomy is particularly relevant. In this situation, the rights of *INFORMATION AND PARTICIPATION IN THE CARE PROCESS* merit analysis.

Right to be informed

As previously defined hereinabove, the General Health Law set out under Article 10 the right to the patient and their family members being provided with *"complete, continuing verbal or written information on their process, including diagnosis, prognosis and treatment alternatives"*.

The patient autonomy Law dealt more specifically with patient autonomy, stipulating the patient as the holder of this right in the form of verbal conveyance, although leaving a written record thereof on the medical record. The right not to be informed was also set forth thereunder, were this to be the patient's wish or as a result of therapeutic need, when the knowledge of the situation might seriously affect the patient's health. In this case, this Law also set forth that, in addition to leaving a written account on the medical record, that the decision be notified to persons connected to the patient by family or *de facto* relationships.

Chapter VII of the appendix to Recommendation 2003/24 of the Council of Ministers of the European Council on the organization of palliative care revises the subject of communication, setting forth that an appropriate climate and attitude are required, that it must be adapted to the patient's wishes concerning being informed and to the emotional or cognitive barriers and must be adapted to the patient's needs[5].

In the palliative care document published by the Ministry of Health and Consumer Affairs (1993)[108], it was recognized that communication was a difficult stumbling block to overcome and that bad news had to be given slowly, continuously and progressively, as a process which might require several discussion sessions. As key principles, this document contributed that of "not lying" and "keeping realistic hope".

In a survey conducted on more than 6,000 medical professionals nationwide in Spain, it was found that 85.77% of these professionals would wish to be informed of their situation in the event of having a disease in the terminal stage[188]. However, due to the difficulty involved, a large percentage of patients die without knowing sufficient information about their disease.

On the other hand, the patient not only has a right to receive the information, but to their entire care process being recorded on the medical record, to which the patient shall have access provided that they so desire, with the exception of the subjective annotations and information to third parties[187].

Right to participate in the care process

The right to participate in the care process is related directly to the right to be informed described in the immediately preceding section hereinabove. It would be difficult for a patient to participate in the decision-making is they did not previously avail of truthful information concerning their process.

The Council of Europe recognized in its Recommendation of 2003 that palliative care should be patient-oriented, taking into consideration their values and preferences, the core aspects being dignity and autonomy[189]. Previously, the Council of Europe had drafted a text known as the Oviedo Convention, in which some patient rights in this regard were cited. Said Convention was ratified in Spain, having entered into effect on January 1, 2000[190].

From the legal standpoint, informed consent is the main exponent of the principle of autonomy[191].

It is the patient autonomy Law proper which resolves this right, doing so in Chapter IV thereof on referring to informed consent and advance directives. This Law defines informed consent as "the free, voluntary, conscious agreement of a patient, manifested in full use of his/her faculties after having received adequate information in order for an act having a bearing on their health to take place".

Consent is verbal as a general rule, although written consent must be granted in invasive procedures and in those entailing risks or having a negative bearing on the patient's health.

In some palliative care procedures, it is recommended requiring written consent, some of these procedures including derivative surgical techniques, palliative radiation therapy, invasive analgesic techniques, and invasive home treatments, diagnostic procedures using a contrast medium or blood transfusion[192].

Terminal-stage patients may choose those treatments which are considered proportional in their environment, being entitled to responsibly refuse exceptional, disproportionate or alternative means of treatment having dubitable probabilities of success. This attitude must be respected and not mistaken for suicidal behavior[193].

In palliative care, informed consent may display certain peculiarities resulting from the special vulnerability, the changing symptomatology, the short life expectancy, the onset of complications, the uncertainty, and the relevance of the family and the intervention-bond of the treatment team. Within this context, obtaining the patient's permission to perform certain actions is not an easy matter.

For this reasons, having knowledge of the patient's opinion concerning certain aspects prior to the point in time at which it is necessary that a decision be made, in the form of living wills and advance directives is highly useful. Some of these issues which are particularly relevant are the place of death, placement in healthcare centers or living facilities, and the use of artificial feeding o hydration, the cancellation of some treatments or the use of palliative or terminal sedation.

Despite the patients' right to self-determination and that their wishes be freely expressed and respected being part of the authority of the member States, several Council of Europe Recommendations exist in this regard[189]. Thus, for example, Recommendation Rec 1976/779 advises the State to review those matters related to the written statements of legally competent individuals[66]. Recommendation Rec 1999/1418 urged the States to safeguard the right of self determination of terminal or dying patients[4]. Lastly, Recommendation Rec 2003/24 recognized that palliative care must be patient-oriented and guided by their needs, taking into consideration their values and preferences[5].

In Spain, advance directives (or living wills) have been regulated under the patient autonomy Law, which defines these advance directives (living wills) as the document by which persons of legal age state their wishes beforehand in order for their wishes to be fulfilled at the point in time at which situations arise under which circumstances they are not capable of personally expressing themselves concerning the care and treatment of their health.

This Law proper devolves the responsibility in each Health Service for regulating the appropriate procedures to guarantee full compliance therewith. In particular, the Autonomous Communities have greater freedom to further expand upon those precepts of the Law which, even though basic, do not refer directly to those citizen rights related to their health[194]. This devolvement has now been undertaken by the Autonomous Communities by means of the enactment of patient autonomy-related Laws within the scope of their authorities or by means of the regulation (Decrees) and creation (Orders) of Autonomous Community registries of living wills or advance directives[195].

The situation at the State level in Spain is shown in following (Table 8).

Table 8. Legislation related to patient autonomy or living wills (advance directives) applicable in the different Autonomous Communities.

Administration	Legislation
State	Basic **Law 41/2002 of November 14th** regulating patient autonomy, patient clinical documentation and information-related rights and obligations. A **Draft Royal Decree** is currently in the process of being presented to regulate the National Advance Directives Registry and the corresponding Computer-based Personal Data File.
Andalusia	**Law 5/2003 of October 9th** on Living Wills. **Decree 238/2004 of May 18th**, regulating the Registry of Living Wills in Andalusia. **Order of May 31, 2004** creating the computer-based personal data file known as the Registry of Living Wills in Andalusia.
Aragon	Aragon Health **Law 6/2002 of April 15th**, Art. 15. **Decree 100/2003 of May 6th** in passage of the Living Will Registry-Organization and Operating Regulations.

Table 8. Legislation related to patient autonomy or living wills (advance directives) applicable in the different Autonomous Communities (cont'd)

Administration	Legislation
Asturias	Decree on Advance Directives and Law on Rights and Obligations of Health System Users in the Principality of Asturias currently pending publishing.
Balearic Islands	**Law 1/2006 of March 3rd on Living Wills,** revoking Article 18 of Balearic Island Health Law 5/2003 of April 4th.
Canary Islands	**Decree 13/2006 of February 8th**, regulating advance directives in healthcare and the creation of the corresponding Registry.
Cantabria	**Autonomous Community of Cantabria Healthcare Planning Law 7/2002 of December 10th,** Art. 34**. Law 6/2001 of November 20th**on the care and protection of persons in a situation of dependency, Art. 7.3. **Decree 139/2004 of December 5th**, creating and regulating the Cantabrian Advance Directive Registry. **Order SAN 28/2005 of September 16th** creating the computer-based personal data file of the Cantabrian Advance Directives Registry. **Order SAN 27/2005 of September 16th,** setting out the Cantabrian standard advance directives document.
Castile and Leon	**Law 8/2003 of April 8th** on personal health-related rights and obligations. Article 30 regulates the term Advance Directives. **Order SBS/1325/2003 of September 3rd**, publishing the user information guide rights and obligations charters. **Order SAN 687/2006 of April 19th**, proceeding to the creation of computer-based personal data files.
Castile-La Mancha	**Law 6/205 of July 7th**, on the Declaration of Advance Directives concerning one's own health. **Decree 15/2006 of February 21, 2006**, of the Castile-La Mancha Advance Directives Registry.

Table 8. Legislation related to patient autonomy or living wills (advance directives) applicable in the different Autonomous Communities.

Administration	Legislation
Catalonia	**Law 21/2000 of December 29th** on Health-related rights to be informed and Patient Autonomy and Clinical Documentation, Art. 8. **Decree 175/2002 of June 25th**, regulating the Advance Directive Registry.
C. Valencia	**Law 1/2003 of January 28th** on Autonomous Community of Valencia Patient Rights to be Informed, Art. 3 and 17. Autonomous Community of Valencia Government Council **Decree 168/2004 of September 10th,** regulating Living Wills and creating the Autonomous Community of Valencia Centralized Living Will Registry. Health Council **Order of February 25, 2005** in further expansion of Decree 168/2004 of September 10th, regulating the Living Will document and creating the Centralized Living Will Registry (Official Journal of the Autonomous Community Government of Valencia of March 15, 2005).
Extremadura	Autonomous Community of Extremadura **Health Law 10/2001 of June 28th**, Art. 11.5. **Health Information and Patient Autonomy Law 3/2005 of July 8th**, regulating, under Chapter II, Articles 17-22, the stating of living wills, revoking subparagraphs g), h), J), k) and m) of Article 11, Section I, paragraph 5 of this same Article and subparagraph c) of Article 12 of Law 10/2001 of June 28th.
Galicia	**Law 3/2001 of May 28th**, regulating patient informed consent and medical records, Art. 5. **Law 3/2005 of March 7th** in amendment of Law 3/2001 of May 28th, regulating patient informed consent and medical records, Art. 5.
La Rioja	**Health Law 2/2002 of April 17**, Art. 6.5. **Law 9/2005 of September 30th**, regulation the healthcare-related Advance Directive document. **Decree 30/2006 of May 19th**, regulating the Autonomous Community of La Rioja Advance Directive Registry. **Health Council Order 8/2006 of July 26th** on how to execute an advance directive document before Administration staff.
Madrid	**Law 3/2005 of May 23rd,** regulating the exercise of the right to set out healthcare-related advance directives and creating the corresponding registry. Autonomous Community of Madrid Government Council **Decree 101/2006 of November 16th**, regulating the Autonomous Community of Madrid Advance Directive Registry. **Order 2191/2006 of December 18th,** in further expansion of Decree 101/2006 of November 16th, regulating the Autonomous Community of Madrid Advance Directive Registry and setting out the official application forms for registry of the advance directives and for their renewal, amendment or substitution (Official Journal of the Autonomous Community of Madrid No. 302 of December 20th).

Table 8. Legislation related to patient autonomy or living wills (advance directives) applicable in the different Autonomous Communities.	
Administration	**Legislation**
Murcia	**Decree 80/2005 of July 8th** in passage of the Advance Directives Regulations and the Advance Directives Registry. **Correction of errors of February 16, 2006** (Official Journal of the Autonomous Community of Murcia o. 47 of February 25, 2006).
Navarra	**Law 11/2002 of May 6th** on Patient Rights to Advanced Directives, to be informed and to Clinical Documentation, Art. 9. **Law 29/2003 of April 4th**, in partial amendment of Autonomous Community of Navarra Law 11/2002 of May 6th on Patient Rights to Advanced Directives, to be informed and to Advance Directives. **Autonomous Community of Navarra Decree 140/2003 of June 16th**, regulating the Advance Directives Registry.
Basque Country	**Law 7/2002 of December 12th** governing Patient Rights to Healthcare-Related Advance Directives. **Decree 270/2003 of November 4th**, creating and regulating the Basque Community Advance Directives Registry. Health Council **Order of November 6, 2003**, creating the computer-based personal data file referred to as the Basque Advance Directives Registry, adding the same to those managed by the Health Department.

In the order presented by the Spanish National Institute of Statistics (INE).

2.3.2 Objectives and recommendations

General objective 5

Foster the implementation of the bioethics principles and patient participation in their process in accordance with the principles, values and content of the Patient Autonomy Law and the legislation in effect in the different Autonomous Communities.

The inclusion of general measures on end-of-life care in the healthcare services and the access to palliative care team for patients and families in a situation of complexity is a right of patients and families.

Specific objectives

5.1 Inform the patients concerning their condition and concerning the treatment objectives in accordance with their needs and preferences.

Recommendations

- There must be a special section on the patient's medical record for making a record of the patient-informing process as well as of the patient's stated care-related wishes, preferred place of death and those other related to the specific objectives sought.
- The information shall be respectful of the systems of beliefs, preferences and values of the patients and their families.
- The informing process shall be carried out progressively, in a suitable place, taking care of the psychological, emotional and existential aspects. The process will be counseled and supervised by an experienced professional.
- The information will be progressive, in keeping with the process of coping with the situation.
- The right expressed by some patients of not being informed shall be respected.
- Both the initial information and the evolutive changes will be recorded.
- In thee case of small children and adolescents, the information will be in keeping with their age, taking into account their wishes and needs.

5.2 Foster the active participation of the patient or the person to whom the patient delegates responsibility in the decision-making concerning their process and place of death, which will be recorded on the medical record.

Recommendations

- The patient may designate an agent to serve as an interlocutor with the medical team in the event that the patient does not wish to actively participate in the decision-making. If the patient is not able to express their wishes, the participation in the decision-making process will be

carried out through the family, unless the patient were to have designated an interlocutor to act on their behalf in the advance directives or living wills, in which case the participation will be carried out through the latter.

- The professionals of the multidisciplinary team who take part in the care-providing process are involved in the patient's participation in the decision-making and must furnished clear, sufficient information, allowing the patient to express doubts and fears, providing answers to their questions and allowing the patient sufficient time to think matters out.

5.3 Facilitate the decision-making process regarding end-of-life ethical dilemmas (limitation of the treatment effort, feeding and hydration, sedation, etc.) taking into account the patient's values, the existing protocols and/or the ethical recommendations and clinical practical guides. The decision-making process is to be recorded on the medical record.

Recommendations

- Clinical ethics protocols adapted to advanced and terminal-stage diseases will be promoted.
- Recommendations will be available regarding the decision-making process, the recording thereof on the medical record and technical sedation-related aspects.
- The Autonomous Communities will promote the creation of Healthcare Ethics Committees in both Primary and Specialized Care.

5.4 Disseminate to the Autonomous Communities the regulations governing living wills which regulate the registry thereof and the access to this information on the part of the professionals.

Recommendations

- The Ministry of Health and the Autonomous Communities will carrying out campaigns for informing the population and the professionals regarding the possibility of drafting advance directives or living wills in accordance with the different Autonomous Community legislation in force.

- The Autonomous Communities will inform the professionals concerning the way in which the advance directives registry is to be accessed and the requirements for their access.
- The professionals will counsel the patient and their family concerning the regulations and the possibility of making a declaration of advance directives or living will, a record being made of this counseling on the medical record.

5.5 Carry out actions to raise the awareness and inform the general population concerning the objectives, principles and resources of palliative care.

Recommendations

- The Autonomous Communities and the Ministry of Health will carry out information campaigns and will prepare informative pamphlets on the basic principles, objectives and contents of the Palliative Care Strategy.
- The training of the professionals in ethical and patient and family information and communication aspects will be promoted.
- Encourage debate and citizen involvement in palliative care in whatever bodies are designated for this purpose.

Examples of good practices

3.1 "Wings of Life" Documentary

Objective: Raise the awareness of the general population concerning end-of-life care and the importance of the patient's participation in the decision-making process regarding their disease.

Target population: General population.

Scope: Public interest.

Description: The feature-length documentary "Wings of Life" tells the life story of Cristos, a 50 year-old family doctor with multiple system atrophy (MSA) – formerly known as Shy-Drager syndrome – a disabling, fatal, neurodegenerative disease that progressively deteriorates the person's physical condition however leaves the mental capacity intact.

This film was shot in 2003-2006. Antoni P. Canet's idea as the director was to film of testimony of a person revindicating dignity in living and dying, who "recognizes that death as yet another stage in life". The close friendship binding the two afforded the possibility of filming some unique, once-in-a-lifetime images; more than 70 hours of filming and 3,000 pages setting out Cristos' thoughts and concerns during the last days of his life. A life story in pictures.

Aware of the prognosis of this disease (5-year average survival) and after three years of shooting, the film director's team and the family decided, in 2006, to get all of the material together and carry out a project to talk openly about some of the aspects related to a terminal disease. To this end, the author focused on aspects of the public and private aspects of the leading character's life, highlighting the attitude of the medical professions, the palliative care and the family environment, one of those highlighted most having been the role of the caregiver. The testimony of his wife, Carmen Font, also a physician, and that of his caregiver, Omar Karpyza, help the viewers understand the difficult task being carried out by someone who takes charge of caring for an ill person round the clock. Without overdramatizing, the director captures the feelings this disease awakens in his caregivers: fear, joy, sublimation and hope.

The Spanish Family and Community Medicine Society (Semfyc) and the Spanish Palliative Care Society (Secpal) took part in producing this documentary.

References:

Award to the best documentary film, 51st International Film Week in Valladolid. Premi Tirant Especial and Premi Tirant Exhibidores, Autonomous Community of Valencia.

Examples of good practices

3.2 Task force on bioethics as an opportunity to enhance the hospital Palliative Care process

Objectives:

- Enhance the bioethics training of the hospital's professionals
- Debate the ethical dilemmas which arise in daily clinical practice
- Enhance the decision-making process concern problems of an ethical nature

Target population: The hospital professionals

Scope: Palliative Care Unit. "Monte Naranco" Hospital. Asturias. Hospital.

Description: A task force on hospital bioethics based on an opportunity of enhancing the Hospital Palliative Care Process. This task force began its work in July 2002.

Starting meeting with hospital employees interested in this subject.

Setting out the bases of the task force's functioning.

Training meetings (learning the fundamentals of bioethics, of the deliberation method, bibliographic meetings, analysis of solving of practical cases, study of regulations in force …).

Attending related Congresses and Meetings.

Organization of Ethics and Aging forums for debate.

We believe both the Palliative Care Unit as well as the rest of the Hospital to be benefiting from the training of this task force, which is currently in the process of being set up as a Healthcare Ethics Committee.

Evaluation: Over the past three years, this task force has progressively increased the number of meetings held, from eight held in 2004 to the 12 held in 2006, and it has carried out a teaching activity.

Three editions of the Ethics and Aging Forum has been organized: "End-o-life ethics", "Ethical principles in clinical decision-making" and "Advance directives", which were attended by 57 professionals in 2004, 93 in 2005 and 130 in 2006. All of these Forums have been evaluated as being highly satisfactory, those having attended having found them to be highly interesting and applicable.

Institution and center responsible for the intervention: Palliative Care Unit. Monte Naranco Hospital. Asturias.

Examples of good practices

3.3 Effectiveness of a bioethics training course and of the implementation of a checklist in detecting ethical problems in a homecare support team

Objective: To study the concordance of the number of ethical problems identified in the care provided for terminally-ill patients among the members of a homecare support team and a group of experts before and after a bioethics course and the implementation of a checklist.

Target population: Terminal-stage patients for which care was provided by the homecare support team from November 2001 to June 2002.

Scope: Homecare support teams

Description: Before-and-after intervention study following a bioethics course and implementation of a checklist. The main measurements are age, gender, basic disease, number of ethical problems identified by the homecare support team and by the group of experts before and after the intervention. The intraclass correlation coefficient (CC) is calculated as the number of problems identified by both groups before and after the intervention.

Results: A total of 31 cases were studied prior to the intervention, 29 having been studied afterward. Before the intervention, the homecare support team identified an average of 2.7 $\pm$ 2.3 ethical problems per case, the group of experts having identified 11.8 $\pm$ 6.1. The ICC in the number of problems identified is 0.53 (moderate correlation). After the intervention, the homecare support team identified 5.9 $\pm$ 6.5 ethical problems per case, the group of experts having identified 10.7 $\pm$ 7.9. The ICC in the number of problems identified is 0.87.

Conclusions: The course and the implementation of a checklist facilitate the detection of ethical problems in terminal-stage patients on the part the professionals who are not experts in bioethics.

Institution and center responsible for the intervention: Madrid Primary Care District 7. Madrid Health Service.

Bibliographic references:

Barbero J, Garrido S, De Miguel C, Vicente F, Macé I, Fernández C. Aten Primaria 2004; 34 (1): 20-25.

2.4 Training

2.4.1 Current status analysis

Training is one of the cornerstones of carrying out palliative care. Block has stated urgently correcting the existing training deficits as being a top priority in the advancement of palliative care[196]. Some of the measures recommended include the following: setting out and enhancing the existing course curriculums, creation of training and skill certification standards, increasing the number of care programs and their involvement in teaching, increasing palliative contents in books and journals and offering internships at palliative care units.

For the purposes of planning this training, it is recommended that a distinction be made among three different levels[5,6,197]:

- Basic: offered for students and all professionals
- Intermediate: offered for professionals who provide care most often for advanced/terminal-stage patients
- Advanced: offered for those professionals of the specific palliative care resources

Undergraduate training

Undergraduate training has been highlighted as one of the actions having the greatest medium-long range impact on the effectiveness of palliative care[198].

Medicine: Based on the analysis of a survey of Spanish Medical School deans conducted in 2003[199] and on the information from the training programs included on their webpages, it is deduced that only nine thereof have a course on palliative care, as an optative (Autonomous University of Barcelona, Extremadura, La Laguna, Autonomous University of Madrid, Las Palmas, Navarra, Salamanca, Valladolid and Valencia). At the Cantabria School of Medicine, a core course on Oncology and Palliative Care is offered. The white paper on Medical Degrees prepared by the 28 deans of the Spanish Medical Schools includes palliative care as one of the specific skill areas within the Human Pathology block[200].

Table 9 sets out the specific objectives proposed for the Medical curriculum by the European Palliative Care Society based on the recommendations of the “Europe Against Cancer” program[201]. Some of these objectives are common for the different professionals who are involved in palliative care.

Table 9. Specific objectives of the Palliative Care curriculum

Attitudes

- Show that disease is a complex condition entailing physical, psychological, social and spiritual aspects.
- Demonstrate the multidisciplinary focus of palliative care.
- Demonstrate preventive stages for preventing physical, psychological and social problems.
- Emphasize that all interventions should revolve around the patient's needs.
- Identify one's own attitudes toward death.
- Understand that the family forms part of the care unit.
- Demonstrate how the impact and interpretation of the disease depends on personal attitudes.
- Discuss ethical aspects.

Knowledge

- Describe the physiopathology of the symptoms and their handling.
- Identify different care systems and their relationships.
- Describe the aspects of bereavement.

Skills

- Integrate the knowledge from other health areas with clinical data, diagnostic tests and the literature for the purpose of carrying out a decision-making process concerning whether or not supplementary examinations and treatments are indicated.
- Demonstrate various techniques for communicating with patients and family members.

Five basic mastered skills which should be acquired at the undergraduate level have been emphasized: 1) spiritual, sociological, cultural and psychological problems 2) interviewing and communicating skills 3) handling of frequent symptoms 4) ethical aspects and 5) self-knowledge and self-reflection[202].

Nursing: According to the data from a nationwide survey conducted by the Spanish Association of Palliative Care Nursing (AECPAL) in 2005, of the 92 Health Sciences Schools, 55 have a Palliative care course, these courses being optative in 49, elective at 4 and required at 2 (La Rioja and European University of Madrid)[203]. The Spanish Association Palliative Care Nursing proposes specific training being developed in palliative care which will assure the care quality of all of the professionals and unify the initiatives which arise concerning nursing training by defining the nursing skills in this area[204] and will be presenting a proposal for the unification of course curriculum objectives to all University Schools.

With the exception of certain individual initiatives, specific training in palliative care is not included in undergraduate psychology and social work training.

Graduate training

Different specialties, such as Family and Community Medicine[205], Internal Medicine[206], Medical Oncology[207], Radiation Therapy Oncology[208] and Geriatrics[209] include course contents on palliative care in their teaching program. Although this may vary according to the teaching programs, some of these specialists in training complete an optative internship in palliative care units for 1-2 months.

These palliative care internships are an excellent way of learning, just as is stated in the American Clinical Oncology Society recommendation for the specialists in training[202].

Nursing: Palliative Care Nursing is currently recognized as a specialty in Canada, the United Kingdom and the United States.

The Canadian model has developed the Palliative Care Nursing Standards based on the Support Care Model (Davies & Oberle, 1990), the Palliative Care specialty having existed since 2001 with specific skills and prescribing capacity, there currently being over 750 specialist nurses[211].

The United Kingdom model was initially based on developing a specific area of skills which was also based on the development of the Palliative Care Nursing Standards. These standards were defined based on what were referred to as the "7 C's": *communication, co-ordination, control of symptoms, continuity, continued learning, career support and care of the dying phase.* A distinction is made among three skill levels: *Level I: Foundation, Level 2: Intermediate, Level 3: Proficient* (Specialist)[212-213].

In the United States, the advanced skill level is *Advanced Practice Nursing*, the program being titled: *Palliative Care Nurse Practitioner Program.* An examination must be passed to be awarded the Certificate: *HPNA Advanced Practice Palliative Care Certification Examination*[214].

The Spanish Association of Palliative Care Nursing (AECPAL), as a federated society of the SECPAL and the Spanish Union of Scientific Nursing Societies (USECE) proposes the graduate training in Palliative Care Nursing within the Medical-Surgical Care Speciality[215]. It postulates the specified training of nursing professional on the National Commission of Medical-Surgical Care Specialty which was formed on March 8, 2007 and has prepared a proposal for Defining specific Palliative Care Nursing Skills[216].

Medicine: Palliative care has been a recognized medical specialty in the United Kingdom and Ireland since 1987 and in Australia since 1992.

In Canada, after addressing the need of specialized programs, there is a model of training internships on Units for a one-year period for purposes of certification[217]. This is a program aimed at rounding out the training of different specialists.

In the United States, the accreditation of Unit internship training programs has recently been approved as a subspeciality[218].

Recently, palliative care has been accredited as a specialty in Poland and as a subspecialty in Germany, Rumania and Slovakia. In another 10 European countries, there are currently accreditation projects in different stages of being specifically established[219].

In Spain, a widely-shared opinion exists as to the need of advanced training for those comprising the palliative care teams and of accreditation of this training. The SECPAL has proposed the creation of a Specific Training Area in palliative care, considering this to be the figure which best adapts to the past development and current situation of palliative care[220].

Continuing training

The main objective of basic training is impregnation, fostering a change of attitudes which will include palliative measures among the different treatment alternatives. The main objectives of this training would be:

- Knowing the principles, possibilities and organization of palliative care
- Describing the main causes of discomfort in terminal-stage patients.
- Recognizing information and communications as part of the treatment process.
- Being capable of setting out a basic treatment strategy.

The most customary strategy is that of basic palliative care courses being organized for duration of 20-40 hours, which have multiplied in number over the past few years. The contents would be very similar to those dealt with in undergraduate training[221] (Table 10). A recent systematic review on palliative care training interventions points out that although this subject is not sufficiently studied, there seems to be improvement in the knowledge and skills when polyfacetic approaches are used (in-classroom courses, discussion groups, authorizations, self-training, etc.)[222].

Table 10. Contents of basic Palliative Care training

Physical aspects

- The disease progress
- Symptom control
- Pharmacology
- Emergencies

Psychosocial aspects

- Family and social relations
- Communication
- Psychological responses
- Bereavement
- Knowledge of professional and personal feelings

Cultural and religious aspects

- Patient's and caregivers' beliefs
- Spirituality
- Attitudes and practices concerning disease and death

Ethical aspects

- Teamwork

Practical aspects

- Palliative care resources
- Integration of care levels

In this regard, everyday professional communication with support teams at both the homecare and hospital care levels has also shown itself to be an effective training tool[223]. These teams, also knowing the particularly unique aspects of their areas of influence, would be the ideal ones to be in charge of regularly teaching the basic courses.

The intermediate training level entails of broadening of the basic training at the graduate level and includes 60-80 hour courses and internships in Palliative Care Units[197]. The main objective of this training is to enhance the knowledge of the professionals who are most in contact with terminal-stage patients, including professionals related mainly to each one of these areas: oncology, hematology, internal medicine, anesthesiology, geriatrics and infectious diseases. The progressive intermediate-level training for the primary care team professionals as well as those responsible for palliative care within a community scope is also indispensable.

Above and beyond a change in attitudes, the main objective of these courses is to facilitate knowledge and skills for everyday care-providing work with patients, with the counseling of specific teams whenever necessary.

In the current status survey, thirteen Autonomous Communities reported on continuing training activities. In eleven of these Communities, different basic-level courses, workshops and seminars, most of which are in-classroom, are offered mainly for physicians and nurses. Eleven Autonomous Communities reported on activities related to specialists in training, particularly in family and community medicine.

The advanced training must provide and guarantee the professional proficiency of those comprising the specific palliative care teams. In Spain, one of the currently-existing ways of contributing to acquiring these proficiencies is the holding of an advanced Palliative Care course of a duration equivalent to that set out in teaching credits in the highest-level University Graduate Degrees (40-50 credits).

There are currently six Master's courses in palliative care offered in Spain.

2.4.2 Objectives and recommendations

General objective 6

To set out specific continuing training programs for the health system professionals for the purpose of their being able to suitably meet the needs of the advanced/terminal-stage patients and their families.

Three training levels are considered:

- Basic: offered for all professionals
- Intermediate: offered for the professionals who most often provide care for advanced/terminal-stage patients
- Advanced: offered for the professionals of the palliative care teams

Specific objectives

6.1 Set out a Continuing Palliative Care Training Plan in the Autonomous Communities for the primary and specialized care professionals and for those professionals who work specifically in palliative care.

Recommendations

- This training will be basic or intermediate-level depending on how often these professionals provide care for advanced/terminal-stage patients.
- It is recommended that palliative care be included in the Health Sciences degree training curriculums.
- Promote and facilitate rotation on palliative care teams of the resident physicians, psychologists and nurses of the specialties involved in providing care for these patients.
- These plans will be carried out, at any level, following an analysis of the training needs of all of the professionals involved.
- The training programs specified by the time schedule, the contents and the mechanisms responsible for the training will be set out regularly.
- The continuing training in palliative care will be accredited by means of the procedures set out by the Autonomous Communities or the Ministry of Health and Consumer Affairs Continuing Training Committee.
- Emphasize will be placed on the training in communicating with the patients and family members.
- Specific training programs will be created which address the prevention, diagnosis and treatment of the "emotional risks" of the professionals who work with advanced/terminal-stage patients.

6.4 Promote that the professionals of the specific Palliative Care teams avail of specific, advanced, officially-approved and accredited training in palliative care.

Recommendations

- In terms of the time schedule for the implementation of specific graduate training (Specific Skill-Training Area, Advanced Proficiency Diploma or equivalent) on the part of the Ministry of Education and Science and the Ministry of Health and Consumer Affairs, it is recommended that this training be progressively include for the incorporation of professionals into these specific teams.

- The Ministry of Health and Consumer Affairs and the Autonomous Communities will define, within the established channels, the authorities and standards of the training of these professionals.

Examples of Good Practices

4.1 University Palliative Medicine

Objective: To evaluate the impression of the students who have completed the Palliative Medicine course.

Target population: students who have completed the Palliative Medicine course at the University of Las Palmas de Gran Canaria.

Scope: University

Description: An analysis is made of the results of an anonymous survey conducted on the students who have completed the course (3-credit optative source in the 6th year) during the first four years it was offered.

Results: The planned objectives, the subject matter and the teaching and learning methodology are scored very high by 61.03% and high by 33.66%. The proficiency level of the professors is assessed as being high or very high. A total of 91% of the students stated a 90%-100% satisfaction with the course, and what seems even more important, 87.02% considered the three credits to be a very small number of credits for this course, 97.4% thinking that it should be compulsory.

Conclusions: The students had a highly positive opinion of the course, which speaks of the need of promoting and consolidating Palliative Medicine at the undergraduate level.

Institution and center responsible for the intervention: Department of Palliative Medicine. University of Las Palmas de Gran Canaria. Palliative Medicine Unit. Internal Medicine Service. Dr. Negrin Grand Canary Island University Hospital. Las Palmas de Gran Canaria.

Bibliographic references:

Gómez-Sancho M, Ojeda M, García ED, Marrero S, Bautista G. Medicina Paliativa en a Universidad. La experiencia de Las Palmas de Gran Canaria. Med Pal 2006; 13 (4): 192-196.

2.5 Research

2.5.1. Current status analysis

There is little palliative care research currently being done in Spain, and addressing this critical point will undoubtedly contribute to better care on a medium and long-range basis[224]. There are numerous question marks pending optimum answers, it therefore being necessary to promote and support the implementation of both epidemiological analyses as well as clinical trials or qualitative studies[225,226,227,228].

It must be stressed that the research in this area entails some specific requirements and limitations. Along general lines, these limitations are due to the working environment or system, to the patient's conditions, to the specific training of the healthcare personnel, to the implementation of the clinical research methodology per se and, lastly, to the requirements inherent to the deontology in providing care for frail patients[229,230,231,232,233].

The working hypotheses are often surpassed by the complexity of some problems which go beyond the purely clinical issues, or rather that which is proposed by some models which are so intricate that they are impracticable in the terminal stage, the responses being provided therefore being too theoretical and not suited to the specific problem in question.

These difficulties underline the need of increasing the possibilities of research in palliative care by means of project funding, methodological support and stimulus for the creation of multi-canter groups[234,235].

Over the past few years, there has been a growing interest in research in palliative care put forth at scientific meetings and congresses, in specific publications and in research groups.

Palliative Care is a young discipline with mutual ties linking it to many others. This means, on one hand, that there are not many specific publications on this subject and, on the other, that the publication on topics related to palliative care are published in journals of many different types.

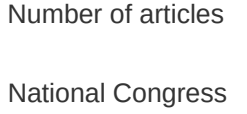
Thus, there are articles to be found both in Internal or Family Medicine journals as well as in Oncology, Anesthesia and Pain, Psychology, Geriatrics, Nursing journals or in those of the different medical and surgical specialties.

This is usually a reflection of the everyday situation confronting professionals from different disciplines who provide care for terminal-stage patients are confronted, or who find themselves under the obligation of dealing with and carrying out techniques or care for palliative purposes.

For example, it can be said that 39 of the 272 articles (14.3%) published over the last five years in the *Spanish Geriatrics and Gerontology Journal* are related to advanced and terminal illness. This is why the analysis of the publications within the scope of Palliative Care must take in not only the specific journals, which are few in number in comparison to those of other areas of Medicine, but rather those of the other related disciplines.

The *Spanish Palliative Medicine Journal* published by the Spanish Palliative Care Society (SECPAL) same into being in 1994 and is the reference Spanish-language journal of reference both nationwide in Spain and internationally, particularly in Latin America. The number of original articles published within the 1994-2006 period is provided in Fig. 6.

Fig. 6. Original research articles in the Spanish *Palliative Medicine Journal* 1994-2006



From the quantitative standpoint, scientific output is remaining constant with some minor variations.

The topics researched to the greatest extent correspond, in general, to symptom control and team organization, these two topics totaling practically 75% of all of those researched (Fig. 7).

Fig. 7 Topics of publications in the Spanish *Palliative Medicine Journal*

Symptom control 35%	Team Organization 22%
Ethical aspects 3%	Death 9%
Training 4%	Professionals 5%
Family 3%	Pharmacology 5%
History of Palliative Care 1%	Psychology 9%
	Dying process 4%

As far as the place of publication is concerned, 60% of the publications are centered in Barcelona, Madrid, Lleida, Valencia and Valladolid.

Based on the Spanish Medical Index, 210 of the 394 articles located on palliative care are from the Spanish *Palliative Medicine Journal*, the remaining 184 being divided among 36 journals, the most important being *Primary Care* (16%), *Psychooncology* (14%), *Annals of Pediatrics* (8%) *Continuing Medical Training* (6%), EMERGEN (6%) *Multidisciplinary Gerontology Journal* (5%) and the *Spanish Geriatrics and Gerontology Journal* (4%).

From the ISOC database, a total of 38 articles have been located, divided among 25 journals, mainly dealing with psychological (45%), ethical (20%) religious (10%) and legal (3%) aspects, among others.

A search was run in the MEDLINE (626) and CINAHL (63) database, limited to Spanish authors.

The CINAHL search, eliminating the articles referenced in MEDLINE, yielded specifically 18 articles, 60% of which are specific publications on Nursing, a total of 11% corresponding to the publication of the European Palliative Care Society.

The studies from the MEDLINE references evaluated were classified into seven groups according to the theme line of the journal in which they were published (Table 11).

Table 11. ARTICLES. Journal Themes	
Main theme	**(%)**
Palliative Medicine and Cancer Support	47
Internal Medicine	16
Anesthesiology and Pain Treatment	10
Oncology	13
Primary Care	8
Nursing	3
Other Specialties	3

The majority of the studies (47%) were published in journals devoted specifically to palliative care or to oncology patient support treatment.

The articles were divided according to their main contents (Table 12).

A total of 72 doctoral theses were defended within the 1987-2006 period (Fig. 8).

Table 12. Main theme of the article	
Main theme of the article	**(%)**
Symptom control	28
Pain	22
Psychosocial and spiritual	21
Implementation	17
Homecare	7
Concept	5

Fig. 8. Doctoral theses published per year on Palliative Care

Palliative care research in the 2004-2007 National Scientific Research, Development and Technological Innovation Plan

With regard to the support of research, the Carlos III Health Institute reports that a total of 100 research projects related to Palliative Care were presented within the 2002-2006 period, a total of 19 of which were funded.

Table 13. Palliative Care research Projects applied for/rejected/funded in Spain since 2001-2005

Year	Applied for	Rejected	Funded	Percentage funded/applied for
2001	20	17	3	15.00
2002	22	14	8	36.36
2003	20	18	2	10.00
2004	23	20	3	13.04
2005	17	15	2	11.76
TOTAL	**102**	**84**	**18**	**17.65**

Source: Carlos III Health Institute

Table 14. Sums granted		
Year	Funded	Total amount (€) + percentage
2001	3	73,714 – 13.63
2002	8	285,113 – 52.74
2003	2	64,975 – 12.00
2004	3	47,725 – 8.80
2005	2	69,020 – 12.77
TOTAL	**18**	**540,547**

Source: Carlos III Health Institute

Research in the Autonomous Community Palliative Care plans

Five Autonomous Communities (Catalonia, Basque Country[236], Galicia, Madrid and Valencia) reported announcements of specific palliative care research in the current status survey.

The Spanish Palliative Care Society (SECPAL) and the Spanish Society of Medical Oncology (SEOM) reported on research scholarships in this field.

Research Groups or Networks

According to the surveys conducted on the scientific societies, there are three monographic research groups on palliative care: CATPAL (Catalonian and Balearic Island Multi-center Research Group), IPALEX (Extremadura Health Service Regional Palliative Care Program Multicenter Research Group) and the Canary Island Research Group.

2.5.2 Objectives and recommendations

General objective 7

Increase the possibilities of research on palliative care.

Specific objectives

7.1 Prioritize and finance lines of research on palliative care on the part of the Ministry of Health and Consumer Affairs and the Autonomous Communities by means of including the same in the announcements of calls for research projects.

Recommendations

The following lines of research will be included, among others:

- Advanced and terminal stage epidemiology
- Symptoms, evaluation and treatment
- Support treatment (nutritional and other aspects)
- Pharmacological interactions
- Evaluation tools
- Evaluation of outcomes and quality improvement
- Prognosis factors in non-oncological patients
- Quality of life
- Palliative care and patient safety
- Palliative care in the elderly
- Emotional aspects and psychological and existential needs of the patients, family members and professionals
- End-of-life bioethics
- Care continuity and organizational models
- Palliative care in small children
- Bereavement care
- Evaluation of care costs and resource consumption
- Equity

7.2 Promote the creation of theme-based cooperative research networks on palliative care

Recommendations

- Integrated, interdisciplinary research will be promoted
- The palliative care teams will have access to reference units for research support and advisory
- Psychosocial and qualitative research will be promoted.

Examples of good practices

5.1 Palliative healthcare in support of the primary care teams in homecare: descriptive study with sentinel networks

Objectives:

- Estimate the prevalence and describe the patients who receive palliative or homecare support from the Primary Care Team
- Evaluate the needs for end-of-life homecare

Specific objectives:

- Describe the functional condition of these patients, the main health problems, the main symptoms treated by way of support, palliative care.
- Describe the use of the healthcare services on the part of the patients.
- Gather information on the lay caregivers.
- Assess the needs for an appropriate intervention in the quality of life in advanced diseases.
- Assess the needs of improvement in the end-of-life support care and palliative care skills.

Target population: Patients who received palliative or support care on the part of the primary care team or supporting healthcare unit in the patient's home at least once during a three-month period (study period).

Scope: Autonomous Community

Description: Descriptive study within the framework of the Spanish healthcare sentinel networks. The reference population is that of those patients of the populations covered by the healthcare sentinel networks ages 15 and above (400,000 inhabitants). As a study measurement, different social, epidemiological and clinical variable of terminal patients and patients with functional disabilities are used, including the Barthel and Kamofsky indexes.

Results: The project will be carried out in five Autonomous Communities and plans to have tentative results in May 2008.

Evaluation: Gathering of epidemiological information relevant for public health and healthcare management. The information gathered from different autonomous communities will provide a picture of the situation in different types of populations with different social and economic structures.

Institution and center responsible for the intervention: Castile and Leon Health Council.

References:

PI 06/1083 FIS.

Examples of good practices

5.2 Effectiveness of a case management model in homecare in bedridden patients, terminal patients, hospital releases and lay caregivers

Objectives:

- Describe the homecare outcomes achieved (functionability, medium-range survival, quality of life, use of services, caregiver overload, patient and caregiver satisfaction) in the three aforementioned groups of patients and in their caregivers when a case management model is implemented through community liaison nurses (CLN's).
- Compare the outcomes achieved in the patients and caregivers for whom care is provided according to the new homecare model (intervention) with those achieved in patients and caregivers for whom care has been provided according to the conventional model (control).

Target population: Bedridden patients, terminal patients, hospital releases and lay caregivers.

Scope: Primary Care Health Districts of Malaga, Almeria, Granada and Costa del Sol.

Description: Prospective, quasi-experimental multi-center study with a concurrent control group conducted within the 2003-2005 period. Study subjects: patients newly included in the Homecare services (terminal, hospital releases and bedridden patients) as well as their caregivers. The patients were assigned to the intervention or control group in terms of whether or not they respectively pertained to Health Centers in which the new model had already been implemented. The follow-up period lasted up to 12 months. The main results variables were: functionality (daily living activities), cognitive function, use of healthcare resources and satisfaction.

Results: 647 subjects were selected, 463 of whom were finally included (intervention: 247, control: 216; caregivers: 44.5%, bedridden: 35.4%, hospital releases: 15.1% and terminal patients: 5%). The baseline condition of the patients in the intervention group was obviously worse, responding to suitability of the established referral criteria. In the bedridden patients, the baseline differences in functionality, in detriment of the intervention group did not equal out at 6 months and at 12 months. On the other hand, in hospital releases, from a starting situation of lesser functionality in the intervention group: Barthel: 47.68 (95% CI: 38.51 – 56.26)

vs. 66.79 (95% CI: 52.06-81.51); p=0.0001, these differences ceased to exist at 2 months: Barthel: 70.44 (95% CI: 60.39 -80.50-85-89), p=0.678. In terminal patients, there were no differences between groups. A lesser number of home visits were found in the intervention group, a major granting of social aid, of interventions of the social worker, of physical therapy and fewer visits of the Health Center caregiver, as well as of the patient having been found. The satisfaction between both groups (SATISFAD-12) differed significantly in favor of the intervention group; 16.88 (95% CI: 16.32-17.43) vs. 14.65 (95% CI: 13.61-15.68) (p=0.001). The overburdening of the caregivers at 12 months was less in the intervention group (Zarit: 49.32 (95% CI: 44.80 -56.71) vs 66.67 (95% CI: 52.84-75.42), p=0.0001. No differences in the institutionalization or mortality were detected.

Conclusions: The new Homecare model solidly identifies the most vulnerable patients and has a positive influence on the functionality of the hospital releases, the overburdening of the caregivers and the use of healthcare services, as well as on satisfaction, with fewer visits. On the contrary, it does not seem to have any effects on the functionality, mortality, institutionalization or readmissions of the most deteriorated patients.

Institution and center responsible for the intervention: Andalusian School of Public Health. Autonomous Community of Andalusia.

References:

Research Project 031 161. Funded by the Healthcare Research Fund.

3. The Strategy evaluation and information system

Introduction

The process of evaluating the implementation of the NHS Palliative Care Strategy as well as the improvements in the care and outcomes which may stem from the same is undoubtedly a complex process, given that two main circumstances concur in this Strategy having a major bearing on this fact.

On one hand, due to this Strategy addressing a certain condition or evolutive stage of the disease process of these persons and not a specific disease or defined group of diseases. On the other hand, because there are not currently any homogenous systems for gathering or processing data available among the different healthcare system players who are involved in this process, nor among the different territorial scopes (even when similar care structures are involved). This entails that, despite registries existing in the different units providing the care – with the scope of both primary and specialized care – practically no information at all standardized for the entire National Health System as a whole is available.

Hence, it is necessary to develop, at the start of this Strategy, a set of actions aimed at initiating the process of preparing information, be it by means of indicators or by means of reports which, in a generally-agreed, gradual manner, will contribute to the current and future knowledge of those key aspects related to the objectives set out in the Strategy.

The aforementioned process will necessarily be gradual, a first selection of aspects the pertinence and feasibility of which have been positively values by the Autonomous Communities being made in this chapter. The information systems will have to be adapted to the needs detected as the strategy progresses and in keeping with future revisions so as to enhance and further broaden the information initially agreed upon.

On the other hand, this does not mean that all of the information stated in following herein can be compiled immediately, given that it is often necessary to carry out some previous work for the greater preciseness of the definitions thereof, as well as for setting out the necessary circuits at both the local and Autonomous Community levels and on the part of the Ministry of Health and Consumer Affairs proper for the mining and exchange of information.

The proposals are grouped into three information modalities. The first two which are more closely related to the situation and evolution of aspects connected to the healthcare system and to the system of providing care for these patients, are based on the compiling of descriptive information and the use of indicators. The third, which is more closely related to the follow-up of the implementation per se of aspects of the strategy deemed relevant for achieving the objectives set out.

A) Descriptive information: functional map of resources

This is considered the prime starting point and addresses the identification of the different types of existing structures, their number and the ways in which they are designed and organized to provide palliative care within the framework of the Autonomous Communities.

This is due to there being different ways of addressing specifically dealing with this problem so that, although there are quite a few similarities with regard to the basic concepts on which the organizational development is based, there is no one single model. Therefore, it is considered mandatory to first know the existing similarities and differences in both functional and name-related terms, etc.

This will make it possible, firstly, to avail of a more solid base of knowledge, in the form of metadata, a prerequisite for comparing quantitative data. Thus, although it is planned for this description to include the specification of the number of specific resources or units currently existing, this is descriptive information which is not directly numerically comparable. This information therefore cannot be sued at this point in time for calculation ratios of professionals until, in light of the information set out, the degree of similarity of each type of resource (material or human) is clarified and it is therefore agreed to address this aspect.

On the other hand, this functional knowledge may serve as a sharing of experiences carried out on the initiative of the Autonomous Communities.

This map would be initially comprised by a relationship in which the following aspects are stated:

- Name given to each one of the currently-existing specific Units, Mechanisms or Teams, and for each one:

— Location (hospital, health center, specialty center, independent building…) and the postal address.
— Environment in which it provides services: hospitalization, outpatient or homecare.
— Geographical scope to which the service is provided: Health district(s) it covers or for which it is a reference point.
— Basic composition, in general terms, of the human resources integrating the different types of structures:

  - Physicians (and type of major specialties)
  - Nursing staff
  - Psychologists
  - Social workers
  - Auxiliary personnel
  - Others.

— Specification of whether they are their own resources or arranged with private entities or associations.
— Number of beds specifically for palliative care.

- The number of each one of these mechanisms and of the human resources of which they are comprised will also be included (3).
- The information will be completed with a brief description of the general organizational mode set out by the Autonomous Community in regard to the basic functions planned for each care mechanism.

In a following phase, to the extent to which the technological advancement of healthcare mapping so allows, geographical maps in the strict sense will be plotted in keeping with said preparation for another type of healthcare mechanisms.

In any case, prior to starting the process of compiling this information, some basic, generally-agreed criteria will be more precisely prepared which will aid in homogenizing this information and will facilitate information being supplied by the Autonomous Communities.

(3) It is understood that the primary care teams of all of the health centers will provide this care at the basic level and that it is not necessary to signpost them, given that the map of local health centers and physician's offices is being compiled through the Primary Care Information System. Similarly, the hospital services which are not specifically for palliative care which also customarily provide this care, such as the oncology services and other hospital services need not be pointed out in this section, it being planned for all of these services to be known by means of another source of information (from the Registry of Healthcare Centers, Services and Establishments). Both of these sources of information are currently under construction.

B) Indicators

1. Percentage of patients for which care is provided by Primary Care Teams

- Formula: a) x 100 / b), where:

  a) Number of patients for whom palliative care has been provided within one year.

  b) Total number of patients estimated for that same year.

- Definitions/explanations:

  — In relation to the numerator:

    - Including all those persons in which the need of palliative care has been explicitly identified in accordance with the criteria set out in the strategy.
    - Also to be included are all those patients who have been recruited and cared for, independently of the degree of intensity of the care.
    - Likewise, it shall include all of those patients for whom care has been provided, independently of their may having died prior to the end of the year in question.

  — In relation to the denominator:

    - The estimate will be made with regard to the total number of deaths caused by cancer and by the group of evolutive chronic disease subject to requiring this type of care.
    - This figure will be calculated annually by applying said estimate to the Personal Health Card (PHC) population of each Autonomous Community on the cutoff date of December 31st every year.

- Sources of information:

  — Numerator: Primary Care Information System (SIAP).

  — Denominator:

— Prepared from the Spanish National Institute of Statistics Death Statistics.

— Personal Health Care (PHC) population. Primary Care Information System. Ministry of Health and Consumer Affairs.

- Levels of breakdown:

— By Autonomous Communities

— By groups of causing diseases: a) oncological and b) "other causes".

- Periodicity: Annual
- Remarks:

— The Primary Care Information System is currently in the process of being developed, it therefore being understood that in order to obtain the indicator, a prior agreement with the Autonomous Communities concerning the registry criteria and the subsequent sharing of the data at the level of the entire NHS is required.

— The use of the Primary Care Information system as a source of Personal Health Card information is considered temporary until the incorporation of all of the Autonomous Communities into the Population Database protected by the NHS has been completed and the mining of this data for this purpose has been agreed.

2. Percentage of patients for which care is provided by palliative homecare Teams

- Formula: a) x 100 / b), where:

a) Number of patients for whom palliative care has been provided within one year.

b) Total number of patients estimated for that same year.

- Definitions/explanations:

— In relation to the numerator:

- Including all those persons in which the need of palliative care has been explicitly identified in accordance with the criteria set out in the strategy.
- Also to be included are all those patients who have been recruited and cared for, independently of the degree of intensity of the care.

- Likewise, it shall include all of those patients for whom care has been provided, independently of their may having died prior to the end of the year in question.

— In relation to the denominator:

- The estimate will be made by means of the following calculation:
  * Sixty percent of the patients having died from cancer in each Autonomous Community during the year in question.
  * More than 30% of the cases of deaths in each Autonomous Community by the list of selected evolutive chronic diseases subject to requiring this care.
- This figure will be calculated annually by applying said estimate to the Personal Health Card (PHC) population of each Autonomous Community on the cutoff date of December 31st every year.

- Sources of information:

— Numerator: Specific records of the homecare support teams and units, through the Autonomous Communities.

— Denominator:

— Prepared from the Spanish National Institute of Statistics Death Statistics.

— Personal Health Care (PHC) population. Primary Care Information System. Ministry of Health and Consumer Affairs.

- Levels of breakdown:

— By Autonomous Communities

— By groups of causing diseases: a) oncological and b) “other causes”.

- Periodicity: Annual
- Remarks:

— Neither homogeneous record system nor any data communication circuit currently exists at the level of the entire NHS for the homecare support tams, a prior agreement with the Autonomous Communities therefore being required.

— The use of the Primary Care Information system as a source of Personal Health Card information is considered temporary until the incorporation of all of the Autonomous Communities into the Population Database protected by the NHS has been completed and the mining of this data for this purpose has been agreed.

3. Percentage of patients for which care is provided by Hospital Teams, Units or Services

- Formula: a) x 100 / b), where:

  a) Number of patients released within one year for whom palliative care has been provided.

  b) Total number of patients estimated for that same year.

- Definitions/explanations:

  — In relation to the numerator:

  - Including all those persons released with the IDC-version 9-MC V 66.7 codes as a secondary diagnosis.
  - All those oncology patients (codes included in Chapter 2 of IDC-version 9 MC) which are shown as a main diagnosis will be distinguished from the total.
  - On the other hand, the specialized Service under whose charge the patient has been will be identified by means of completing the CMBD for this item according to the previously-established abbreviated nomenclature.
  - Likewise, it shall include all of those patients for whom care has been provided, independently of their may having died prior to the end of the year in question.

  — In relation to the denominator:

  - The estimate will be made by means of the following calculation:
    * Sixty percent of the patients having died from cancer in each Autonomous Community during the year in question.

* More than 30% of the cases of deaths in each Autonomous Community by the list of selected evolutive chronic diseases subject to requiring this care.

- This figure will be calculated annually by applying said estimate to the Personal Health Card (PHC) population of each Autonomous Community on the cutoff date of December 31st every year.

- Sources of information:
  - Numerator: CNBD at release from hospital. Ministry of Health and Consumer Affairs.
  - Denominator:
    - Prepared from the Spanish National Institute of Statistics Death Statistics.
    - Personal Health Care (PHC) population. Primary Care Information System. Ministry of Health and Consumer Affairs.

- Levels of breakdown:
  - By Autonomous Communities
  - By groups of causing diseases: a) oncological and b) "other causes".
  - By Hospital Service having provided them the care.

- Periodicity: Annual
- Remarks:
  - Given that the "V" codes are currently voluntary coding, the prior general agreement of the Autonomous Communities concerning the mechanisms for the generalization thereof is required.
  - Similarly, it will be necessary to generally complete the identification of the Service.

4. Offer coverage: Population availing of reference palliative care homecare Teams

- Formula: ID = a) x 100 / b), where:

a) Number of persons who have this type of reference mechanisms in one year.

b) Population for that same year.

- Definitions/explanations:

  — The numerator includes the PHC population whose primary care professionals avail of a Team or Unit of this nature as specific support and aid for this care.

  — The information will correspond to the closing on December 31st every year.

- Breakdown: by Autonomous Communities.
- Sources of information:

  — Primary Care Information System. Ministry of Health and Consumer Affairs.

- Periodicity: Annual
- Remarks:

  — This information is not currently available, a prior general agreement regarding their more precise definition therefore being required.

  — The use of the Primary Care Information System as a source of PHC information is considered temporary, until the incorporation of all of the Autonomous Communities into the Population Database protected by the NHS has been completed and the mining of this data for this purpose has been agreed.

5. Degree of use of step-3 opioids

- Formula: ID = a) x 100 / b), where:

  a) Number of defined daily doses (DDD) of opioids dispensed by prescription and/or supplied in the hospital within one year.

  b) Personal Health Card population for that same year.

- Definitions/explanations:

  — The numerator includes: the dispensing by prescription – on one hand – and the doses supplied at the hospital level – on the other, in DDD, of those pharmaceutical specialties which contain the following active ingredients: Buprenophine (N02AE01) + Phentanil (N02AB03) + Morphine (N02AA01) + Oxycodone (N02AA05).

— The population will be the total PHC (only of actively employed plus pensioners). The PHC population on the cutoff date of December 31st every year will be used.

- Breakdown: by Autonomous Communities, by scope of use (community or hospital).
- Sources of information:

— Pharmaceutical consumption information system. Directorate General of Pharmacy. Ministry of Health and Consumer Affairs.

— Autonomous Community pharmaceutical information systems.

— Personal Health Card (PHC) population. Primary Care Information System. Ministry of Health and Consumer Affairs.

- Periodicity: Annual
- Remarks:

— The use of the Primary Care Information System as a source of PHC information is considered temporary, until the incorporation of all of the Autonomous Communities into the Population Database protected by the NHS has been completed and the mining of this data for this purpose has been agreed.

6. Percentage of professionals who have taken specific basic palliative care training

- Formula: a) x 100 / b), where:

a) Number of professionals who have taken basic, specifically palliative care-focused training in one year.

b) Total number of professionals that same year.

- Definitions:

— Basic training is considered taking specific courses of 20-40 hours in duration.

— Including all those training actions of these characteristics which have been accredited by the corresponding Autonomous Community.

- Source of information: Autonomous Community information systems.
- Levels of breakdown:
  - — By Autonomous Communities
  - — By type of professional (physician, nursing, psychology, social work or others) and field of word (primary care teams, homecare support teams and similar, hospital).
- Periodicity: Annual

7. Percentage of professionals who have taken specific intermediate palliative care courses

- Formula: a) x 100 / b), where:

  a) Number of professionals who have taken specific intermediate-level palliative care-focused course in one year.

  b) Total number of professionals that same year.

- Definitions:

  — Intermediate training is considered as taking:

  - Accredited 40-80 hour courses.
  - Third Cycle (Doctorate) courses.
  - 1-2 month internships in Palliative Care Units
  - Including all those training actions of these characteristics which have been accredited by the corresponding Autonomous Community.

- Source of information: Autonomous Community information systems.
- Levels of breakdown:
  - —— By Autonomous Communities.
  - —— By type of professional and field of work.
- Periodicity: Annual
- Remarks: The criteria currently included in the definition may be subject to modifications in terms of new agreements generally-accepted among the Autonomous Communities.

8. Percentage of professionals who have taken specific advanced palliative care courses

- Formula: a) x 100 / b), where:
  a) Number of professionals who have taken specific advanced-level palliative care-focused course in one year.
  b) Total number of professionals that same year.
- Definitions:
  - —— Intermediate training is considered as taking:
    - Master's courses.
    - Internships in Palliative Care Units of 3 months or longer
    - Including all those training actions of these characteristics which have been accredited by the corresponding Autonomous Community.
- Source of information: Autonomous Community information systems.
- Levels of breakdown:
  - —— By Autonomous Communities.
  - —— By type of professional and field of work.
- Periodicity: Annual
- Remarks: The criteria currently included in the definition may be subject to modifications in terms of new agreements generally-accepted among the Autonomous Communities.

9. Number of research projects funded

- Formula: Number of research projects on palliative care publicly funded in one year.
- Definitions:
  - Including all those projects which have been carried out by means of official funding systems of the Health Administrations, whether State (through the Carlos III Health Institute) or through the Autonomous Communities.
  - Those new projects approved each year will be included, independently of the timeframe for their completion.
- Sources of information:
  - Carlos III Health Institute. Ministry of Health and Consumer Affairs.
  - Autonomous Community information systems.
- Levels of breakdown: None, entire NHS as a whole.
- Periodicity: Annual

C) Implementation follow-up report

The evaluation of the Strategy will consist, thirdly, of a Report summarizing the main actions carried out by the Ministry of Health and Consumer Affairs and the Autonomous Communities in order to achieve the Strategy objectives and the percentage by which the National Health System objectives have been achieved.

The contents and structure of this Report will be agreed upon between the Ministry of Health and Consumer Affairs and the Autonomous Communities at the Strategy Follow-up Committee meeting.

Annexes

I. Characteristics of the advanced/terminal condition in different patient subgroups

1. Oncology patients

Oncology patient care has been undergoing some substantial changes over the past few years, making it necessary to take under consideration the continuity of the care delivered through the Health System and the responsibility, as oncologists, of taking part in and coordinating the specific care throughout all stages of the disease.

General needs

In order to provide quality care, we must know the demands of oncology patients. Several studies have revealed these demands, which are:

- Holistic care, going above and beyond the fundamentals and clinical aspect of the treatment to be oriented more broadly on the patient's wishes and needs.
- People-focused care. The treatment must be organized in terms of the patient's needs and wishes more than based on the convenience of the hospital or the healthcare personnel.
- Good professional care, in other words, that the treatment administered be a top-quality treatment.

In the general intervention of the Oncology Services, this data must have a major impact, it being indispensable for get each Autonomous Community actively involved in order to achieve care planning which will entail truly adapting personnel and assigning specific budget resources for meeting these demands.

In order for a patient to be considered to be in the advanced stage, certain criteria setting the bounds of this condition must be present. In Oncology, a number of parameters are accepted as characterizing and defining this stage, which are:

- Presence of an advanced, progressive, incurable disease, with proven histological diagnosis, after having received standard treatment.

- Little or no possibility of response to the active, specific treatment for the baseline disease. In certain situations, resources considered as specific (oral chemotherapy, radiation therapy, hormone therapy, biphosphonates, 3rd and 4th-line molecules, etc.) must be used due to their positive impact on the quality of life.
- Presence of multiple, changing, multifactor, intense symptoms or problems.
- Emotional impact on the patient, family and treatment team related to the dying process.
- Limited life prognosis in the judgment of the corresponding specialist.

The decision on the part of the clinicians of defining a patient as advanced/terminal must be made solely by experienced, qualified specialists and must be subject to constant review, as new treatments are continuously being applied which change the concepts of treatment for curative purposes and/or therapy for palliative purposes which are bringing these concepts nearer to one another.

Integral care in Oncology encompasses the study of the problems which complicate and accompany the clinical course of neoplasic diseases, whether depending on the tumor, the patient or the treatment. The objectives of integral care are: to prevent, eliminate or alleviate those circumstances which deteriorate the quality of life, make the correct administering of the treatments impossible, by attempting to always improve the patient's living conditions.

Apart from the above, one must not overlook the fact that curative and palliative treatments are not mutually exclusive, but are rather a matter of emphasis. Hence, we will gradually be implementing a greater number and percentage of support-palliation measure as the disease progresses and the patient ceases responding to the specific treatment.

In the case of oncology patients, it is important to distinguish among:

- Support Care: This care is aimed at optimizing the comfort and providing functional and social support to the patients and their family members throughout all stages of the disease. This dimension of cancer patient care emphasizes the oncologist's role in optimizing the quality of life for all patients, including those potentially curable.
- Palliative Care: The objective of palliative care is to optimize the supports and resources for achieving comfort and providing functional and social support for patients and family members when curing is not possible. This dimension of care emphasizes the special needs regarding the control of physical and psychosocial symptoms, education and optimization of the community's resources within a shared care framework.

- End-of-life care: This is the palliative care applied when death is imminent. The patients and their family members confronted with this situation has some special, intense needs which often require intense, personalized care anywhere in any situation.

Oncology patient level of care

The following are defined:

- Stage of low complexity and high degree of family support. Profile of a patient who can be cared for at home by Primary Care and/or support teams.
- Stage of low complexity and low degree of family support. Care can be provided for the patient with at socio-sanitary resources and/or in socio-sanitary centers (medium-long stay institutions) and, if necessary, in palliative care units.
- Stage of high complexity. Usually requiring the involvement of specialized units or teams prepared for providing solutions to particularly complex symptoms.

The degree of clinical complexity in oncology patients which is specific thereto is determined by: the nature, type, spread and evolution of the tumor, use of specific treatments of a palliative nature (conventional RT, high-rate RT, LF, palliative chemotherapy, biological therapies, radiosurgery, endoscopy, etc.) emergency situations with use of specific examinations in Specialized Care, the physician-patient relationship and difficult family situations.

Further explanation: The presence of symptoms and their intensity are independent of the life expectancy prognosis (with the exception of the performance status, anorexia-cachexia syndrome, dysnea and delirium) and the different types of tumors, this playing a major role in planning this care in relation to oncology patients.

2. Patients with chronic, evolutive, non-oncological diseases

Traditionally, the palliative care programs have focused their attention on persons ill with cancer. However, there is a high percentage of individuals without any oncological disease whose end of life is

also quite difficult and who may benefit from the implementation of these programs. Lastly, dying of cancer is not so different from dying from heart failure, a COPD or a non-recoverable ictus[237].

The small degree to which Palliative Medicine is devoted to persons with chronic, evolutive, non-oncological diseases can be explained by a number of particular aspects which hinder the unit to provide this care from undertaking the provision thereof.

The main barriers identified include the lack of a predictive model for determining a limited life expectancy prognosis, the reigning culture of the many different specialties which provide care for these diseases which are more focused on curing, and the difficulties for combining high-tech techniques with the care which is known as palliative.

Likewise, it is highly difficult to establish the point in time for initiating palliative care. These are diseases which entail numerous crises that are overcome to then return to a baseline situation which will be bearable for the patients, their family members and professionals. This evolution makes end-of-life information and communication much more complex.

Within the framework of the working agreement set out between the National Health System Quality Agency and the Autonomous Communities (4), a research project has been gotten under way, coordinated through the Basque Country Health Department, with the participation of the Canary Island Health Service Evaluation and Planning Department.

This study employs two methodological approaches for the purpose of ascertaining the validity of the criteria proposed for starting palliative care, as well as the barriers and needs of this care. The methods consist of a systematic review of scientific literature and qualitative research from the standpoint of the patient, family members and socio-sanitary professionals.

The findings of this research will serve for carrying out the strategy proposed in this document.

Geriatric patients

Older people have traditionally received less palliative care than younger people, and the services have been focused, above all, on cancer. Some of the existing barriers for achieving better palliative care for older persons include:

(4) This agreement is carried out through the Health Technologies Evaluation Agency.

a) Lack of awareness and knowledge of the magnitude of this problem.
b) Lack of palliative care health policies for older persons and for the diseases they usually have.
c) Lack of aptitude or training in those places where these older persons are currently cared for and where they die.
d) Self-complacency and age-related discrimination with regard to the need of providing high-quality care.
e) Incorrect suppositions concerning the needs and wishes of older people or regarding their ability to cope without special help.
f) Complexity for coordinating palliative care packages within different scopes and for connecting health/social support with care.

Given the advanced age of many of the patients with organ insufficiencies and their particular complexity (comorbidity, polypharmacy, presence of disabling geriatric syndromes, accompanying psychosocial problems, atypical aspect of symptoms, lack of specific prognosis factors, high-dependency situations being readily mistaken for terminality), integral geriatric evaluation is an ideal tool for suitable decision-making of prognostic value and for planning care and follow-up.

These patients could therefore particularly benefit from the care coordinated between primary care and Geriatric units through multidisciplinary teamwork, care levels including homecare and the aforementioned integral geriatric evaluation.

Organ insufficiencies

Organ insufficiencies are ranked among the leading causes of death in Western countries. Their incidence is also continuing on the rise. Advanced-age patients meet the terminal disease criteria defined on page 21, paragraph 1.3 (Strategy Target Population) of this document.

The symptom load borne by these patients is comparable to that suffered by cancer patients at the end of their lives. However, when the care provided to terminal oncology patients is compared to the care provided for patients with advanced-stage organ insufficiencies, the results of the cancer patients are always better. The main reasons alleged to justify these worse results is the difficulty of making a life expectancy prognosis in this type of patients.

The National Hospice and Palliative Care Organization (NHO) drafted a number of prognosis criteria to facilitate access to palliative care on the part of non-oncology patients. The basic criteria for the different organ insufficiencies are:

- Cardiac Insufficiency: NYHA grade IV, despite optimum treatment; FE< 20%, frequent decompensations.
- Respiratory Insufficiency: Dyspnea at rest without any response to the use of bronchodilators; FEVI < 30%; Hypoxemia < 55; hypercapnia > 50; tachycardia at rest; frequent acute-on-chronic episodes.
- Hepatic Insufficiency: Child state C, frequent decompensations.
- Renal Insufficiency: creatinine clearing < 10 and serum creatinine > 8 mg/dl, without indication of dialysis. Diuresis < 400 ml/d.

In all cases, the existence of severe medical complication during the development of the diseases is required for their inclusion. Despite the validity of these criteria being debated, their use has made it possible for non-oncology patients to access specific palliative care services. Work is currently being done on preparing prognosis indicators which will make it possible to establish the prognosis of organ insufficiencies more precisely. Meanwhile, some professionals suggest continuing to use the NHO criteria in order to implement a more palliative-focused treatment perspective for all those patients with advanced stages of organ insufficiencies in the different levels of care in the health system.

The key points in providing care for patients with advanced-stage organ insufficiencies are:

- Improve healthcare professional-patient communication: particular importance must be placed on the diagnosis and prognosis-related information, try to ascertain the patient's values and preferences for follow-up and treatment and record advance directives.
- Improve the symptomatalogical treatment and evaluation: an evaluation and systematic monitoring of the symptomatology must be carried out for the purpose of assuring their appropriate treatment.
- Integral evaluation of the patient and their family: including clinical, functional, nutritional, affective, cognitive, social and spiritual aspects.
- Systematically include the family, particularly the main caregiver, in the care plan, making them a party to the interventions and activities to be carried out.

- Set out a proper coordination for assuring care continuity.

Dementias and other neurological processes

These processes comprise a group of diseases causing major personal and social impact due to their high morbimortality. The most frequent of these diseases is Alzheimer-type senile dementia (ATSD) (41% of dementias), following by vascular dementia (38% of dementias). The prevalence of dementia among persons over age 65 is 8%, totaling over 30% among those over 80 years of age and increasing exponentially with age.

Recent studies rank ATSD among the 10 leading causes of mortality in Spain. Ranked second, the most frequent neurodegenerative disease is Parkinson's disease, with an incidence of 4.5-16 cases per 100,000 inhabitants per year, which also increases with age, up to 90 per 100,000 among those over 75 years of age.

Outstanding among the primary demyelinizing diseases is Multiple Sclerosis, as a result of its being the most important cause of neurological disability among young adults. The most outstanding of the neuromuscular diseases is Amyotrophic Lateral Sclerosis, with an incidence of 2-3 cases per 100,000 inhabitants per year.

Most of the studies have been conducted on ATSD as a result of this being the most frequent dementia. Reisbert et al discovered the main symptoms which characterize the different stages an ATSD patient goes through on the GDS scale (global deterioration scale), which has been simplified for practical use into the FAST scale. A patient in GDS 7 stage (highly severe cognitive deterioration) and even in GDS 6 must be considered to be subject to receiving palliative care.

The following are considered terminal stage indictors in patients with dementia:

- A cognitive function below 6 on the Mini-Mental State Examination (MMSE) or a cognitive deterioration such as to make it impossible to conduct this examination.
- A global deterioration of the self-maintenance of the subject, given as:
  - Score above 13 on the Dementia Rating Scale.
  - Situation equivalent to grade E on the C.A.P.E.
  - Situation of dependency for performing all basic daily living activities, objectified by the Katz index or another equivalent tool.
  - Stage 7 of the Reisberg classification (GDS/FAST)

Despite it all, it is difficult to determine when a patient with a neurodegenerative disease enters into the terminal stage and how long this stage may last (5). A number of parameters have therefore been set out, which, when arising together, may be predictors of a life expectancy of less than 6 months:

- Related to the functional condition:
    - D rating or worse on Katz Index.
- Related to the nutritional condition:
    - Albumin lower than 2.5 g/dl.
    - 10% weight loss over the past 6 months.

The cause of death in these patients is usually an intercurrent infection (pneumonia, urinary infection, sepsis) or the aggravation of the baseline disease, and the survival may be conditioned by the aggressiveness of the treatment administered.

The Medical Guide of Non-Oncological Palliative Care (6) includes the following, in addition to the aforementioned, in its prognosis criteria and terminality criteria:

- That, following prior informing-communication, the patient and/or family have chosen symptom control treatment over curative treatment.
- That the patient presents clinical documentation indicating progression of the primary disease:
    - Successive evaluations, supplementary studies.
    - Several emergency room visits and/or hospitalizations during the past 6 months.
    - Numerous demands for healthcare at home or in assisted living facilities.

(5) The BANS-S scale (Bedford Alzheimer Nursing Severity Subscale) is also applicable, even in the most advanced cases of dementia. This scale makes it possible to evaluate the severity of the disease in advanced cases and bears a relationship to mortality following a fever. This scale is comprised of 7 items: dress, sleep, language, eating, mobility, rigidity/flexibility and visual contact. Each item is scored from 1 to 4, where 1 indicates normalcy and 4 total dependency. The score ranges from 7 (no deterioration) to 28 (severe deterioration).

(6) Spanish Palliative Care Society

In highly-evolved dementias, there are many factors which may aid in decision-making:

- FAST (Functional Assessment Staging) > 7c.
- Rapid evolution of the deterioration.
- Barthel Index = 0 (total dependency for activities of daily living).
- Presence of complications (comorbidity, repetitive infections – urinary, respiratory -, sepsis, fever despite antibiotic therapy…).
- Major dysphagia.
- Desnutrition.
- Dehydration.
- Pressure ulcers refractory to treatment, grade 3-4.

In neurodegenerative diseases, the prognosis is usually more uncertain, which also makes it advisable to take a combined active and palliative stance, accepting the idea of nearing death and taking into account and respecting the ideas and beliefs of the patients.

Ictus

Ictus is a health problem of increasing magnitude due to the aging of the population. It is the leading cause of permanent disability in adults and of permanent neurological sequelae in both sexes, and the second-ranked cause of dementia in the developed countries.

In Spain, ictus is ranked third among the causes of general mortality, being ranked first regarding severe disability and second in dementias. In 2004, ictus caused an absolute mortality of 34,250 persons, representing a rate of 80.2 / 100,000 inhabitants, with an incidence ranging from 150 to 323 cases per 100,000 inhabitants.

The frequent comorbidity and long-term disability give rise to a major use of sociosanitary resources, due both to the duration of the hospital stay and the related disability and the multidisciplinary approach required.

According to the 2000 Catalonian Health Plan, those patients affected by an ictus and institutionalized in long-stay geriatric and chronic beds displayed the following disabilities:

— Degree of dependency:

- 37.5% slight
- 27.8% moderate
- 34.7% major.

— Cognitive deterioration:

- 34.8% capacity intact or borderline
- 17.3 slight or moderately severe deterioration
- 44.8% severe or highly severe deterioration.

The patients with a past history of ictus are at a very high risk of experiencing further vascular episodes, not only cerebral but also ischemic cardiopathy, thus increasing the possibility of worsening and terminality, with a prognosis of permanent disability and loss of quality of life. This has repercussions on families and caregivers, who may have affective symptomologies such as stress, anxiety, depression and changes in social functioning, with interpersonal relations being affected and even social isolation.

Factors of poor prognosis:

- FAST (Functional Assessment Staging) < 7c.
- Absolute dependency for activities of daily living (Barthel Index = 0).
- Presence of complications (comorbidity, repetitive infections – urinary, respiratory -, sepsis, fever despite antibiotic therapy…).
- dysphagia.
- Desnutrition.
- Pressure ulcers refractory to treatment, grade 3-4.

AIDS

The analysis of the epidemiological data reveals a rise in the age at which AIDS is diagnosed, of the prevalence and of AIDS patient survival, who are dying at increasingly older ages (15% case-fatality rate at 6 months of the diagnosis in Catalonia).

The availability of highly active retroviral therapy (HAART) has achieved a major drop in the number of advanced immunodeficiency cases, the number of cases of infections, tumors and HIV mortality decreasing , turning AIDS into a chronic disease.

The palliative care of AIDS patients goes by the same general principles as caring for terminal-stage patients. However, the evolution of the disease per se, the affecting of many different systems, the immunosuppression and the past history of drug addition leads to this care being of certain special characteristics.

- Difficulty of identifying the situation of terminality, given that sudden changes take place in the clinical condition.
- Changing pattern of the disease and its treatment, with relatively fast changes due to the complications and treatment innovations.
- Complications frequently associated with AIDS: blindness, dementia and several neurological disorders, neoplasias, skin lesions, associated opportunistic infections and transmissible diseases.
- Average age younger than that of other terminal-stage patients, with greater knowledge concerning their disease, greater difficulty accepting death and with awareness and prior experiences of friends and family members in a terminal AIDS situation.
- In our environment, it usually affects IVDA's, many of who still continue taking drugs and/or are in a situation of social exclusion.
- Unconfirmed efficacy of antiretroviral therapy in terminal-stage patients.
- The non-AIDS related diagnoses are taking on increasing importance as the cause of hospitalization and mortality among AIDS patients.

Due to the possible active diseases which terminal-stage AIDS patients may have, general and environmental preventive measures must be take in the home (counseling, health education and information provided to caregivers and family members, infection prophylaxis, preventive measures, availability of preventive material and its proper use). This, as well as the care provided to the drug-dependent family members, are in conjunction with all of the conventional measures to be carried out and to be bolstered in the care of caregivers of terminal-stage patients.

Factors of poor prognosis for the evaluation and follow-up of the HAART treatment:

- Patient 50 years of age or older.
- Having contracted this disease as an intravenous drug user.
- CD4 below 50/mm^3.
- Viral load of less than 100,000 copies/ml.
- CDC stage C.

It would be necessary to add to these factors those which are related to opportunistic diseases or complications which are life-threatening for AIDS patients:

- CNS lymphomas
- Progressive multifocal leukoencephalopathy
- Visceral Kaposi's sarcoma refractory to treatment
- Debilitating syndrome with body mass loss of more than 33%
- Rejection of antiretroviral treatment

3. Pediatric patients

General concepts

Pediatric palliative care is of special characteristics:

- Society in general does not expect children to die, and families in particular tend to believe that the medical field is capable of curing almost all diseases. These expectations lead the family and sometimes the healthcare personnel to reject a formal transition toward interventions which are not oriented toward curing the patient.
- The death of a child is an event for which the healthcare community and the family environment are not sufficiently well-prepared, and the child dies in hospital in most cases.
- Estimating the point in time at which a child will die is uncertain and can be an obstacle to setting out palliative care if the estimated survival time is considered to be a criterion for receiving these services.
- Few pediatricians are trained in joint decision-making and in caring for a terminal-stage child, there additionally being a legal void with regard to the decision-making centered on the child and the family.

Basic principles of pediatric palliative care

1. The criterion for admission to a pediatric palliative care program will be the improbability of the child reaching adulthood. A short-range prognosis of survival is not required.

2. The care unit is the child and the child's family.

3. The palliative care services must be available for the children and their families wherever they prefer or is suited to their needs. This may be at the hospital, in primary care or in their home proper.

4. The palliative care is focused on the prevention and relief from their suffering (especially pain) and on the physical, social, psychological and existential support of the child and their family.

This is independent of their possible choice of continuing with treatments which will prolong the child's life.

5. Pediatric palliative care must be carefully planned, by evaluating the existing needs and designing specific protocols (neonatology, oncology, pneumonology, metabolopathies, cardiology, intensive care).

6. The children and their families must be included in the decisions, which requires previously providing them with complete information concerning the disease and the possible treatment options.

7. Pediatric palliative care is carried out within the framework of a multidisciplinary team which must be permanently responsible. This team must be institutionally recognized and availing of the suitable funding to allow its feasibility and availability.

8. The psychological support and, in due course, the follow-up of the bereavement must be carried out by professionals trained in pediatric palliative care.

The terminal-stage child

Definition

- Patient with an advanced, progressive disease after having received appropriate treatment.
- Minimal or no possibility of response to the specific treatment for the baseline disease. In certain cases, treatments considered specific due to their ability to enhance the quality of life (Radiation therapy) must be used.
- Prognosis of limited life expectancy.

Guidelines for action

- The care of terminal-stage children must be provided in the place considered most appropriate for each individual child by means of a family decision duly guided by the healthcare team responsible for the patient.
- The possibility must always be available of care being provided for the terminal-stage child in the hospital environment in which he/she has previously been treated.
- At the hospital, the child must be cared for by the healthcare personnel responsible for his/her specific treatment with the support of other specialists necessary to cover all of their care needs in this stage.

- One alternative to the treating hospital can be the hospital (regional, etc.) located nearest to the home of the child's family. In this case, fluent communications among the healthcare teams of both hospitals must be guaranteed in order to assure the continuity and efficacy of the care.
- Another alternative may be the family home, with care provided on the part of primary care. In this case, it is necessary for there to be a home hospitalization program carried out by a multidisciplinary team of at least pediatricians, nursing and auxiliary personnel possessing training and experience and which will guarantee round-the-clock care.

II. Conclusions of the National Health System Meeting on Palliative Care – Present and Future. December 2005

1. Evidence exists at the national and international level of the usefulness and efficacy of the integral palliative care programs in terms of quality of life, dying with dignity and patient and family member satisfaction.

2. The programs and interventions in palliative care must be designed in keeping with the patients' needs and preferences, around which the providing of this care must be organized, taking into account for this purpose the different locations, levels of care and degrees of specialization and complexity possible.

3. The recommendations, priorities and criteria to be employed in the design and organization of palliative care have now been exhaustively set out, being a paradigm on which to base those set out by the WHO and the Council of Europe, it being necessary for policies and clear leadership to be set out in order make their implementation and final development possible.

4. Access to quality palliative care programs must be guaranteed for all patients during the advanced and terminal stages of their disease, independently of their sociodemographic characteristics and place of residence, at any level of care, including the intervention of specific teams with regard to more highly complex situations.

5. The programs must be integral and integrated into our country's health system model, avoiding the creation of single separate structures of resources not connected to the rest of the system. Cooperation, shared care and information coordination and exchange mechanisms must be substantial parts of the design of these programs, such that the care, referral and complexity criteria and the idea resources for each case will be set out more precisely.

6. Provided that the preferences, existence of family support, the patient's conditions and complexity of the care so allow, homecare must be considered to be the ideal level of care so that the patients will remain integrated into their environment the longest time possible. Agile, fluid coordination among the care teams and the homecare support teams and the specialized acute and medium and long stay hospital palliative care resources is therefore required.

7. Sufficient experience and evidence also exists of efficient, quality palliative care models and programs in our country. These experiences must be exchanged and comprised the basis of programs and interventions in those Autonomous Communities where palliative care has been developed to a lesser degree.

8. At this point in time, palliative care in the different Autonomous Communities and even within these Communities is heterogeneous in terms of accessibility, coverage, organization, resources and outcomes.

9. It is therefore necessary to avail of a common palliative care strategy for the entire NHS, the basic principles of which will be the basis of measures adapted, as is logical and as is under their authority, to the needs, demographic, territorial and resource-related characteristics of each Autonomous Community.

10. This Strategy must guarantee all that which has been set forth hereunder and mainly assure equal opportunity and access to palliative care in similar terms of quality and benefits.

11. The training of the professionals at all levels of care and of all professional categories at both the undergraduate and graduate levels must be a priority for the academic and health institutions, the handling and control of symptoms and more frequent situations, placing special emphasis on pain control, must be a priority.

12. The professionals must also have standards and protocols for taking action which are adapted to the care-providing activity in palliative care and which will aid them in making decisions in both clinically and ethically complex situations.

III. External reviewers

- Spanish Federation of Parents of Children with Cancer
- Carlos III Health Institute
- Cecilia Sepúlveda Bermejo. Senior Adviser Cancer Control – World Health Organization
- Eduardo Bruera. Chief of the Palliative Care Service of the MD Anderson Hospital in Houston.
- Liliana De Lima. Executive Director of the International Association for Hospice and Palliative Care (IAHPC).

IV. Glossary of terms

Complexity: Set of factors of greater difficulty or intensity of needs which customarily require the intervention of a palliative care team. Complexity depends both on the characteristics of the patient as well as on hard to control problems, the need for certain diagnostic or treatment actions and family adaptation-related problems.

Crisis of need: Acute situation characterized by the onset of one or more specific physical, psychological, social or spiritual needs which diminish the patient's comfort and quality of life and which alter the adaptation and emotional stability of the family and require a specific intervention in order to be remedied.

Palliative care: Focus which enhances the quality of life of patients and families which are confronted with problems related to life-threatening diseases through the prevention and relief of suffering by means of the impeccable, early identification, evaluation and treatment of the pain and other physical, psychological and spiritual problems.

Palliative care team: The palliative team's core activity is confined to palliative care. These teams are customarily devoted to providing care for patients with more complex, intensive care needs and therefore require a high level of training, personnel and means. These teams are comprised of physicians and nurses, with the necessary cooperation of a psychologist and social worker and the collaboration of other professionals. The composition of the teams will depend upon the demographic and geographic characteristics and on the degrees of need of the regional healthcare structures in question. These teams also carry out teaching and researching duties to different degrees.

Homecare support team: Palliative care team which takes action in the home following interconsultation with the responsible professionals. These teams may carry out counseling duties or direct interventions.

Hospital support team: Palliative care team which takes action in hospital following interconsultation with the responsible professionals. These teams may carry out counseling duties or direct intervention.

Levels of palliative care:

The basic, primary, general levels of palliative care or palliative approach refers to the care which must be provided to all patients who require this care, both in primary and specialized care.

The level of specific, secondary, specialized or advanced palliative care takes in different types of interventions of the palliative care teams in regard to situations of complexity.

Some authors term third-level care as being the hospital care in Palliative Care Units.

Target population of the Strategy: This Strategy is targeted on those patients with cancer and chronic evolutive diseases of any age in the advanced/terminal stage. The palliative interventions will be based mainly on the patient's and family's needs, more than on a specific expected survival time.

Advanced-terminal stage of disease: The criteria proposed for defining a patient as being in the advanced/terminal stage are as follows:

- Progressive, advanced, incurable disease.
- Prognosis of limited life expectancy.
- Very little possibility of response to specific treatments.
- Evolution of a fluctuating nature and frequent crises of need.
- Intense emotional and family impact.
- Repercussions on the care-giving structure.
- High demand and use of resources.

Palliative care unit: These are specific palliative care hospital units manned by an interdisciplinary team. These units may be located in acute or sociosanitary hospitals. These units frequently also carry out hospital support team and outpatient consultation duties.

V. Glossary of abbreviations

AC	Autonomous Community
AECC	Spanish Association Against Cancer
AECPAL	Spanish Association of Palliative Care Nursing
AEC	Community Nursing Association
AEP	Spanish Pediatrics Association
AEPCP	Spanish Association of Clinical Psychology and Psychopathology
ARINDUZ	Basque Palliative Care Society
ATSS	Spanish Social Work and Health Association
DG	Directorate General
ESAD	Homecare Support Team
ESD	Home Support Team
ESH	Hospital Support Team
FAECAP	Federation of Community Nursing and Primary Care Associations
ICO	Institut Catalâ d'Oncología
IES	Institut Estudis per la Salut
MFyC	Spanish Family and Community Medicine Society
MSC	Spanish Ministry of Health and Consumer Affairs
PADES	Catalonian Homecare and Support Team Program
PC	Palliative Care
SACPA	Andalusian Palliative Care Society
SADEI	Asturian Society of Economic and Industrial Studies
SCBCP	Catalonia-Balearic Palliative Care Society
SECPAL	Spanish Palliative Care Society
SEEGG	Spanish Society of Geriatric and Gerontological Nursing
SEEO	Spanish Ontological Nursing Society
SEGG	Spanish Society of Geriatrics and Gerontology
SEMERGEN AP	Spanish Society of Primary Care Physicians
SEMFYC	Spanish Society of Family and Community Medicine
SEOM	Spanish Society of Medical Oncology

SEOP	Spanish Society of Pediatric Oncology
SEOR	Spanish Society of Radiation Therapy Oncology
SES	Extremadura Health Service
SMCP	Madrid Palliative Care Society
SOGACOPAL	Galician Palliative Care Society
SSC	Sociosanitary Center
SVCP	Valencian Palliative Care Society
UAB	Autonomous University of Barcelona
UCP	Specific Palliative Care Hospital Unit
UFISS	Interdisciplinary Saciosanitary Operating Units
UHD	Home Hospitalization Unit
UHPV	Polyvalent Hospitalization Unit
UOC	Univesitat Oberta de Catalunya