

Palliative Care Strategy of the National Health System 2010-2014 Update

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Palliative Care Strategy of the National Health System

2010-2014 Update



GOBIERNO
DE ESPAÑA

MINISTERIO
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E IGUALDAD

Plan de Calidad
para el Sistema Nacional
de Salud



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Presentation

The Ministry of Health, Social Policy and Equality includes the improvement of existing Palliative Care in Spain as one of the objectives of the National Health System Quality Plan. In 2005, to promote cohesion and safeguard access equality and quality of services, the Ministry undertook the project to elaborate a Palliative Care Strategy for the entire National Health System.

The Quality Agency of the National Health System coordinated the project, involving professional and civic associations directly interested in Palliative Care, and also the administrations of the Autonomous Communities. After more than a year of intense and fruitful work and exchanges of ideas, the Palliative Care Strategy of the National Health System was approved, by unanimity, on the 14th of March of 2007 by the Interterritorial Council of the National Health System. The Strategy establishes the project must be evaluated two years after passing. To this end the Monitoring and Evaluation Committee (MEC) was formed and the resulting report submitted to the Interterritorial Council on May 31st of 2010, and subsequently approved.

We are now presenting the new Strategy for the 2010-2014 period, as an essential element to consolidate the improvements incorporated to the care received by patients at advanced or terminal stages of a life limiting illness, as well as the care received by their relatives.

This Strategy is the culmination of a broadly participative process, where all the scientific and patients associations, as well as the Autonomous Communities and other institutions have contributed their work. I thank all of them very especially for their efforts and good work for having brought up to date this important tool that will help to improve the quality of life of the persons needing palliative care and their relatives, as well as the overall quality of the National Health System.

Leire Pajín Iraola
Minister of Health, Social Policy and Equality

Introduction

The Palliative Care Strategy of the National Health System (NHS), was approved by unanimity by the Interterritorial Council of the NHS on the 14th of March of 2007, validating the consensual work between the institutional representatives and the experts from various field related to health care provision during the last stages of life. The most immediate effect noted has been an obvious increase of visibility of palliative care in the Spanish health system.

The Monitoring and Evaluation Committee, constituted on the 12th of March of 2008 by representatives of the Autonomous Communities, of INGESA (National Institute for Health Care Management) and of the scientific associations, patient associations and experts in the areas related to the Strategy, established by consensus the methodology for the evaluation that was planned to be implemented two years after the Strategy was passed. A questionnaire model was designed to collect specific information at the Autonomous Community level. The remaining information has been gathered from existing health care information provided by the Institute of Health Care Information and the General Department for Pharmaceutical and Health Products.

The evaluation included a set of quantitative indicators, a qualitative evaluation of achievement of the objectives relative to care giving processes, organizational and/or management processes, and a description of the map of palliative care devices and resources of the NHS.

The Health Care Provision and Quality Planning Office (Oficina de Planificación Sanitaria y Calidad (OPSC)), collated this information into an evaluation report that was submitted to the Interterritorial Council of the National Health System on the 31st of May of 2010.

The evaluation, despite the limitations of the information sources and the need to better adapt the records and information systems, has provided valuable data. There is now a detailed analysis of care provision, organizational, ethical, educational and research related aspects pertaining to palliative care in Spain.

The results of the evaluation show weaknesses and strengths. A two year span is insufficient to achieve all the established objectives, however, it has been possible to detect the start of a positive change in the care provided to patients and family members, as was intended from the start of the Strategy.

In recent years numerous palliative care plans have been published by the Autonomous Communities. Very few administrations still lack them. A model for integrated care provision for patients and family members and an organizational model have been arrived at by consensus. The latter has been

designed in two levels. A basic level oriented to all patients in general and an specific level aimed at patients with more complex needs.

The palliative care structures and resources map shows a significant increase in recent years, however, their heterogeneity persists, existing differences in access and equitability.

Numerous training and Strategy disseminating actions have been implemented. In terms of research it is worth mentioning the sparse financing that exists for palliative care projects.

Since the Strategy was approved, the most relevant observations and evidence pertaining to the different lines published in national and international journals have been analyzed (up to May 2009). Taking into consideration the contributions of the evaluation findings and the review of new evidence, the Monitoring and Evaluation Committee established, by consensus, the objectives for the Palliative Care Strategy of the National Health System 2010-2013, incorporating modifications to some of the objectives as well as new recommendations. In general, it was considered that the large majority of the objectives were fully current and needed a longer period of time to be attained. In each of the strategic lines the objectives are preceded by a summary of the evaluation completed and a report on new evidence. Examples of Good Practices related to the strategy and selected amongst those submitted by the members of the Institutional Technical Committee, can be consulted at the following site: http://www.mspsi.es/organizacion/sns/planCalidadSNS/docs/paliativos/BUENAS_PRACTICAS_C_PAL IATIVOS2007_9.pdf The road opened by the Strategy still presents significant challenges. Palliative care must be generalized for all patients that need it, including patients with chronic non-oncological conditions and the pediatric population. The specific level mentioned above must provide habitually, in complex situations, continued, expert, high quality care. To do this it is essential to integrate physicians and nurses with mental health professionals and social workers into interdisciplinary teams. Continuity of care and integration of levels of care are still improbable in patients with intense needs and frequent changes of location. As the Strategy recommends, it is necessary to extend palliative care education in upper degrees curricula and look for ways to ensure the members of interdisciplinary teams receive advanced training. Lastly, it is important to note that palliative care evaluation and research project financing criteria must be reviewed. An effort on the part of the medical profession to contribute to the design and methodology of such research would also be desirable.

In order to address all these challenges, the Monitoring and Evaluation Committee has formed three work groups. The Evaluation Group will propose improvements to the existing indicators and standards of the Strategy, incorporating the direct results of patients and family member's interventions, such as: relief from pain and other symptoms, information received,

and degree of satisfaction. It would be also advisable to have a minimum homogeneous set of data on the quality of care at the national level.

The Training Group will design and plan training at the basic, intermediate and advanced levels, as well as awareness rising and dissemination actions on palliative care for the public at large.

The objective of the Continuity of Care Group is to analyze the ways to deepen the relationship between the various levels of health care provision, including new information systems.

Undoubtedly, the Palliative Care Strategy will continue to bring improvements to the care received by patients and family members during a particularly vulnerable stage when there is a great need of health care services.

1. Overview

1.1 Methodology

Updating the Palliative Care Strategy for the 2010/2014 period includes:

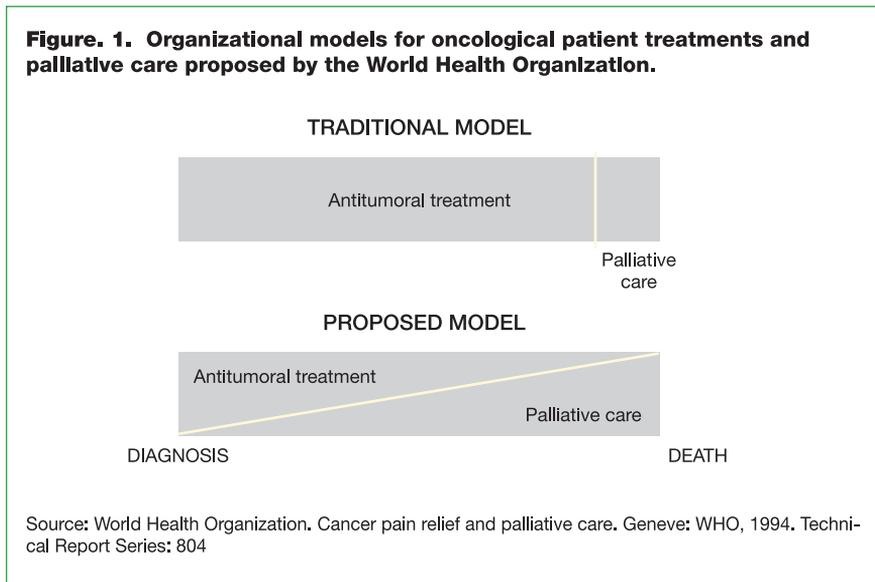
1. **New scientific evidence made available after the Strategy was approved:** knowledge from models and examples already being practiced, in our country and in other countries, have not been excluded, even if they were not published, provided they were pertinent to some of the Strategy review's objectives, and had been implemented during a sufficiently long period of time to verify their usefulness.
2. **The analysis of the evaluation results:** within the situational analysis of each strategic line is included a summary of the evaluation results, showing the general status of the objectives at that time. This section summarizes the results of the 7 general objectives, which include both the answers filled in by the Autonomous Communities to the questionnaires on the 33 specific objectives, as the indicators obtained through information available from the General Department for Pharmaceutical and Health Products and the Health Care Information Institute, that has put together a map of resources available at the Ministry's site: (<http://www.msc.es/organizacion/sns/planCalidadSNS/cuidadosPaliativos.htm>).
3. **Examples of good practices:** have been compiled and are available at the website of the Ministry of Health, Social Services and Equality, (http://www.mspsi.es/organizacion/sns/planCalidadSNS/docs/paliativos/BUENAS_PRACTICAS_C_PALIATIVOS2007_9.pdf). These are examples of good practices developed in the Spanish context that have proved their efficacy and effectiveness.
4. **Redefining and proposing new objectives and recommendations.**
5. **Indicators:** the indicators that have been currently approved and those review-pending by the Monitoring and Evaluation Committee evaluation group are presented.

1.2. Palliative Care: Definition, AIMS and target population

This section contains already specified aspects of the first version of the Strategy that continue to be current due to their relevance.

Definition of palliative care

The World Health Organization (WHO) adopted, in a key document for the development of palliative care published in 1990, the definition proposed by the European Association of Palliative Care as “the total active care of patients whose illnesses do not respond to curative treatment. The control of pain and other symptoms, as well as addressing the psychological, social and spiritual issues is of primordial importance”. The document also highlights that palliative care must not be limited to the last days of life, but needs to be applied gradually as the illness advances and according to the needs of patients and family members (Figure 1)¹.



Later, the WHO broadened their definition of palliative care as: “The approach that improves the quality of life of patients and family members facing the problems associated with life threatening illnesses, by preventative care and alleviation of suffering through early identification and impec-

able evaluation and treatment of pain and other physical, psychological and spiritual problems²⁷.

The definition is completed with the following palliative care principles:

- Provide relief from pain and other symptoms.
- Are life affirming and consider death as a normal process.
- Do not attempt to either accelerate or delay death.
- Integrate spiritual and psychological aspects in patient care processes.
- Offer a support system to help patients live as actively as possible until the onset of death.
- Offer a support system to help the family adapt during the illness and during mourning.
- Use a team approach to address the needs of patients and their families, including emotional support during mourning when appropriate.
- Improve quality of life and may also influence positively the course of the illness.
- Are applicable in an early manner during the course of the illness, together with other treatments that may prolong life, such as chemotherapy or radiotherapy, and include the necessary research to better understand and manage complex clinical situations.

Aims of the Strategy

Mission

Improve the quality of the care provided to patients at advanced or terminal stages of their illness and to their families, promoting an integrated and coordinated response from the health care system to address their needs while respecting their autonomy and personal values.

Objectives

The Autonomous Communities (ACs) must establish appropriate, viable and measurable commitments for contributing to the homogeneity and improvement of the palliative care provided by the National Health System.

Values

- The right to alleviate suffering.
- The intrinsic value of each person as an autonomous and unique individual
- Quality of life understood as defined by each individual patient
- Patient and family members' expectations about how the health care system will address their needs at the end of life stage.
- Solidarity with suffering.

Principles

- Accompanying the patients and their families according to their actual needs.
- Integrated care, accessible and equitable.
- Continuity of care and coordination of the various levels of health care provision.
- Open and honest communication.
- Ethical reflections and participation of the patients and their families in the decision making process.
- Competence and continuing professional development of practitioners to ensure the needs of patients and their families are suitably addressed.
- Interdisciplinary team work.
- Therapeutic actions based on the best available evidence.
- Non-discrimination regarding age, gender or any other characteristic.

Target population

The strategy is directed at patients of any age diagnosed with cancer or progressive chronic illnesses that are at an advanced or terminal stage. Palliative interventions will be based essentially in the needs of patients and relatives rather than on the specific expected survival time.

The criteria proposed to define patients at an advanced and terminal stage of their illnesses are³:

- Incurable, advanced and progressive disease.
- Limited life prognosis.
- Small possibility of response to specific treatments.
- Oscillating evolution and frequent needs crises.
- Intense emotional and familial impact
- Repercussions on the care givers' structure.
- High demand and use of resources.

Annex I (page 125) of the 2007 Palliative Care Strategy contains the characteristics of advanced and terminal stages of the disease of different patient subgroups:

- Cancer patients.
- Patients with progressive chronic illnesses.
- Pediatric patients.

The text can be consulted at:

(http://www.msc.es/organizacion/sns/planCalidadSNS/pdf/excelencia/cuidadospaliativos-diabetes/CUIDADOS_PALIATIVOS/estrategiaCuidadosPaliativos.pdf)

1.3. Bringing up to date the Palliative Care situation in Spain

1.3.1. Regulatory framework

As noted in the first version of the Strategy, the right of terminal patients to receive care is a right acknowledged by international organizations and a health service clearly described in the Spanish legislation.

Also mentioned were the various technical reports issued by the World Health Organization^{4,5,6}, its European office^{7,8,9,10}, Resolutions of the European Council,^{11,12,13,14,15} as well as their repercussion in Spain^{16,17} and their inclusion as basic service in the “National Health System Cohesion and Quality Act”¹⁸ as well as in the common services portfolio of the National Health Service¹⁹.

On May 10th of 2005, the Health Commission of the Congress of Deputies passed a motion requesting the Government to evaluate the situation of palliative care in Spain, to apply the document “Bases for Developing a National Palliative Care Plan” and to promote the creation by the Autonomous Communities of palliative care units, amongst other actions²⁰.

A recent resolution adopted on January 29th of 2009 by the Parliamentary Assembly of the European Council²¹ considers palliative care as an essential component of health care based on a human concept of dignity, autonomy, human rights, patient rights, and a generally acknowledged perception of solidarity and social cohesion. In addition it recommends palliative care as a model of innovative social and health care policies.

1.3.2. Epidemiology

Need of palliative care in the existing population

During 2008, according to the National Institute of Statistics, 386,324 died in Spain bringing the death rate up to 8,264.35 per million of inhabitants per year. The method proposed for estimating the target population of palliative care is similar to that described by the McNamara *et al*²² study. Ten pathologies have been selected to run a least squares estimation: cancer, cardiac insufficiency, hepatic insufficiency, renal failure, chronic obstructive pulmonary disease (COPD), amyotrophic lateral sclerosis (ALS) and motor neuron diseases, Parkinson, Huntington, Alzheimer and AIDS. The cause and number of deaths due to said causes have been selected from the National Institute of Statistics (NIS) database. Certain pathologies have been associated in some cases to fit them to the McNamara pathology list.

The number of deaths caused by cancer and by all the other nine non-oncological causes selected by McNamara has been obtained from the mortality figures and their classification by causes published by the National Institute of Statistics (Instituto Nacional de Estadística, INE). The results, organized territorially by Autonomous Community are shown in Table 1.

Table 1. Mortality by cause and Autonomous Community (2008)

NUMBER OF DEATHS BY SELECTED CAUSE									
CODES USED BY THE WHO'S INTERNATIONAL CLASSIFICATION OF DISEASES (ICD) 10									
<i>MALIGNANT TUMORS: C00-C97</i>									
<i>BENIGN TUMORS: D00-D48</i>									
<i>CARDIAC INSUFFICIENCY: I11 + I13 + I50</i>									
<i>RENAL FAILURE: N18</i>									
<i>LIVER FAILURE: K703 + K704 + K711 + K713 + K714 + K715 + K717 + K721 + K729 + K74</i>									
<i>COPD: J40 + J42 + J43 + J44</i>									
<i>MOTOR NEURON DISEASES G10 + G12.2 + G20 + G30 + G31</i>									
<i>HIV / AIDS: B20 + B21 + B22 + B23 + B24</i>									
2008 DATA									
<i>Both genders</i>	Malignant tumors	Benign tumors	Cardiac insufficiency	Chronic kidney failure (ckf)	Liver failure	Copd	Motorneuronal diseases	IHV/AIDS	Total
Andalusia	15,808	591	4,547	600	1,100	2,336	2,232	259	27,473
Aragon	3,341	137	828	207	119	397	507	35	5,571
Asturias	3,552	59	649	109	149	475	497	35	5,525
Balearic Islands	1,980	51	578	103	95	208	292	50	3,357
Canary Islands	3,697	103	567	127	201	384	389	67	5,535
Cantabria	1,487	58	270	39	42	186	198	15	2,295
Castille and Leon	7,399	256	1,798	248	223	912	984	54	11,874
Castille-La Mancha	4,425	132	1,011	130	141	817	621	31	7,308
Catalonia	15,976	569	3,607	698	754	2,349	3,012	138	27,103
Valencian Community	10,288	331	2,319	437	566	1,426	1,696	154	17,217
Extremadura	2,665	117	641	88	75	323	336	20	4,265
Galicia	7,660	221	2,260	203	383	1,151	903	65	12,846
Madrid	11,581	401	2,572	366	428	1,345	1,247	171	18,111
Murcia	2,564	112	525	120	144	380	404	27	4,276
Navarre	1,405	28	289	44	33	200	259	12	2,270
Basque Country	5,653	157	938	188	263	669	868	52	8,788
La Rioja	737	35	196	16	22	85	158	7	1,256
Ceuta	124	6	25	5	7	16	17	4	204
Melilla	97	7	26	6	6	16	12	3	173
Total	100,439	3,371	23,646	3,734	4,751	13,675	14,632	1,199	165,447

Table 1. Mortality by cause and Autonomous Community (2008) (continuation)

<i>Men</i>	Malignant tumors	Benign tumors	Cardiac insufficiency	Chronic kidney failure (ckf)	Liver failure	Copd	Motorneuronal diseases	IHV/AIDS	Total
Andalusia	9,980	293	1,523	295	805	1,933	789	208	15,826
Aragon	2,069	84	283	112	87	290	199	26	3,150
Asturias	2,184	27	186	56	119	403	160	23	3,158
Balearic Islands	1,239	22	204	55	67	166	93	43	1,889
Canary Islands	2,319	52	207	80	148	301	146	51	3,304
Cantabria	959	34	108	17	30	147	55	11	1,361
Castille and Leon	4,588	136	585	128	158	748	365	42	6,750
Castille-La Mancha	2,834	72	333	71	101	668	266	23	4,368
Catalonia	9,726	307	1,241	352	479	1,812	1,069	109	15,095
Valencian Community	6,430	168	795	226	391	1,104	629	113	9,856
Extremadura	1,715	56	199	41	60	288	127	18	2,504
Galicia	4,750	117	765	100	264	795	326	53	7,170
Madrid	6,967	201	813	190	286	1,029	419	131	10,036
Murcia	1,588	64	196	60	107	317	139	24	2,495
Navarre	871	16	94	22	25	163	93	10	1,294
Basque Country	3,625	92	343	107	198	496	313	40	5,214
La Rioja	471	19	79	9	15	73	60	4	730
Ceuta	68	5	6	2	3	11	3	4	102
Melilla	57	6	15	4	4	12	7	3	108
Total	62,440	1,771	7,975	1,927	3,347	10,756	5,258	936	94,410

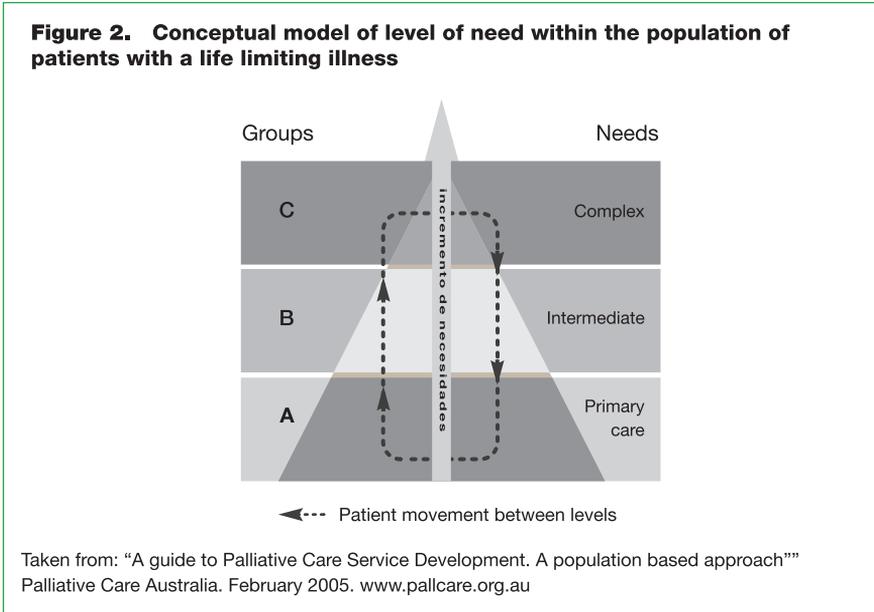
Table 1. Mortality by cause and Autonomous Community (2008) (continuation)

<i>Women</i>	Malignant tumors	Benign tumors	Cardiac insufficiency	Chronic kidney failure (ckf)	Liver failure	Copd	Motorneuronal diseases	IHV/AIDS	Total
Andalusia	5,828	298	3,024	305	295	403	1,443	51	11,647
Aragon	1,272	53	545	95	32	107	308	9	2,421
Asturias	1,368	32	463	53	30	72	337	12	2,367
Balearic Islands	741	29	374	48	28	42	199	7	1,468
Canary Islands	1,378	51	360	47	53	83	243	16	2,231
Cantabria	528	24	162	22	12	39	143	4	934
Castille and Leon	2,811	120	1,213	120	65	164	619	12	5,124
Castille-La Mancha	1,591	60	678	59	40	149	355	8	2,940
Catalonia	6,250	262	2,366	346	275	537	1,943	29	12,008
Valencian Community	3,858	163	1,524	211	175	322	1,067	41	7,361
Extremadura	950	61	442	47	15	35	209	2	1,761
Galicia	2,910	104	1,495	103	119	356	577	12	5,676
Madrid	4,614	200	1,759	176	142	316	828	40	8,075
Murcia	976	48	329	60	37	63	265	3	1,781
Navarre	534	12	195	22	8	37	166	2	976
Basque Country	2,028	65	595	81	65	173	555	12	3,574
La Rioja	266	16	117	7	7	12	98	3	526
Ceuta	56	1	19	3	4	5	14	0	102
Meiilla	40	1	11	2	2	4	5	0	65
Total	37,999	1,600	15,671	1,807	1,404	2,919	9,374	263	71,037

Source: Ministry of Health, Social Services and Equality. Institute of Health Care Information. Mortality by pathological cause.

Need for specific palliative care.

Patients suffering intermediate or complex situations may require the intervention of a specific palliative care team (Figure 2)



According to studies done in Australia²³, and calculations from other authors, appropriate palliative care coverage could be provided by specific teams for 60% of the oncological patients, and for 30% of the non-oncological patients (provided the nine causes selected by McNamara are observed)^{24,25,26,27}.

According to these calculations and the estimations of the palliative care needs described above, the basic palliative care level in Spain would include 3,621 patients per 1 million inhabitants and year, of which 1,755 per 1 million inhabitants and year must be cared for by specific palliative care teams (48.5%).

1.3.3. Evaluation of the current situation

In recent years several documents have been published on the situation of palliative care in Europe. The European Association for Palliative Care (EAPC) has analyzed indicators of the development of palliative care meas-

ures in 52 countries of the European region of the World Health Organization²⁸. Spain occupies the 11th place in the provision of specific palliative care and 4th place in a “vitality” classification that takes into account publications and the existence of associations, scientific meetings and directories of palliative care services.

A report of the European Parliament published in May 2008 evaluated the development of palliative care in the 27 Member States, analyzing persistent challenges, highlighting national practices that could be models for other countries, and identifying channels for future advances. Spain is included amongst the countries with greater level of integration in the national health system, occupying 7th place when a global development index is applied²⁹.

The evaluation of the Palliative Care Strategy, submitted to the Interterritorial Council on May 31st of 2010, included a set of quantitative indicators, a qualitative evaluation of attainment of objectives relative to health care provision processes, and organizational and/or management aspects, as well as a description of the map of existing palliative care devices and resources. (<http://www.msc.es/organización/sns/planCalidadSNS/cuidadosPaliativos.htm>).

An important contribution of the Strategy’s evaluation has been to have, for the first time, a set of data and indicators of the actual situation and development of palliative care in Spain. It will serve as baseline and control for future comparative analyses. In addition, the evaluation has made possible to analyze some evolutionary changes in the two years that have elapsed since it was instated.

In relation to the quantitative indicators, certain amount of complexity must be ruled out in order to obtain data, and this suggests there is a need to improve the information gathering systems regarding palliative care.

The percentage of patients with palliative care needs registered in primary care information systems is of 25.7 % of the population estimated in 2007 and 22.1 % of that estimated in 2008. Considering that primary care is the entry gateway to the system, and that its databases should contain the entire population receiving palliative care, these figures suggest that said population is infra-recorded. The percentage of patients cared for by palliative care teams in relation to the estimated population was 30.7% in 2007 and 29.4% in 2008. The percentage of patients cared for by palliative care teams, units or hospital services was 17.9% in 2007 and 19.2% in 2008. This indicator must be disaggregated in the future according to the nature of the different hospital structures and services, however, the fact that the recorded figures are insufficient remains.

In a global manner there is evidence of a progressive consumption of third step opioids (in the WHO’s analgesic ladder scale), particularly of fen-

tanyl. The total consumption of different opioids expressed in daily intake dosages defined by 1000 inhabitants and year for 2008, are as follows: morphine 0.38; fentanyl 1.59; oxycodone 0.08 and buprenorphine 1.95.

During 2007 and 2008, 12,809 health care providers have received training in palliative care, of these: 1,545 at the intermediate level and 479 at the advanced level.

Two research projects on palliative care and 31 projects for the Autonomous Communities were financed in 2007 and 2008 by the Health Research Fund (Fondo de Investigación Sanitaria, FIS).

The Strategy proposes an interdisciplinary integrated health care model for patients and their families, based on the collaboration between different care provision levels and accessibility in the various health areas or territories. The qualitative evaluation of attainment of objectives relative to care provision processes and organizational and/or management processes shows some of the strides achieved by having developed this model. Most of the Autonomous Communities include in a specific plan the objectives related to identifying, evaluating and establishing therapeutic plans, while half of the Autonomous Communities considered them management objectives.

There has been an increase in regional palliative care plans. In March of 2009, ten (10) Autonomous Communities already had in place specific palliative care plans or programs, another has already published its plan, and four others are close to publishing theirs. As shown by the quantitative indicators, both home care and hospital care coverage needs to be increased for palliative services. Organizational aspects relative to shared information systems must be optimized, as well as care provided in special homes, specific access of patients and family members to psychological and sociofamilial intervention, and support to the medical professionals providing the care.

The objectives relative to the patient autonomy strategic line are included on most of the Autonomous Community's plans, although actions are still needed to mainstream them into the clinical practice.

In terms of the map of palliative care devices and resources a gradual increase has been noted in recent years, however, these resources must continue to increase according to the high need and high demand for this type of care. Also detected is a considerable heterogeneity between the various Regions. Palliative care resources specific to the pediatric population are very scarce.

It is considered convenient for the next evaluations to have quantitative data on the control of pain and other symptoms, recording information in the patient's chart and of the decision making process and the satisfaction with the care received. To do this, and to develop the Strategy more in depth, it was decided to form work groups within the Monitoring and Evaluation Committee.

2. Developing strategic lines

2.1. Strategic Line 1: Integrated Care

2.1.1. Current situation:

The Strategy proposes a model of interdisciplinary Integrated Care for patients and their families, based on the collaboration between the different levels of care provision and in the conditions of accessibility in the various territories or health areas.

A multicentric European study³⁰ carried out in 22 countries has analyzed **the characteristics of 3,013 patients seen at various palliative care structures**. Of this number, 94% had been diagnosed with cancer, 60% was receiving home care, and the expected time of survival for most of them was between one and six months. It was noted that the importance of the patient's need to receive palliative care is more important than having an exact survival prognosis in order to be included in palliative care programs. Although determining the prognosis is a very complex issue, a systematic review of the different guideline tools that can be used to estimate survival in palliative care has been published³¹, including tools that are pathology-dependent and those that depend on the clinical-biological characteristics of the patient.

Several works highlighting the importance **of palliative care in the non-oncological patients**, as underlined in the Strategy, have also been published. An analysis of conventional care received by 102 patients in their nineties suffering from cardiac insufficiency or advanced dementia that died at the two university hospitals of our environment, showed numerous areas that could be improved^{32,33}. The need to establish guidelines for identifying and managing terminal cardiac insufficiency has been noted³⁴. A review of the Geriatric Cardiology Unit of the Spanish Society of Cardiology³⁵ analyzes the terminal cardiomyopathy criteria noting the objective is to achieve maximum wellbeing from an integrated perspective, improving the quality of life before death and avoiding aggressive treatments that consume resources without providing results. The European Society of Cardiology³⁶ has also published a document of recommendations, which objectives are to improve existing knowledge on the need for palliative care of patients with cardiac insufficiency, improve the accessibility and quality of palliative care, and promote the development of cardiac insufficiency-oriented palliative care services.

In the case of COPD, detailed recommendations have already been published, detailing the position of the American Thoracic Society³⁷, as well as evidence-based reviews based on palliative approaches³⁸.

The Bioethics Work Group of the SEMICYUC³⁹ (the Spanish Society for Intensive and Critical Medicine and Coronary Units) has prepared recommendations on how to provide treatment for patients at the last stages of life that are in critical conditions, analyzing the decision making process surrounding the removal of futile or disproportionate treatments and palliative sedation.

A recent literature review has analyzed a less known aspect: palliative care for patients with persistent and severe mental illnesses⁴⁰.

Although the Regional Palliative Care Plans or Programs include non-oncological patients as part of their target population, the number of non-oncological patients included in palliative care programs is still small. Analyzing and exchanging the available information on palliative care for patients with progressive chronic illnesses has been recommended. It would also be appropriate to analyze, in depth, the available data on palliative care for the pediatric population.

Various studies have analyzed palliative care **in children**, a population that despite the fast advances continue to be underrepresented. The standards for pediatric palliative care of the European Association for Palliative Care (EAPC)⁴¹ have been published, as well as revisions on the definition, needs detection, symptom relief, professional response, and needs for support and training⁴². Setting up a consultant team for pediatric palliative care made possible to detect multiple needs pertaining to the control of symptoms and of communication⁴³.

Integrated assessment includes the **physical, psychological, social and spiritual needs**. A study of the Work Group on Spirituality at the End of Life of the SECPAL (Spanish Society for Palliative Care)⁴⁴ has compiled the perception of the medical profession regarding the spiritual needs of patients at the end of their lives. A taxonomical classification listing 12 types of existential-spiritual needs that may contribute to a better appreciation and assessment of this dimension has been proposed.

Various publications highlight the importance of a suitable **evaluation**. A relevant systematic review has analyzed 99 measures used to evaluate care at the end of life stage and its results⁴⁵. The more robust measures were found to be those related to symptoms, quality of life and satisfaction, while those pertaining to continuity of care, advanced planning, spirituality and wellbeing of the caregiver were found to be weaker.

One of the instruments more often used to assess the intensity and control of symptoms is the ESAS scale (Edmonton Symptom Assessment System), a system that has been subjected to numerous validation tests^{46,47,48}.

Pain control is an obligatory reference when analyzing patient comfort⁴⁹. Opioid consumption, despite its lack of specificity, is widely regarded as a very objective indirect indicator of pain control. A detailed study has shown a progressive increase in opioid consumption, measured in a defined daily dose (DDD) per one thousand inhabitants and year, in Spain, from 1982 to 2006⁵⁰. The authors note the important increase in consumption of fentanyl versus the stabilization of morphine, considered as the opioid of choice for the third step in the analgesic ladder scale of the WHO. The trend is similar in Nordic countries⁵¹ and in different health areas of our environment^{52,53}.

A review on the palliative actions with **greater degree of evidence**⁵⁴ has been published. Most noteworthy are: administration of opioids for treating pain and dyspnea, antialgic treatments using non-steroidal anti-inflammatories, radioactive isotopes and radiotherapy, psychotherapy, tricyclic antidepressants and serotonin reuptake inhibitors for treating depression.

Most of the Autonomous Communities state palliative care teams systematically use symptom evaluation tools. Two Regions mention the ESAS (Edmonton Symptom Assessment System). The most often evaluated symptom is pain. In one of the Autonomous Community the evaluation showed that 60% of palliative care teams recorded the presence and intensity of pain. Three Autonomous Communities reported on symptom monitoring in primary care. One Autonomous Community has included in the health management contract the assessment of symptoms in patients admitted to oncology wards. Mainstreaming symptom monitoring practices at all care levels is recommended.

Most of the Autonomous Communities have adopted the Palliative Care Clinical Practice Guide issued by the National Health System (Osteba, Ministry of Health). Also, some other Regions report they have been compiling Guides on opioids, sedation, subcutaneous route, bereavement care and Alzheimer's disease. *GuíaSalud* (a body from the National Health System concerned with improving health care services) has evaluated two Clinical Practice Guides on Palliative care, one of them (Osteba) complies with the quality criteria established.

Several Autonomous Communities have organized training activities regarding the last days of life stage. According to the evaluation of one of the Regions, having protocols on this late stage of life is considered as a quality indicator, 82.3% of palliative care teams have them. In other Autonomous Community it has been proposed to interview the relatives of deceased patients as a quality control measure. One Autonomous Community includes in its program contracts having agony protocols available at the Emergency Services Ward.

In terms of **care provision planning**, the introduction of clinical trajectories at one palliative care unit has been favorably evaluated⁵⁵.

Establishing a therapy treatment plan is an action contemplated in all the palliative care programs of the self-governing administrations. Most of the Regions note that it is a habitual practice in specific teams. Some Regions have evaluated compliance by auditing patient clinical histories, particularly at the primary care level, with results ranging between 42% and 76% rate of compliance. There are several coordination protocols between palliative care teams (clinical reports, periodic meetings, history of home care received by the patient), the most noteworthy being initial projects aimed at shared electronic histories.

Integrated family assessment is a key objective of palliative care. A recent study done in our environment has described the habitual profile of the main caretaker⁵⁶: average age 54 years, 85.4% women, 43.7% daughters, 73.6% living with the patient. It has been shown that the reduced Zarit scale makes possible to identify, at the primary care level, who are the overburdened caregivers or dependents living with the patients⁵⁷.

A systematic review has analyzed the instruments used to evaluate the care received by the patient based on the opinions of the relatives after the patient's death⁵⁸. The conclusions are that it is an interesting method and the authors proposed developing and validating a specific tool for this objective. An Australian study in which this methodology was applied to the parents of children that died of cancer has brought to the surface the existence of multiple needs for information, access to multidisciplinary teams, and practical and economical assistance⁵⁹.

The satisfaction of the relatives of patients with terminal illnesses in a Health Center was high, particularly in relation to accessibility and the information received⁶⁰.

Integrated family assessment is also contemplated in all the palliative care programs of the Autonomous Communities. One Autonomous Community applies systematically the Zarit's Caregiver Burden Scale, and other Region recommends using genograms as routine practice. In terms of evaluation indicators, some Autonomous Communities propose satisfactions studies, audits of how/whether assessment information is recorded in clinical histories, identifying the main caregiver and recording this information, or the percentage of genograms performed. Audits revealed that the rate of compliance with socio-sanitary services provision was of 53.4%. One Autonomous Community has created a proposal for improvement after completing a study based on the perspective of the family members. Evaluating the capacity for providing care must be part of the integrated evaluation and it appears that it is still insufficient. The experiences garnered from training workshops and developing written and audiovisual materials may

contribute to give the relatives a more grounded sense of serenity and result in better care for the patient.

Bereavement care is an essential aspect to be considered for Spanish palliative care teams. 88.6% of the 80 teams that answered a questionnaire stated they offer care during the bereavement, although the presence of psychologists and social workers is limited⁶¹. The authors underline the need for a greater variety of intervention strategies. Currently, there is an ambitious randomized study in the early stages of implementation that is intended to help define what would be more appropriate care for bereaved persons at the primary care level⁶².

The Strategy proposes having systematic **recording and evaluation** systems to account for the results of palliative care. A review that has examined the experience of the minimum set of data in the United Kingdom has been recently published. It contains suggestions on models for data gathering at the different care levels⁶³. A Canadian review supports designing common information systems⁶⁴.

The evaluation shows that most of the Autonomous Communities identifies and records patients that are at advanced and/or terminal stages of a life limiting illness. Two Autonomous Communities reported on the recommendations and incentives offered by code V66.7 (ICD-9) common to primary care and hospital care. The recommendation was to systematize the records of patients at advanced and/or terminal stages in all the Autonomous Communities, and to unify the records generated by primary care, hospital care and specific palliative care teams.

Several Autonomous Communities have already in place systems to evaluate the results obtained at the primary care and palliative care teams levels. Two Autonomous Communities have set up Palliative Care Observatories to evaluate results in depth. It has been considered that to provide suitable evaluations having a unified patient registry and shared digital patient histories would be the ideal situation. The Monitoring and Evaluation Committee of the Strategy is working, amongst other objectives, on creating a work group to create a minimum data set on palliative care.

2.1.2. Objectives and recommendations

General Objective 1:

Provide patients at advanced or terminal stages of life limiting illnesses and their relatives assessments and Integrated Care adapted, at any given time, to their actual situation, at any level of care, and throughout the length of their illness.

Specific objectives

1.1. Identifying patients at advanced or terminal stages of life limiting illnesses early, and enter this observation in their clinical records.

Recommendations

- Identification should be routinely done by the medical provider in charge of the patient. In any case, it is recommended to have a consultation with the appropriate specialist to define, in a suitable and accurate manner, whether the patient is at an advanced or terminal stage in order to optimize the palliative therapeutic plan.
- Define the criteria used to qualify and define «terminal stage».
- The palliative care teams will participate in the meetings of the tumor committees concerned with patients at an advanced or terminal stage of a life limiting illness.
- Improve records (update the ICD 9/10 and CIAP codes) and unify criteria in all the Autonomous Communities.

1.2. Having a therapeutic treatment and care plan that has been coordinated with the different health care providers involved at the primary care and hospital levels based on an integrated assessment adapted to the physical, emotional, socio-familial, spiritual and cultural needs of patients that have been identified as being at an advanced and/or terminal stage.

Recommendations

- Within the individualized treatment and care plan, there will be a defined assessment model that would include all the needs, and a system of classifying care-related problems as found.
- This model will include, at the least, aspects relative to pain and other symptoms, to the functional capacity and the level of dependency, to the cognitive assessment, the level of awareness of their situation as patients, the psycho-social history, and the therapeutic strategy that should include a treatment and care plan.
- At the primary care level, periodical visits will be scheduled according to the established therapeutic plan and the minimum criteria established for the intervention criteria during the palliative care process. The visits regime for a patient in the last stages of life will be established, at the least, every 1-2 weeks according to their needs.
- The primary care teams will have the instrumental and pharmatherapeutic means necessary to provide care for patients in palliative care.

1.3. Carry out an integrated assessment of the patient's family, with special emphasis on the actual caregiver(s) to prevent burn out, promoting self-care and establishing the care they themselves need.

Recommendations

- Include genograms in the integrated assessment.

1.4. Evaluate the capacity for providing care of relatives and caregivers and give them educational support.

Recommendations

- The main caregiver and the specific members of the social and family support network must appear in a visible place in the patient's clinical records.
- Implementing a protocol to identify the risk of family members giving up supporting the patient (caregivers level of strain).
- After the death of the patient, the need for psychosocial support for the relatives during bereavement will be assessed.
- Implementing a protocol to identify the risk of pathological bereavement.
- These protocols will be emphasized for children, adolescents, elderly couples and people with scarce or inexistent social support networks.
- Establishing referral mechanisms to providers specialized in complex bereavement situations.

1.5. Establishing a monitoring system for appropriately evaluating the control of pain and other symptoms, with a minimum periodicity of one or two weeks, according to needs.

Recommendations

- Establishing a measuring and classification system for pain and other symptoms using validated instruments.
- Using the ESAS instrument for the systematic evaluation of symptoms.
- For elder patients at terminal stages, monitor pressure ulcers, falls, confusion syndromes and incontinence.
- For patients with difficulties for oral expression, collect the assessment of pain directly from their caregivers and explicitly from direct observation.
- Evaluate systematically the level of satisfaction of patients and family members with the results and the process of care.

1.6. Rethink the care objectives after identifying the onset of agony or «last days» at any care level, intensifying comfort measures and evaluating the results. At this stage special attention should be given to living wills.

Recommendations

- Implement a clinical practice protocol for the agonic stage.
- Evaluate the family's capacity to face the last moments of life and the complex situations that may be derived from the event, contributing reflection elements and or support elements during the decision making process if necessary.

General Objective 2

Provide care for patients at advanced and terminal stages of their illnesses based on the best practices and scientific evidence available.

Specific objectives

2.1. The Autonomous Communities should establish actions and evaluation procedures for the palliative care process.

Recommendations

- These procedures will include the referral criteria and circuits connecting the different resources, including those specific to palliative care.
- The procedures will be created with the participation of professional teams involved in the process.

2.2. Each Autonomous Community should have a systematic recording and evaluation system to process the clinical results of patients at advanced and terminal stages.

Recommendations

- Evaluate, at the least, the degree of control of pain and symptom, number of home visits and visits to the emergency unit, the number, duration and place of hospitalizations and the place of death.
- Incorporate to manual or electronic Clinical Histories record keeping systems, at all the levels of care provision, mechanisms that make possible and facilitate recording the patient as a «patient in palliative situation», as well as updating the general process of record generation, (ICD 9/10, CIAP etc.)
- Enable, in each territorial area, a tool that makes possible to have one sole record for «patients in palliative situation» as well as updating the essential process that generates the records.
- Have a national system of minimum indicators decided by consensus.

2.3. The Autonomous Communities should implement integrated clinical practice guides according to the quality criteria established by the NHS.

Recommendations

- The Autonomous Communities will establish suitable Clinical Practice Guides with the collaboration and consensual acceptance of the health providers involved in the affected processes.
- Establishing a plan to disseminate said guides to all members of the medical profession and related fields.
- The Clinical Practice Guides must include the patient's perspective through the agency of patients Associations.

2.4. Establishing guidelines for specific interventions based on the available scientific evidence for patients of any age suffering progressive chronic illnesses that are at advanced and terminal stages.

Recommendations

- Have specific recommendations for high prevalence pathologies and for low prevalence pathologies with a high demand for care needs.
- Include within these recommendations integrated assessments completed by specialized services (geriatric units or others).
- Promote pilot projects for palliative interventions in certain subgroups of this patient population.

2.2. Strategic Line 2: Organization and coordination

2.2.1. Current situation

Existence of an explicit organizational model: there is an increase in palliative care plans produced by the Autonomous Communities. Ten of them already had specific plans or programs in this area (Table 2). Later another Autonomous Community published its plan and four others are working on theirs for imminent publication.

Tabla 2. Regions that have specific plans	
Autonomous Community	Specific Plans
Andalusia	Yes
Aragon	Yes
Asturias	No*
Balearic Islands	No*
Canary Islands	No
Cantabria	Yes
Castille and Leon	No*
Castille-La Mancha	No*
Catalonia	Yes**
Valencian Community	No***
Extremadura	Yes
Galicia	Yes
Madrid	Yes
Murcia	Yes
Navarre	Yes
Basque Country	Yes
La Rioja	No
Spain	10

* The specific plan was already created by still approval pending in March 2009.
** Independent strategic line included in the Socio-sanitary Master Plan.
*** At the time of evaluation (March 2009) the plan was in the draft phase (currently published).

The amount of palliative care devices and resources (Table 3) has increased gradually in recent years. Nevertheless, these resources must continue to increase according to the existing high need and demand. Also, a considerable heterogeneity between the various Autonomous Communities has been detected. The actual, specific resources to provide palliative care for the pediatric population are very few.

Table 3. Palliative care devices

Autonomous Communities	ESD	UHD	ESH	ESM	PCU	Beds PCU	Other
Andalusia	14 (5 AECC)	2	1	20 (7 AECC)	15	232	-
Aragon	8	-	-	-	1	26	(a)
Asturias	2 (1 AECC)	1	-	-	3	51	-
Balearic Islands	3	-	-	-	2	36	-
Canarias	3	-	-	2	3	41	-
Cantabria	-	-	-	3	1	25	-
Castille and Leon	13 (11 AECC)	5	-	-	10	136	-
Castille-La Mancha	14	-	-	-	9	28	-
Catalonia	73	-	23	-	27	358	(b)
Valencian Community	1 (AECC)	23	-	-	6	106	-
Extremadura	-	-	-	8	-	-	(c)
Galicia	7 (1 AECC)	11	-	-	7	130	-
Madrid	17 (6 AECC)	-	11	-	15 (1paediatric)	298	-
Murcia	14	-	9	-	-	-	-
Navarre	1	-	-	-	2	45	(d)
Basque Country	1 (AECC)	10	3	1 (AECC)	10	113	-
La Rioja	5	-	1	-	1	10	-
Ceuta y Melilla	2 (2 AECC)	-	-	-	-	-	-

ESD: Home Support Team

ESH: Hospital Support Team

ESM: Mixed Support Team

PCU: Palliative Care Hospitalization Unit

UHD: Home Hospitalization Unit

AECC: Spanish Cancer Association

(a): 5 convalescing hospital units, with 359 beds

(b): 257 beds allocated to palliative care in Mixed Multipurpose Units, 10 mixed hospital support teams (UFISS), 15 palliative care ambulatory evaluation teams (EAIA-CP) and 6 multipurpose (EAIA-P).

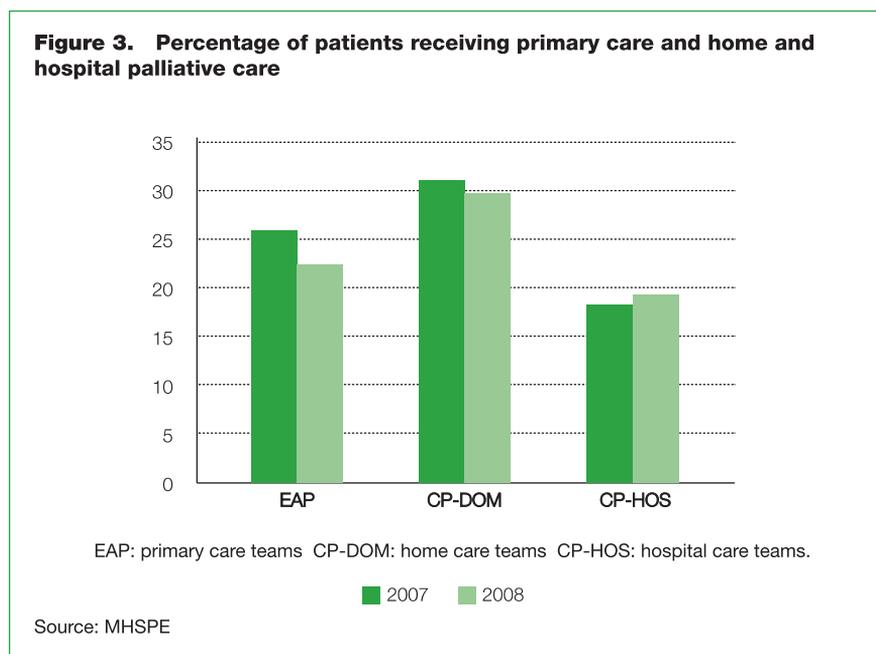
(c): 11 beds allocated to palliative care managed by the ESM.

(d): 2 beds allocated to palliative care at the Oncology Unit

Patients that have received care: The percentage of palliative care patients recorded in the **primary care** information system is 25.7 % of the population estimated in 2007 and 22.1 % of the population estimated in 2008 (Fig 3). This indicates an obvious under-registration given that all patients receiving palliative care are assigned to a primary care center. A large majority of them are oncological patients.

The percentage of patients assisted by **palliative home care teams** in terms of the estimated population was 30.7% in 2007 and 29.4% in 2008. The high heterogeneity should be noted, and again, oncological patients make up the large majority of this population.

The percentage of patients assisted by **palliative care teams, units, or hospital services** was 17.9% in 2007 and 19.2% in 2008. This indicator needs to be disaggregated in the future to differentiate the oncological patients from the rest, and also to differentiate the source of care: support team, palliative care unit in acute care hospitals or in socio-sanitary facilities. This notwithstanding, the figures observed show a low percentage of patients processed.



Ways to achieve better **coordination** between primary care and hospital care are being explored⁶⁵. Setting in place common measures to evaluate symptoms within a health territory together with treatment and care plans, and symptom control guides showed an increase in the frequency the symptoms were documented. The care provided proved also to be more efficient⁶⁶ as a result of this measure. Establishing integrated systems reduces the frequency with which patients have to resort to emergency services⁶⁷.

Despite the difficulties entailed in designing comparative studies, several publications support the existence of an **advanced or specific level of palliative care to be provided in complex situations**^{68,69}. A scale of palliative complexity based on patient-dependent, caregiver-dependent and health care providers-dependent factors has been proposed. This scale includes symptoms, functional and cognitive situation, socio-economic situation,

level of information and communication, ethical aspects, treatment needs and team conflicts⁷⁰.

Benefits derived from **home care support programs** continue to be documented. In a Californian study that included 298 patients, satisfaction with the care received increased significantly, while hospital resources and costs were reduced⁷¹.

Using a quality of life scale specific to palliative care and validated in Castilian Spanish (POS scale) has shown significant improvement of pain and other symptoms, of information and addressing issues pending after the intervention of a palliative hospital care support team⁷².

A volunteer-based plan participated by several Associations⁷³ has been set in motion in one Autonomous Community. The authors note that volunteer-based initiatives are a suitable approach for complementing the care and support provided to terminal patients by the health system.

In terms of **Continuity of Care** and exchange of information, the actions reported by the Autonomous Community tend towards starting a unified records system at the primary care level where the clinical records codes of patients with palliative care needs will be entered, and with an option to link it to treatment and monitoring protocols. The Autonomous Communities also report working on improving coordination between care levels, so continuity of care can be enabled by integrating primary care information systems with those of specialized care, as well as creating a unified electronic medical history. In order to make possible the coordination between care levels, direct communication protocols have been established. Some of the Autonomous Communities have established Palliative Care Area Commissions. One of their missions is to favor said coordination.

Most of the Autonomous Communities have information systems that interlink primary care and home support teams with the Emergency Services. In some cases this structure is also supported by the palliative home care history. Some Palliative Care Units (PCUs) have 24 hours hotlines. One Autonomous Community has a specific localized provincial 24/365 call center service attended by physicians and nurses. In another Autonomous Community there is a 12 hour telephone help line and there are plans to establish a computer system for coordinating palliative care- emergency services 24 hours/day.

It should be noted that specific **psychological and socio-familial support and intervention** resources are limited. As described by the Autonomous Communities, the trend is to work on developing palliative care programs that have specific psychosocial resources for patients and their families. In addition to the Integrated Care provided by the palliative care teams, these resources would involve other providers, such as psychologists, social workers and volunteers. The support/supervision activities of

these providers are not systematically planned. The type of actions implemented by some Autonomous Communities are: training for providers that work with advanced and terminal patients to prevent stress and professional fatigue, to approach psychoemotional aspects and acquire interpersonal emotional and communication skills. One Autonomous Community organizes periodic supervision activities (emotional support) for providers working in these teams. Some Autonomous Communities report that the task of providing support falls informally on the psychologists of the teams. Another Autonomous Community periodically evaluates the levels of stress of the members of these teams using the Maslach questionnaire. Three Autonomous Communities refer to the Integrated Care Program for patients at advanced stages of their illnesses and their families as part of the Social Responsibility program of the La Caixa bank.

In terms of how providing palliative care affects the providers that provide it, a review has been published on the **psychological intervention in palliative care in Spain**⁷⁴. 51% of the 201 palliative care teams that participated in the survey had a psychologist on board. In 46% of these teams the psychologists worked full time on this task. The main function was to provide psychological care for patients and relatives, followed by advisory functions to the team in general, prevention of burn-out, and education and research.

A study carried out in another Autonomous Community showed a low burn-out level as evaluated with the Maslach, questionnaire in a group of 60 palliative care providers⁷⁵. Favorable results have also been published regarding psychological intervention on 15 palliative care providers within our environment with significant differences for the anxiety, depersonalization and personal fulfillment variables⁷⁶.

2.2.2. Objectives and recommendations

General Objective 3:

Having an explicit organizational model so patients can receive palliative care according to their needs and at the appropriate time, adapting it to different situations and territorial demarcations.

Specific objectives

3.1. Implementing in each of the Autonomous Communities a regional palliative care model presented as a specific program or plan that details the bodies in charge of coordinating and managing it.

Recommendations

- Establishing the levels of palliative care provision within the services portfolio of each regional health service.
- The Autonomous Communities should define a model that describes the organic and functional bodies the palliative care teams report to.
- Introduce annual objectives for palliative care in the health services contract programs and in the management contracts.

3.2. The primary care teams will be responsible for providing home palliative care to patients at advanced and terminal stages, in coordination with other specialized health care services.

Recommendations

- At the level of each Autonomous Community, or territorial demarcation as may be the case, there will be a Palliative Care Commission composed by medical and social providers of both care levels and endowed with the specific resources considered necessary.
- This Commission will be responsible for disseminating the exiting protocols – arrived at by consensus - guides, and clinical practices.
- The appropriate regulations will be put in place to facilitate home use of any medical drugs and instruments necessary for delivering appropriate care.

3.3. The primary care teams will be backed up by a referral palliative care team (for general and/or home care support in complex cases).

Recommendations

- The providers will have a map of referral resources and their access criteria.
- This information will be readily available and disseminated to the public.
- The palliative care teams will cooperate with specialists to assess jointly patient cases. They will also act as liaisons with the primary care teams, reporting to them the results of their interventions.

3.4. Have available, for all patients that require it, a specific hospital palliative care team and/or unit for referrals.

Recommendations

- The providers will be familiar with the map of specific resources for referral in their area and their access criteria.
- This information will be readily available and disseminated to the public.

- The palliative care hospitalization units can be located in acute care hospitals or in medium-long term stay hospitals.
- The Palliative Care Units will focus specially in the comfort of patients at advanced or terminal stages of their illness by offering: individual rooms, permanent company, care geared to provide comfort, and meals taken without following a hospital Schedule or menu.
- It is recommended that the Autonomous Communities establish an accreditation system for the referral Palliative Care Units.

3.5. Provide palliative care coverage for patients admitted in special housing in the same conditions offered for the general public.

Recommendations

- Establishing a map of specific and/or shared resources adapted to high risk or high needs populations.
- The providers will be familiar with the resource map for referrals and the access criteria of the resources.
- Measures will be established to allow patients admitted in closed institutions access to palliative care resources.
- Palliative care training will be provided to caregivers and staff working at these centers.

3.6. The medical professionals providing direct care to patients will have, from the time advanced or terminal stages of a disease are detected, duly updated clinical information, a needs assessment, and a therapeutic and care plan, particularly whenever the patient is moved to a different center.

Recommendations

- When information technology applications allow, the primary and specialized care providers will have access to clinical information. The goal being to move towards a shared clinical records system.
- Patients and/or their families will have access to a document containing a minimum set of data regarding their cases and how they are monitored that must include, at the least, basic clinical information and an updated list of problems and treatments.
- The levels of care (primary and specialized) will be coordinated and both will work on shared care provision models to ensure the continuity of medical care. Joint protocols for interdisciplinary intervention will be in place.
- Coordination protocols –arrived at by consensus by the different levels of care– will be in place when a patient is admitted or discharged from hospital, to ensure confidentiality.

- An intra-hospital protocol will be in place to route patients that need it to palliative care units and thus reduce unnecessary visits to the emergency services. Conversely, an extra-hospital protocol will allow referring patients directly from primary care to palliative care units.

3.7. Providing care coverage for patients 24 hours a day 7 days a week.

Recommendations

- This coverage will be provided by coordinating the various care services responsible for the patients and the continuous care and emergency services.
- Including the use of shared protocols and systems to access the updated clinical information of the patient.
- A telephone hotline attended by experts will be available 24 hours a day to care facilities to prevent unnecessary emergency services and hospitalizations.
- Procedures will be established between the continued care services, primary and specialized care to provide information, protocolize actions and give a coordinated response to emergency situations.
- The physician in charge of the patient will report when patients enter the agonic stage –using the method in place in each Autonomous Community– the normal emergency services or those services designated to provide services outside the normal schedule of primary care facilities or specific palliative care facilities. This notification will include detailed information of the clinical situation and treatments, particularly those treatments provided during home care.

3.8. Implement, gradually, a specific access system for patients and relatives, to specialized psychological support and socio-familial intervention that is adapted to their needs.

Recommendations

- The providers will be familiar with the map of specific resources for referral in their area and their access criteria.
- This information will be readily available and disseminated to the public.
- Having protocols for detecting and assessing problems, intervention and referrals for the different levels of complexity to provide appropriate care for the psychosocial needs of patients and their families. «Receiving specialized psychological and sociofamilial support and care that is adapted to the recipient's needs» means the care provided by

mental health and social work professionals with experience and training in palliative care. These providers will habitually be part of the palliative care teams.

3.9. Implementing, gradually, a support and/or supervision system to address emotional and group-relational issues of the providers working with patients at advanced and terminal stages.

Recommendations

- The providers will have access to updated information of existing support and/or supervision resources
- The National Health System services, and especially those with high activity in this field, will have access to specific protocols and measures for identifying risk and address professional stress and burnout.

General Objective 4:

Establishing an organizational system that ensures coordination between the different medical and social resources and promotes integrated actions.

Specific objectives

4.1. Establishing a system in the Autonomous Communities to coordinate the various institutions with competences and social and medical resources to organize integrated support services for patients and caregivers.

Recommendations

- To provide support for patients without family, and/or support or relief to caregivers, access will be provided to centers equipped to provide palliative care and to provide information on the availability and access criteria to the existing resources.
- Establish the referral criteria for support centers equipped to address the emotional, social, and familial aspects related to patient relocation.
- Developing volunteer programs to accompany patients and family members.
- Develop protocols that specify how to select, educate, provide practical training, supervise, acknowledge and evaluate volunteers.
- The Autonomous Communities will establish mechanisms to manage medical transportation of patients between the various Regions when the care team considers that patient relocation to a different center is part of the Integrated Care provided at the end of life period.

4.2. Establishing caregiver support programs that provide information on services, resources and materials that facilitate and speed up the bureaucratic processes.

Recommendations

- Establishing, in each area, a set of caregiver support measures such as:
 - Formulas that facilitate administrative processes for caregivers, such as obtaining their own prescriptions and that of the patients amongst other paperwork.
 - Making telephone consultations available to quickly resolve questions about care.
 - Informational brochures that are basic and to the point for caregivers and explain how to manage the most often presented and predictable situations and problems.
 - Orthoprosthetic material lending programs for materials that can be returned, such as wheelchairs, walkers, etc.
- Social workers will also establish the necessary actions to implement the required social and family services.
- Efforts to establish systems that can quickly address urgent needs for social care will be implemented (i.e., cases of caregiver burnout, absence of a caregiver, etc.).
- Programs to promote caregiver wellbeing will be created: support groups, socio-therapeutic groups, health education groups.

2.3. Strategic Line 3: Patient autonomy

2.3.1. Current situation:

The objectives relative to patient autonomy are already included in most of the Autonomous Communities plans, although actions to mainstream them in the clinical practice are still needed.

Informing patients on their illness, status and on the therapeutic objectives is a key goal of the Strategy.

Several studies have analyzed the importance of information. An in-depth review has presented the available evidence on the appropriate manner to communicate «bad news»⁷⁷. Also, two systematic reviews have been published highlighting the need for and individualized and careful process^{78,79}. Another review stresses the difficulties providers face to «tell the truth»⁸⁰. The reasons included lack of training, stress, lack of time to take care of emotional needs, fear to have a negative impact on the patient, requests from relatives and a feeling frustration for not being able to offer curative treatments.

A communication model for the end of life stage has been proposed. It includes starting palliative measures, progressive worsening of the condition, limitation of the therapeutic effort and responses for requests to maintain disproportionate treatments⁸¹.

Several Autonomous Communities have undertaken training actions to address this issue. One example is an Informational Guide aimed to the general public. In another Autonomous Community the results of the quality evaluation of socio-sanitary centers showed a 60-70% rate of attainment of indicators related to delivery of information.

Another Autonomous Community has analyzed the information delivered to patients, relatives and primary care personnel by home care teams. Information is delivered as: treatment sheets (100%), a presentation document (75%), printed tips and advice (75%), medical or nursing report (50%) and a subcutaneous medication administration schedule (12.5%)⁸².

A suggestive phase II study analyzing the feasibility of implementing the Dignity Therapy in elderly patients living in elder homes has been published. It addressed issues related to reviewing the patient's life, the relationship to their families, expectations and things left to be done⁸³.

In terms of the active participation of the patients, more than half of the Autonomous Communities state having a Specific Plan that contemplates the involvement of the patient –or of the person designated by the patient to this effect- in the decision making process on how to process the patient and decide upon a place of death, so the process and how the decision was reached can be entered into the medical record. It has appeared convenient to insist on the need to reflect the ethical decision making process in the clinical records.

A study carried out in a palliative care unit whose majority of patients come from rural areas, has analyzed the preferences on the place of death of 424 patients and 441 families⁸⁴. 93% of the patients and 85% of the families that stated their preferences chose for the patient to die at home, although no preference was collected for nearly half of the patients. A high degree of concordance existed between patients and relatives and the preferences of the patients were fulfilled for 89% of the cases.

In regards to **palliative sedation** a literature review with recommendations on standards⁸⁵ and a systematic review from the perspective of nursing care have been presented⁸⁶.

Several Autonomous Communities report having in place training activities oriented to facilitate **decision making when faced with ethical dilemmas at the end of life stage**.

An Autonomous Community has developed a Draft Law on the Rights and Guaranties of the Dignity of Persons facing the Prospect of Death. Another Autonomous Community has posted links to the Bioethics

Committee in its official website as a reference and to obtain information on the resolution of cases. Another Autonomous Community has proposed creating interdisciplinary work groups in acute care hospitals to review existing plans and documentation and to establish action guidelines.

The issue of living wills has also attracted considerable attention. A descriptive study has brought into relief the favorable attitude of nursing staff towards using living wills, even though only 63.1% knew there are laws that regulate them and 32.3% had read the document⁸⁷. A study done with physicians yielded similar percentages (69.6% knew about legal regulations and 37.6% had read the document)⁸⁸. In another study done in two basic health areas, 88.8% of the 395 individuals interviewed were not aware of the existence of a living will document⁸⁹, 67.8% would sign it in case of suffering from a terminal illness, and 56.3% at the time of the interview.

A systematic review shows the effectiveness of interventions aimed at increasing formulation of living wills, with oral information delivered in various sessions as the most effective⁹⁰. One publication presents a careful non-randomized controlled design to investigate the effectiveness of measures to incentivize living wills amongst individuals from two health areas of Andalusia⁹¹.

In Spain, all the Autonomous Community have **living wills** regulations, however, the general awareness of the population and providers alike should be increased, as well as access of medical providers to the document. In Spain the body responsible for this issue is a national registry that reports to the General Directorate of Cohesion and High Level Inspection.

Thirteen Autonomous Communities have implemented **awareness and information actions to inform the general public** on the objectives, principles and resources pertaining to palliative care. Several have implemented dissemination campaigns in the mass media. Some Regions have published informational guides and brochures on Palliative Care Plans. An Autonomous Community has established agreements with patients associations to disseminate information on palliative care. An aspect meriting special emphasis would be the dissemination of information on existing palliative care resources.

2.3.2. Objectives and recommendations

General Objective 5:

Promote the application of bioethical principles and patient participation in their own medical processes according to the principles, values and contents

of the Patient Autonomy Act and of the current legislation of the various Autonomous Communities.

Including general measures on care at the end of life stage in the health system and access to palliative care teams for patients and families going through complex situations is a right of patients and family members.

Specific objectives

5.1. Inform the patients on their health status and on the therapeutic objectives according to their needs and preferences.

Recommendations:

- The clinical records of the patients should have a specific section designated to record the information process (information delivered to patients) as well as the wishes they express in relation to the care, preferred place of death and any other wish expressed in relation to the specific objectives pursued.
- The information will be respectful with the belief system, preferences and values of the patients and their family members.
- The process of information will be done gradually, in a suitable place, taking care of the psychological, emotional and existential aspects.
- The process will be advised or supervised by an experience qualified professional.
- The information will be delivered gradually, adapting it to the time the patient needs to cope with or face the situation.
- The expressed desire of some patients to not be informed will be respected.
- All information delivered, the initial information and the progressive subsequent changes will be recorded in the chart.
- In the case of children or adolescents, the information will be adapted to their age, but also taking into account their wishes and needs.

5.2. Promote the active participation of the patients or their representatives (persons on which the patients have delegated this responsibility) in the decision making process to determine the desired place of death, which will be recorded in the clinical records.

Recommendations:

- Each patient can designate a representative to act as interlocutor with the medical team on behalf of the patient, in the event said patient would not wish to actively participate in the decision making process. If the patient is not able to express his or her will, the family members will be involved in the decision making process, unless

the patient had already designated a representative to that effect in prior instructions or in the living will, in which case this person will be the participant.

- The members of the multidisciplinary team providing the care should be responsible for patient participation in the process. They should deliver sufficient information in a clear manner, allowing the patient to express doubts and fears, answering their questions and giving them the necessary time for reflection.

5.3. Facilitate the decision making process when confronted with ethical dilemmas at the end of life stage (such as limiting the therapeutic effort, food and hydration, sedation, etc.) taking into account the personal values of each patient, the protocols and/or the ethical recommendations and the Clinical Practice Guides according to the ethical standards of quality at the end of life stage. The decision making process will be recorded in the clinical history.

Recommendations:

- Promoting clinical ethics protocols adapted to advance and terminal stages situations.
- Having recommendations on the decision making process, on how to record the process in the clinical history, and on technical aspects of sedation.
- The Autonomous Communities will promote the creation of Care Provision Ethics Committees for both the primary care and the specialized care levels.

5.4. Disseminate in the Autonomous Community living wills regulations and foster the access of medical providers to such information.

Recommendations:

- The Ministry of Health, Social Policy and Equality and the Autonomous Communities will undertake information campaigns for the general public and for medical providers on the possibility of patients writing prior instructions or living wills in agreement with the various regional legislations.
- The Autonomous Communities will inform the medical profession on the manner and requirements needed to access the prior instruction records.
- The medical providers will advise each patient and their families on existing legislation and the possibility of writing a set of prior instructions or living wills. This advice will be recorded in the clinical histories.

- Undertake awareness rising and information campaigns for the general public on palliative care objectives, principles and resources.

Recommendations:

- The Autonomous Communities and the MHSPE will implement information campaigns and issue informational brochures explaining the basic principles, the objectives and contents of the Palliative Care Strategy.
- Promoting training for medical providers in ethical aspects, in delivering information and in communicating with patients and their families.
- Favoring public debates and participation in palliative care in the bodies designated to that effect.

2.4. Strategic Line 4: Training

2.4.1. Current situation:

Training in palliative care for medical providers should begin during university training⁹². Order ECI/332/2008 of the Ministry of Education and Science⁹³ on the requirements to practice medicine include amongst the competences the students must acquire before qualifying: being able to indicate the most suitable therapeutic treatment for the most prevalent acute and chronic conditions and for illnesses at the terminal stages. The Human Clinical Training includes Palliative Medicine. The AECPAL, the Spanish Nursing Association for Palliative Care (*Asociación Española de Enfermería en Cuidados Paliativos*) has proposed a nursing curriculum for palliative care⁹⁴ structured in three levels of competence: basic (pre-degree), intermediate (ongoing education) and advanced (specialization and post-graduate). The European Association for Palliative Care (EAPC) has studied the situation of advanced training in Europe⁹⁵. Palliative Care is a medical specialty in the United Kingdom and Ireland and it is considered a sub-specialty in five other countries: France, Germany, Poland, Romania and Slovakia. Other ten countries, including Spain, have shown interest in the sub-specialization approach or in specific training. A very important step in the advanced training approach is that the American Board of Subspecialties (USA) has acknowledged palliative medicine as a sub-specialty that includes acquiring competences in the care of patients and relatives, medical knowledge, practice-based learning and improvement, communication and interpersonal skills and professionalism^{96,97}. The need for training programs that allow

physicians, nurses and other providers of medical care to work in nursing homes has also been pointed out⁹⁸.

During 2007 and 2008 in Spain, 12,809 health care providers received basic training, another 1,545 intermediate training, and 479 advanced training. Most of them were physicians and nurses. Basic training entails receiving specific courses between 20 and 40 hours. Intermediate training includes 40-80 hour accredited courses, Third Cycle courses (doctorates) and 1-2 month stays in Palliative Care Units. Advanced training includes Master courses and Stays of 3 months or more in Palliative Care Units. Training activities at these three levels should be increased. In addition of having quantitative data, it appears necessary to exchange information of basic criteria to plan for this training.

2.4.2. Objectives and recommendations

General Objective 6:

Establishing training programs for continuous and specific education for medical personnel of the health system in order to qualify them to appropriately care for the needs of patients at advanced and terminal stages of their illnesses and their families.

Training would be structured in three levels:

- Basic: aimed at all health care providers.
- Intermediate: aimed at those medical providers that care most often for patients at advanced and terminal stages.
- Advanced: aimed at members of palliative care teams.

Specific objectives

6.1. The Autonomous Communities will establish a Continuous Palliative Care Training Plan for primary care providers, specialized care providers, and all those in the medical profession that specifically provide palliative care.

Recommendations

- This training will be given at the basic or intermediate levels according to the frequency with which said providers care for patients at advanced and terminal stages.
- Including palliative care in the Health Sciences university curricula.
- Promote and facilitate the rotation in palliative care teams of medical, psychology, and nursing interns completing the practical aspect of their degrees in the specialized areas required by these patients.

- These plans would be implemented at any level after having analyzed the training needs of the medical providers involved.
- Training programs in which the chronograms, contents and the bodies responsible for imparting the teachings are specified will be offered periodically.
- Accreditation for continuous training in palliative care will be granted through the channels established by the Autonomous Community or the Continuous Education Committee of the Ministry of Health, Social Services Policy and Equality.
- The aspect of communications skills needed to address patients and families will be emphasized.
- Creating specific training programs focused on prevention, diagnosis, and treatment of «emotional risks» faced by the providers working with patients at advanced and terminal stages.

6.2. Promoting actions to ensure there is regulated and accredited specific advanced training for providers of palliative care teams.

Recommendations

- To gradually include this type of training that will enable physicians, nurses and other providers of medical care to join specific palliative care teams according to the specific chronogram for implementing postgraduate training, (Specific Training Area, Advanced Accreditation Diploma, or equivalent accreditation) devised by the Ministry of Education and Science and the Ministry of Health, Social Services and Equality (MHSSE).
- The MHSSE and the Autonomous Communities will define, within the established channels, the competences and training standards for these physicians, nurses and other providers of medical care.

2.5. Strategic Line 5: Research

2.5.1. Current Situation:

Research pertaining to palliative care presents difficulties that are mostly related to the heterogeneity of the populations included in the studies, the large range of health care services encompassed, and the complexity to apply to such subject basic research principles⁹⁹. The authors of the report from which these thoughts have been extracted, propose a set of solutions to facilitate the design and develop the research project. Another review proposes several recommendations for research, particularly in the field of

clinical essays¹⁰⁰. A group of researchers contribute lessons learned while they were trying to secure financing and developing their projects pertaining to the barriers that exist for patients to receive suitable symptom management¹⁰¹.

A group of Canadian experts finds the priority for pediatric palliative care research is to explore the priorities of the patients and their families, which are the services that bereaved relatives need, control of the pain and other symptoms and strategies to relieve suffering¹⁰²

A bibliometric analysis highlights the progressive increase in publications addressing palliative care and end of life stage care issues, arguing that the heterogeneity of research methodologies and journals may enrich our understanding of the dying process in our contemporary society¹⁰³.

Between 2002 and 2008, in Spain, 26 applications for financial aid were submitted to the Health Research Fund of the Carlos III Institute (FIS-ISCIII) for research projects and studies to evaluate health technologies and health services. Of these, six projects were financed (two in the 2007-2008 period). It has been recommended that the causes to deny funds for the other projects should be analyzed and a palliative care research line should be started.

The Autonomous Communities financed 13 research projects in 2007 and 18 in the 2008. According to data provided by these administrations, 6 of them have financed palliative care research projects in 2007-2008.

To date, there is no thematic network of cooperative research in palliative care.

2.5.2. Objectives and recommendations

General Objective 7:

Promote the palliative care research.

Specific objectives

7.1. The MHSSE and the Autonomous Communities should assign priority to and finance palliative care research lines by including them in the call for papers of research projects.

Recommendations:

The following research lines, amongst others, should be included:

- Epidemiology of the advanced or terminal stages of a life limiting illness.
- Symptoms, evaluation and treatment.

- Support treatment (nutritional and other aspects).
- Pharmacological interactions.
- Evaluation tools.
- Evaluation of results and improvement of quality.
- Prognosis factors in non-oncological patients.
- Quality of life.
- Palliative care and patient safety.
- Palliative care for the elderly.
- Emotional aspects and psychological and existential needs of the patients, relatives and medical care providers.
- Bioethics at the end of life stage.
- Continuity of Care and organizational models.
- Palliative care for children.
- Bereavement care.
- Evaluation of care costs and resource consumption.
- Equity.

7.2. Promote the creation of thematic networks for cooperative research in palliative care.

Recommendations:

- Promote integrated and interdisciplinary research.
- The palliative care teams should have access to referral units to obtain research advice and support
- Qualitative psychosocial research should be promoted.

3. Evaluation

3.1. Current situation

The first edition of the present Strategy was structured around three types of information provided for evaluation.

- A. Descriptive information: functional resource map:** Identifies the different type, number and manners the already existing structures are conceived and organized to provide palliative care within the administration frameworks of the Autonomous Communities.
- B. Strategy indicators.**
- C. Implementation monitoring report**

This report summarized the main actions implemented by the Ministry of Health, Social Services and Equality and the Autonomous Communities to attain the Strategy objectives and the percentage of attainment of said objectives within the NHS.

3.2. New Indicators

The Strategy will be evaluated using the following indicators:

- A. Descriptive information:** created by the Health Information Institute and periodically updated can be found at: <http://www.msc.es/organizacion/sns/planCalidadSNS/cuidadosPaliativos.htm>
 - A.1: Palliative care resources of the National Health System**
 - A.2: How palliative care is structured in the National Health System**
- B. Evaluation indicators:**

The following table contains the indicators (old and new) that will be used for evaluating the Strategy and the reports that will be included after the contributions and conclusions of the work group of the monitoring committee constituted to that effect.

Table 4. Evaluation Indicators

Strategic Lines	Indicators	Sources
1. INTEGRATED CARE	Degree of third step opioid use	SI-CF
2. COORDINATION AND ORGANIZATION	Percentage of patients cared for by primary care Teams	SIAP
	Percentage of patients cared for by Home Palliative Care Teams	REUSD
	Percentage of patients cared for by Hospital Teams, Units or Services.	CMBD/ MHSSE
3. PATIENT AUTONOMY	Given the importance of this concept, it has been suggested that compliance with objectives about information, patient participation and the decision making process should be verified by reviewing the patients clinical records.	
4. TRAINING	Percentage of health care providers that have received specific basic training in palliative care	Autonomous Communities
	Percentage of health care providers that have received training specific intermediate training in palliative care	
	Percentage of health care providers that have received specific advanced training in palliative care	
5. RESEARCH	Number of research projects financed	ISCIII
		Autonomous Communities

Abbreviations: **SI – CF:** NHS Pharmaceutical Consumption Information System; **SIAP:** Primary Care Information System; **REUSD:** Specific Records of the Home Support Units; **CMBD:** Minimum Set of Basic Data; **ISCIII:** Carlos III Health Institute

Glossary of terms

Complexity: a set of factors that contribute to greater difficulty or intensity of needs that usually require the intervention of a palliative care team. Depends both on the characteristics of each patient, as on problems that are difficult to control, on the need of taking certain diagnostic or therapeutic actions and on the difficulties of the family to adapt to the situation.

Needs crisis: acute situation characterized by the onset of one or several specific physical, psychological, social or spiritual needs that reduce the comfort and quality of life of the patient, and alters the adaptation and emotional stability of the family, requiring specific interventions to resolve it.

Palliative care: approach that improves the quality of life of patients and family members facing problems associated to life-threatening illnesses by preventing and alleviating suffering by means of early identification and impeccable evaluation and treatment of pain and other physical, psychological and spiritual issues.

Palliative care team: their main activity is limited to palliative care. Usually they provide care for patients with special and more complex and intensive care needs, and therefore the professionals that integrate the team requires higher level of training, personnel and resources. The teams are composed by physicians and nurses and the psychologists and social workers and other professionals in related fields that cooperate with the medical professionals. The composition of the teams depends on the demographic and geographic characteristics of the area, the levels of need of the territorial health structures. The teams also carry out educational and research activities.

Home support team: palliative care team that intervenes at the patient's home after consulting with the physicians responsible for the patient. They can provide advice and direct intervention.

Hospital support team: palliative care team intervenes in the hospital after consulting with the physicians responsible for the patient. They can provide advice and direct intervention.

Levels of palliative care:

The basic, primary or general levels at which palliative care is delivered, as well as the overall approach of care, refers to the care that must be provid-

ed to all the patients that need it, at the primary care or specialized care levels. Specific, secondary, specialized or advanced levels of palliative care contemplate different types of interventions of the palliative care teams before complex situations. Some authors consider hospital care delivered at Palliative Care Units as the third level of care.

Genogram:

Is a graphic representation of the personal, biological and legal relationships of a family spanning at least three generation. It is used mainly to analyze whether the problems of one of its members may or may not be related to the family context and the changes it has experienced through time.

Advanced-terminal stage: the criteria proposed to defined patients at advanced or terminal stages of their illness are:

- Incurable, advanced and progressive disease
- Limited life prognosis
- Small possibility of response to specific treatments
- Oscillating evolution and frequent needs crises
- Intense emotional and familial impact
- Repercussions on the care givers' structure
- High demand and use of resources

Palliative care Unit: hospital units specifically used for palliative care provided by an interdisciplinary team. These units can be located in acute care hospital or in socio-sanitary facilities. Often, the units also provide hospital care and ex-center visits.

Glossary of acronyms

AECC	Spanish Cancer Association (Asociación Española Contra el Cancer)
AECPAL	Spanish Nursing Association for Palliative Care (Asociación Española de Enfermería en Cuidados Paliativos)
AEC	European Nursing Association (Asociación de Enfermería Comunitaria)
AEP	Spanish Pediatric Association (Asociación Española de Pediatría)
AEPCP	Spanish Association of Clinical Psychology and Psychopathology (Asociación Española de Psicología Clínica y Psicopatología).
ARINDUZ	Basque Association of Palliative Care (Sociedad Vasca de Cuidados Paliativos)
ATSS	Spanish Association of Health and Social Work (Asociación Española de Trabajo Social y Salud)
AC	Autonomous Community (Comunidad Autónoma)
CP	Palliative Care (Cuidados Paliativos)
ESAD	Home Care Support Team (Equipo de Soporte de Atención Domiciliaria)
ESD	Home Support Team (Equipo de Soporte Domiciliario)
ESH	Hospital Support Team (Equipo de Soporte Hospitalario)
FAECAP	Federation of Community Nursing and Primary Care Associations (Federación de Asociaciones de Enfermería Comunitaria y Atención Primaria)
ICO	Catalonian Institute of Oncology (Institut Català d'Oncologia)
MFyC	Family and Community Medicine (Medicina de Familia y Comunitaria)
MSC	Ministry of Health and Consumer Affairs (Ministerio de Sanidad y Consumo)
MHSPE	Ministry of Health, Social Policy and Equality (Ministerio de Sanidad, Política Social e Igualdad)
MSPSI	
PADES	Home Care Delivered by Support Teams Program (Programa de Atención Domiciliaria por Equipos de Soporte)
SACPA	Andalusian Society for Palliative Care (Sociedad Andaluza de Cuidados Paliativos)

SCBCP	Catalonian-Balearic Society for Palliative Care (Sociedad Catalano- Balear de Cuidados Paliativos)
SCLCP	Castilla-León Society for Palliative Care (Sociedad Castellano Leonesa de Cuidados Paliativos).
SECPAL	Spanish Society for Palliative Care (Sociedad Española de Cuidados Paliativos)
SEEGG	Spanish Society of Geriatric and Gerontological Nursing (Sociedad Española de Enfermería Geriátrica y Gerontológica)
SEEO	Spanish Society of Oncological Nursing (Sociedad Española de Enfermería Oncológica)
SEGG	Spanish Society of Geriatrics and Gerontology (Sociedad Española de Geriátrica y Gerontología)
SEMERGEN AP	Spanish Society of Primary Care Physicians (Sociedad Española de los Médicos de Atención Primaria)
SEMFYC	Spanish Society of Family and Community Medicine (Sociedad Española de Medicina de Familia y Comunitaria)
SEOM	Spanish Society of Medical Oncology (Sociedad Española de Oncología Médica)
SEOP	Spanish Society of Pediatric Oncology (Sociedad Española de Oncología Pediátrica)
SEOR	Spanish Society of Oncological Radiotherapy (Sociedad Española de Oncología Radioterápica)
SES	Extremadura Health Service (Servicio Extremeño de Salud)
SMCP	Madrid Society of Palliative Care (Sociedad Madrileña de Cuidados Paliativos)
SOGACOPAL	Gallician Society of Palliative Care (Sociedade Galega de Cuidados Paliativos)
SVCP	Valencian Society of Palliative Care (Sociedad Valenciana de Cuidados Paliativos)
UCP	Hospital Specific Unit of Palliative Care (Unidad Específica de Cuidados Paliativos Hospitalaria)
UFISS	Functional Interdisciplinary Socio-sanitary Units (Unidades Funcionales Interdisciplinarias Sociosanitarias)
UHD	Home Hospitalization Unit (Unidad de Hospitalización Domiciliaria)
UHPV	Multipurpose Hospitalization Unit (Unidad de Hospitalización Polivalente)

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This strategy 2010-2014 is part of the Quality Plan for the National Health System and is an update of the previous strategy that was adopted by the Interterritorial Council of December 2007. This document, as a result of reflection and effort, set and agreed between the Ministry of Health, Social Services and Equality and the Scientific and Patient Societies, collects the conclusions of the evaluation of the previous strategy, the new scientific evidences, the new agreed objectives, as well as the collection of good practices and rules for the period 2007-2009. This Strategy tries to contribute to the improvement of palliative care and the cohesion of our Health Care System, with the purpose of the benefit of our citizens.



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