

## National research about the procedures on palliative medicine in Spain

**The aim of this activity** is to research & evaluate the medical literature talking about the procedures on palliative medicine, reflect on the palliative medicine and strategies and on the current procedures used in the training of the first years students enrolled in EU medical universities or used by the professionals & volunteers active in the medical world of work.

### Objectives:

- Identification of the operational procedures reported to be used by the students during the hospital internship in pre-clinical years; identify the needs of the target groups in connection to the use of specific procedures
- Research of specialised recent literature in connection to these procedures
- Identify the ways to introduce new & consensually agreed procedures on palliative medicine to the academic medical field (university) and the medical world of work (hospitals, hospices)
- Collect information on specific sectorial impact, country differences, cultural specific aspects, etc.
- Identify innovative solutions that have been implemented & found to be effective to meet the needs of those who use/will use procedures on palliative medicine

### Structure:

## 1. DEFINITIONS

### 1.1 General meaning: operational procedure in palliative care

End of life is a complex circumstance to afford, requiring a special approach. For that reasons health professionals should manage several different situations, included those related to the dying process emotional impact. The role of quality in this special setting is extremely important in order to give all the guarantee to patients and family and promote the best quality of life<sup>1</sup>.

Palliative health care present several obstacles for patients and families, clinical setting involves a plurality of different professionals, treatments and clinical circumstances where quality is not always allowed in the best way. The application of standardized

procedures consents to improve physical and psychological care, coordination among professionals and improve the quality of care.

A procedure is a specific action strategy<sup>2</sup>, as consequence we can define operational procedure a pathway describing specific steps of clinical intervention with the aim to promote health care. In Palliative care medicine the application of standardized procedure is commonly a consequence to the need to solve a clinical problem in a defined time.

## 1.2 Specific operational procedures

### 1.2.1 Communicating the diagnosis of severe illness (Bad news)

Diagnosis communication is one of the most difficult aspects of clinical relationship in palliative care. “Bad news” is a kind of information frequently generating negative patient’s expectation<sup>3</sup>. Most health professional lack of structured training on how to deliver bad news, and this aspect has particular consequences in palliative care<sup>4</sup>. The aim of communication in clinical relationship is: giving information, persuasion/stimulation patients’ attitudes, reduce patient’s suffering, promote patient’s satisfaction, keep a realistic hope, and reduce professional’s discomfort. Even than patients and professionals agree with this aims, frequently they have difficult to recognize reciprocally their role<sup>5</sup>.

The use of a structured interview can improve doctor-patient communication<sup>6</sup>. There are several different communication models in scientific literature, but all present the following common characters<sup>3, 7, 8</sup>: a) health professional must be prepared to discuss with the patient his/her clinical circumstance in an accurate location. b) Explore patient’s information and identify what kind of details he wants to know. c) Clinical data clarification and right assessment of clinical records to avoid misunderstanding. d) Use an appropriate language promoting patient’s emotional disposition to receive the information, i.e. “I’m sorry to notice you” or “as a consequence of the diagnostic test I must give you a bad news” etc. e) give the news in a clear, honest and concise way. f) active listening to solve doubts, validate and normalize patient’s answer g) give complementary information step by step in a realistic way in order to patient’s and family’s needs. h) monitoring patient.

Problems frequently detected by palliative care professional in order to approach bad news regard the lack of time, the challenging combination of honesty and truth without emotional patient’s distress, approach patient’s environment, answer to the emotional patient’s needs and discuss life expectancy. The approach to all this circumstances could be influenced by patient’s and family’s cultural background. Asian

patients prefer involve family in order to deal bad news, and they prefer avoid questions about life expectancy<sup>5</sup>.

Several training programs have been developed about communication in palliative care, but just few have been assessed in the right way. Recent systematic review about the efficacy of training programs among medical students and health professionals affirms the high rate of success of these programs depends on the application of a student-based teaching model. This methodological approach has a cognitive character focused on students' skills, a behavioural character oriented to life experience and role-playing and an emotional character centred on health professional perception after each training session<sup>9</sup>.

### **1.2.2 End of life care: palliative care services, aggressive treatment, and cardio-pulmonary resuscitation**

To reach good palliative care service is essential to have a comprehensive understanding of clinical aims and patients views<sup>10</sup>. The American College of Physicians (ACP) considers of strict relevance discuss with chronic patients those aspects related to the clinical objective of a treatment in order to improve patient's quality of life, avoid unnecessary treatment and reduce health care costs, improve family perception<sup>11</sup>. A multi-centric research showed how good communication about end-of-life care can reduce cost up 37.5%, with a consistent resources saving up \$1000 during the last week of patient's life<sup>12</sup>. Moreover, there are evidences to conclude discussion with patients and families are not related to an increase of emotional distress<sup>13</sup>. Frequently the poor quality of doctor-patient communication depends on the lack of knowledge about patient's needs, expectations and values, with a consequent big impact on patient's information and decision-making processes. Generally the identification of clinicians who have patients in charge is not easy and this could complicate discussion about end-of life, especially when patients receive information and discuss with the doctor in an advanced stage of his/her clinical circumstances. Despite there aren't evidences about who should give information among the physicians of the palliative care team, the general agreement in relation to this topic is that information process must be managed always by the same clinician, leading information processes and assuming the responsibility about decision making processes at the end of life<sup>14</sup>. The ACP suggests the following systematic approach in order to focus discussion about end-of-life-care with chronic patient: a) Specific training programme with a case-based learning methodology and interactive session promoting communication skills among clinicians. b) Identify patient at risk: develop a standard procedure to discuss with patients with diminished life expectancy (6 months-1 year), such as heart failure patients with 2 or more previous admissions during the last year, patients with cancer severely injured or terminal patients with kidney illness. c) Use specific alert system

during the ambulatory treatment to start the discussion about the future clinical circumstances. d) Patients and carers education: previous discussion about the future decision making processes about the treatment, giving prognostic information to the patient in reason of a time line proportional to his/her ability to process the contents. e) Be focused before on values and general aims before to agree about procedures. f) use a specific topic guide during the conversation as following:

- Evaluate patient's understanding about clinical circumstances
- Assess information patient's wish
- Speak about prognostic information
- Discuss general treatment objective
- Consider fears and concerns
- Discuss about functions and functionality patient wont loose
- Expectancy related to the consequences associated to the use of specific treatments
- Sharing patient's wishes with family and relatives

g) Indicate in the medical records the principal agreement with the patient specifying: 1) the name of a representative in the case of capacity lack; 2) cardio-pulmonary resuscitation orders and advanced directive in case of specific vital support application procedures. h) Monitoring the quality of treatment using specific process indicators.

### 1.2.3 Mapping patients network

Social network represent a big support for everyone, especially when persons are in a personal crisis for some reasons. The action of social network can improve patient's coping and skills and help him/her to face obstacles. Chadi<sup>15</sup> defines social network as a group of persons, family's members, neighbours, friends helping a person or a family with a real support. Social network are constituted by four principal elements: family, friendship, work relationship and community relationship. An effective social network can help to reduce the tension generated in the context of palliative care. The lack of social support is generally associated to a higher level of anxiety and a poorer quality of life perception with cancer patients<sup>16</sup> moreover the wish to die and suicide risk are higher among patients with poor social network<sup>17</sup>.

As example of social network efficacy we can enumerate support to help patients to be punctual at the meeting, pick the children up in the school or other social activities, or a simple active listening of patient's concerns<sup>18</sup>.

Patient's social network can include group or individual psychotherapy, in this case is extremely important consider what patients wants really know about his/her diagnosis, prognosis and treatment. Several empirical researches show patient's psychological improvement as a consequence of therapy group or individual psychotherapy<sup>19</sup>. Most patient patients receiving group therapy improve their satisfaction and manage pain and anxiety in a better<sup>20</sup>. In palliative care to map patient's social network health professional must consider the following aspects<sup>21</sup>:

- Collect all data related to patient's social and family life
- Detect patient's social needs
- Assess his/here core social live, i.e. spouse, partner or sons considering: characters, expectations, believes, typology of relationship, carers
- Identify other family members, relatives or friends
- Consider formal or informal social network: people available an circumstances where they can support the patient
- Relational aspects: characters and quality of patient's social life in relation to the family setting and environment
- Emotional aspects: how patient/family perceive and cope with illness
- Social aspects interfering with the process and patient's clinical circumstance

#### 1.2.4 How to address the needs of caregivers

In reason of the progressive growing of elderly population the role of carers is always more important in the contemporary health care system. We define "carer" those persons in relation with a patient with a severe illness and give him/her help and support in a multiple aspect of his/her everyday life<sup>22</sup>. 60 per cent of cases, patient's principal carer in palliative care are family members. Understand carers' needs and manage emotional distress is essential in the management of palliative patients<sup>23</sup>.

The concept of "carer burden" refers to the physical, psychological and socio-economical difficult during the care of a palliative patient<sup>24</sup>.

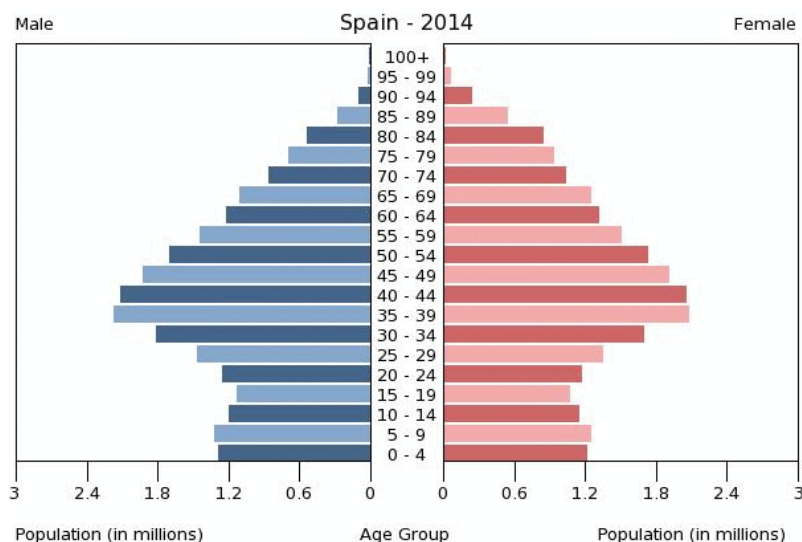
Palliative care of a terminal patient includes daily life attention to the basic needs (eat, mobility, etc.), and symptoms control and psychosocial distress. Normally palliative care team expects patient's carer learn to care the patient independently, without a formal supervision of its skills<sup>25</sup>. However, unbalance between carers' real and expected knowledge is one of the sources of emotional distress. This carer's burden is also a risk factor for his/her physical and mental health, as well as for the impairment of the quality of life and the increment of mortality<sup>26</sup>. Most of principal carers they felt overburdened in some circumstance. A cohort study about patients with oncological illness, cardiac insufficiency or chronic obstructive pulmonary disease showed that the degree of

emotional overload increases with the time<sup>27</sup>. However, the factors related in special way with the development of the burden were the patients' needs in relation with every aspect of everyday life odds ratio [OR]=23.13, 95% confidence interval [CI] = 5.94, 90.06 and patient wish to a better communication [OR] = 2.53, 95% [CI] = 1.16, 5.53. In the same way with progress of illness carers perceive do not be prepared to the patient's death and an impairment of their quality of life<sup>28</sup>. In this way the role of palliative care team is essential to improve carer's perception related to the quality of care received by patient at the end of life<sup>29</sup>. A recent meta-analysis identified specific intervention strategies about carers focused on psychological education, improving the emotional impact of carer's task, the development of specific skills and the ability to develop others in reason to the patient's clinical circumstances evolution. Therapeutic counselling and the development of a self-care strategy are essential to consent carers' physical, emotional, social and spiritual needs<sup>30</sup>.

Given and cols. Identified few areas such as essential in order to assess carers' needs: 1) current carers' need; 2) address changing; 3) carer's professional circumstance; 4) financial needs; 5) palliative care services needs, i.e. house, hospices, palliative care unit at hospital, and timing to change the typology of service; 6) carer's knowledge and skill; 7) competence to care and need or duty to do it; 8) carer's expectation<sup>31</sup>.

## 2. National Statistical data

Health Care System in Spain has a decentralized management spread between Central Government and Autonomous Regions, each one with a specific and independent health care policy and strategy. For that reasons statistical data related to palliative care in Spain are not centralized in a national database reporting the exact characters of users' target group, as well as are the specific resources allocated at national level. Spanish population in the last decades has been on a rise consistently; in 2011 the population census estimated rate was 46.815.916<sup>32</sup>, estimated population in 2015 has been estimated in 46.815.916<sup>33</sup>. Population is distributed as following:



The total extension<sup>34</sup> Spain's surface is 505.990 km<sup>2</sup> with a population density rate of 92/km<sup>2</sup>, its nominal Gross Domestic Product estimated in 2014 is a total of \$1.407trillion, it means the country has the 14<sup>th</sup> largest economy in the world, with an average per capita income of \$ 30.278<sup>33</sup>. In 2014 Spain had a number of physicians per 1000 inhabitants of 4.6 and a number of nurses per 1000 inhabitants of 5.2<sup>35</sup>.

In June 2014 the "Asociación Española Contra el Cancer (AECC) presented the "Report about the Current Situation of Palliative Care in Spain"<sup>36</sup> considered by stakeholders in palliative care as the most representative of the current situation in in the country. In reason of the statistical data showed in the report in 2012 died in Spain 402.950<sup>37</sup> persons, 215.388 patients needed palliative care; among them 94.894 were oncological patients. The "Sociedad Española de Cuidados Palliativos (SECPAL)" published a report related to 2013 where they indicated the availability in Spain of 458 Units/Resources dedicated to palliative care. The number of physicians in palliative care is 567, whether the number of nurses is 1016, the ratio per palliative care team has 1,24 physicians and 2,22 nurses per Unit/resource. Among 458 Units/resources 383 were specific, attending only end of life patients and 75 not specific. The ratio inhabitant per Unit/resource in Spain is 102.026/458 considering the population estimation of 46.727.863 in 2012. This ratio could change among different autonomous regions in Catalonia is 44.529 and in Canary Island 191.384<sup>36</sup>. A difficult to consider these data form a national perspective is the lack of data homogeneity, because there aren't evidences about the characters of each Unit/resource, we don't know if data available are referring to specific or non specific Unit/resources, if the teams are or not multi-disciplinary etc. A big difference among autonomous region is related to the composition of each Unit/resource team in reason of the palliative care service setting, there are

team with a multi-disciplinary composition including a psychologist, occupational therapist, volunteer, social worker or others. Another reason for the consistent heterogeneity of data is the existence of a specific policy in each autonomous region, among the 17 regions only 10 have a regional strategy plan about palliative care, 5 region are discussing about the approval of the plan and 2 are without a defined strategy.

### 3. Legislation about palliative care in Spain

In Spain the Autonomous Regions have the power to legislate about health care system. Central Government can develop health law but Autonomous Regions have the last word in order to how enact the legislation. In the Constitution of 1978<sup>38</sup> there aren't specific references to palliative care, even though in the art. 43.1 there is a more general reference to the "health right respect and public health protection" as duties of public institutions. For that reason at national level there's not a specific legislation about palliative care and a common definition of palliative care services. Just three Autonomous Regions such as Andalucía<sup>39</sup>, Aragón<sup>40</sup> and Navarra<sup>41</sup> have legislated a specific law about the end of life process where the concept of palliative care is defined in a more or less common way. The Art. 5 of the Andalusian law establishes the following definition of palliative care: "a group of coordinated clinical interventions focused on the improvement of patients' and families' quality of life, and approaching all issues related to a terminal illness through suffering prevention and relieve, as well as pain and other physical and psychological symptoms relieve and assessment"<sup>39</sup>. The subjects regulated in the current Spanish legislations are resumed in the following chart:

1- Information	5- Euthanasia and Assisted suicide
2- Informed Consent	6- Treatment Refuse
3- Advanced Directives	7- Terminal Sedation
4- Confidentiality	8- Withholding, Withdrawing, Do not resuscitate orders

The legal foundation of information, informed consent, advanced directives and confidentiality are established at national level in the law 41/2027<sup>42</sup>. Each Autonomous Region has defined the conditions related to the informed consent and advanced directives. Otherwise the euthanasia is not specifically defined in Spanish law even though there is a reference in the art. 143.4 of Penal Code: "Those who provoke or cooperate in an active way with direct action aimed to determine the death of other



person, in reason of him/her proper self-requirement, when the victims suffered of a serious illness leading to determine his/her death, or provoking serious suffering will be punished”, in the same article collaboration and induction to euthanasia are punished. Treatment refuse is regulated in a general way in the law 41/2002 in reason of those situations where patient doesn't accept a specific clinical procedure, but there are any reference to end of life situation. As discussed previously only three Autonomous Regions regulated palliative care with an appropriate legislation about the civil rights and the guarantees related to human dignity during the end of life. The legal framework express the new conditions related to the information process, informed consent and advanced directive. However, it regulates in a more specific way treatment refuse, treatment withhold and withdrawn, no resuscitation orders and terminal sedation. Another aspect of the legal framework I palliative care is confidentiality and carers support in dying process. In order to health professional duties, physicians must inform and respect patient's will in making decision processes, especially in order to the contents of advanced directive and therapeutic intervention limitation. There is a specific reference vulnerable population such as legally unpaired competence patients and minor mature patients to make decision processes at the end of life.

#### **4. National strategy about palliative care in Spain**

Approximately 255,000 people in Spain each year require palliative care to relieve symptoms and improve quality of life lost due to an advanced illness or terminally ill. Many of these patients (over 5,000 per year) are children or young people under 19. For them, unfortunately, specific resources are still very few. Back in the eighties, health professionals who treated terminal patients in Spain began to realize the need to provide medical and psychological support during the last phase of their patients' lives. Controlling pain and symptoms, palliative medicine in Spain began to develop more rigorously in order that patients could spend with dignity their last days<sup>43</sup>. Under the leadership of oncology specialist Jaime Sanz Ortiz<sup>44</sup>, the first unit of palliative care in Spain launched in 1982 at the Marqués de Valdecilla Hospital in Santander. In 1985, this same physician published the first scientific paper on the carefulness for the terminally ill<sup>45</sup>. Fifteen years after the formalization of the hospice-palliative medicine, it was observed that it had developed harmoniously and progressively in all levels of care, teaching and research. Coverage was 0.9% in 1989 and reached 20% in 1998<sup>46</sup>. In subsequent years Spain held its first national congress in palliative care (1995) and in 1998, an agreement was signed with the Spanish Association against Cancer (Asociación Española contra el Cáncer-AECC), equipping many hospitals with home care mobile units. In 1999 the National Palliative Care Plan was approved and

thereafter, all regions of the country gradually established care services for late stage and end-of-life patients<sup>47</sup>. In 2011, 30% of patients who died annually in Spain by a terminal illness underwent palliative specific treatment through home care or hospital units. Of these, 62% were served by the various agencies that comprise the National Health System (Sistema Nacional de Salud-SNS), 34% by private entities or by concerted cooperation agreement with the SNS (mainly the AECC)<sup>48</sup>. In the yearly description given by the Journal of Pain and Symptom Management<sup>49</sup> in 2013, Spain is placed among the countries of Group 4A (Preliminary Integration); hence, it is outside the group of countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision. Thus, there is still much work to do. Data reveal that two years ago, 458 resources were functioning for a population of 47.6 million. Ratio of services to population in Spain was 1: 102,026 distributed across geography, but not homogeneously (Catalonia leading with 1: 44,529). A majority of patients accessing palliative care services in Spain have a cancer diagnosis. However, palliative care researchers have developed a programme (NECPAL- Necesidades Paliativas; Palliative Needs) to identify non-cancer patients in need of palliative services. The programme is based in the British experience of the Gold Standards Framework, and consists in the early identification of chronic patients in need of palliative care approach in the conventional services. With the upgrade of the Palliative Care Strategy 2010 – 2014<sup>50</sup>, the Ministry of Health included a set of quantitative indicators, a qualitative assessment of the fulfilment of the objectives and a description of the device map and palliative care resources. It was concluded that about 50% of patients in need of palliative care did not have access to this service. Consequently: a) Patient registration system in primary healthcare facilities is not effective enough; b) Care coverage does not reach much of the population. Amongst the most urgent requirements<sup>51</sup>: 1) Resources must grow to respond the increased need and demand for care of the Spanish aged population. 2) Non-cancer chronic patient's palliative approach in conventional services has to be included, although this is now addressed by Catalonia and Galicia with the NECPAL programme; 3) The home and hospital coverage for palliative care teams needs to be augmented; 4) Organizational aspects of shared information systems must be optimized; 5) Attention in special homes, specific access to psychological intervention for patients and families and support to specialist training has to be guaranteed. (Spain provides palliative care training for physicians, even if it is not yet recognised as a medical or nursing speciality).

In order to tackle these and other necessities, the Spanish Society for Palliative Care (SECPAL) was created in 1992. It is the body that brings together more than 1800 professionals working in the field. Since 1994, SECPAL publishes the "Palliative Medicine" magazine (Medicina Paliativa. Scored with 0,162 in Journal Citation Reports-2013. Indexed journal in: Science Citation Index, Scopus, ScienceDirect) which is the

only Spanish publication specialized in hospice-palliative care so that shows the work carried out in Spain and Latin America. This multidisciplinary journal aims to share knowledge and experiences in order to respond to the multidimensional patient care and his/her immediate environment. Training programs, congresses and meetings organized by this body have increasingly greater impact on Spanish society. In 2001 Núñez Olarte published an article<sup>52</sup> about the key ethical issues in clinical practice in palliative and end-of-life care in Spain and how these issues are influenced by Spanish culture. Although there is a general consensus that a new philosophy of care is needed, the interpretation and application of this general philosophy are different in diverse sociocultural contexts. The Spanish palliative care movement has shifted its focus from starting new programs to consolidating and expanding the training of the professionals already working in the existing programs. Still, as said above, half of the terminally ill does not receive the required assistance. Universities have not incorporated palliative medicine at the undergraduate levels and the current lack of specialists in this field is still not alleviated. Despite that mass media coverage has greatly increased in the last years (see below), Spain needs a law to ensure a dignified death for all patients. The current law requires that doctors offer palliative care but the formulation of this obligation is extremely ambiguous. Andalusia is the first region that regulated dignified death with the approval of the Bill of Rights and Guarantees of the Dignity of Persons in the Process of Death<sup>53</sup>. This law prohibits aggressive therapy and allows patients to refuse treatment that artificially prolong their life permitting palliative sedation to alleviate the suffering of the sick. Navarra and Aragon in 2011 passed similar laws. The foremost national newspapers and public access information sources have extensively faced the topic in the last five years. Accordingly, in the library of the best-selling newspaper in Spain (El País), for the period 2010-2015 there is more than 800 news and opinion articles related to palliative care and end-of-life issues. Since January 2015, the Spanish public television has addressed the issue of palliative care with two documentaries, an interview with a specialist and a movie. All were broadcasted around February 4, World Cancer Day.

## 5. Palliative care services in Spain

Palliative care in Spain are considered a patients' right to protect the end of life and are organized principally in three different service areas<sup>54</sup>: 1) Primary or basic services: conventional care; 2) Secondary or specialized services 3) Tertiary, for those hospitalized patients requiring complex care. Spread in this three different area there are specific typology of services<sup>4-6</sup>: a) Conventional services: they improve the quality of services among the task group of patients with serious or terminal illnesses. This kind of

services are available: 1) Primary or basic medicine as home services, where patients are assisted by palliative care professional at home; 2) Hospitalized services, they can be available only at hospital or in day-hospital, generally are provided through the units of oncology, geriatrics and internal medicine 3) Hospices. b) Specific services: multidisciplinary team with specific training in palliative care available for terminal patients. This kind of service provides an integral care, where a multidisciplinary team work with a specific palliative care technology devices with formal procedures and intervention protocol. Specific palliative care services they are located in university hospital with clinically complex target group of patients, where research and medical teaching are practised. Palliative care support team operating at home and hospital provide other kind of specific services. General hospital they have also specific Units for palliative care with an independent number of beds specific for palliative patients. Team working at home are referred to Day-hospital services or general medicine services for outpatients or hospices. Standard resources related to palliative care services in Spain<sup>55</sup> consist: a) a support team available for each kind of area of palliative care, i.e. primary medicine, specialized or tertiary; b) a home care service team available per 100-150.000 inhabitants, c) hospital service and day hospital or ambulatory service in the hospital.

Among palliative care services available for patients in Spain there are:

1) Patients and family and support<sup>56</sup>: patients and carers share with a multidisciplinary palliative care team decision making processes related to the end of life, clinical evaluation and monitoring, medical teaching and research, social network and quality of life assessment;

2) Psychological support<sup>57</sup>: the principal function of palliative care team in Spain is psychological support to the patients and carers in order to manage emotional distress and at the same time avoid palliative care professionals burn out. Psychologists have also a coordination role in the team in order to control patients' pain and support family through the development of an action plan and specific common therapeutic aims. Finally psychologists are involved moreover with oncological patients to control anxiety and adaptation difficulties process.

3) Home care services<sup>58</sup>: in Spain palliative care home services are required in a rate of 400 clinical cases /100.000 inhabitants. Target group of patients requiring this kind of service have more than six months life expectation. Home palliative care services benefits are efficacy in control pain, and other symptoms, reduce hospitalization and emergency care services more than 30%, promotion of scheduled admissions toward emergency admissions and probability rate to die at home up 50%-70% with a final result to reduce cost up the 50%.

4) Pain control<sup>59</sup>: control pain is an essential requirement in palliative care, treatment aims are oriented to improve patient's comfort and protect his dignity in the end of life process.

Among the patients clinical characteristic requiring palliative care there are the following<sup>56</sup>: a) Oncological patients, with an evidence based diagnosis of oncological illness, progressive and advanced with limited available treatments and a limited prognostic; b) HIV terminal patients in the following clinical circumstances: progressive oncological pathology associated, progressive neurological pathology: HIV-encephalopathy, progressive Karnofsky Syndrome etc.; c) Patients with advanced chronicle illnesses such as terminal chronicle kidney failure, chronic obstructive pulmonary disease, hypoxemic respiratory failure, heart failure without surgical option treatment available or transplant; coronary illness, chronicle hepatic illness without radical available treatment; d) progressive and not reversible neurological illnesses: stroke with a big functionality impairment, head injury and progressive dementia, Creutzfeldt-Jakob related illness, advanced neuropathy, irreversible coma with different aetiology, chronicle psychopathy in elderly people with comorbidity and great functionality impairment, patients with mobility impairment for more than 2 months

Palliative care service model adopted in Spain<sup>57</sup>: 1) care model need population-oriented integrated with regional services and resources available 2) model focused on quality services as a consequence of citizens' right health, entirely funded by public incomes, universal and available for all patients requiring it; 3) care system focused on patients' and families' needs 4) care system sumministred through the action of multi-disciplinary team, systematic pathway and scheduled interventions with a clinical ethics assessment, quality indicators in order to assess quality of service, efficiency, satisfaction and sustainability, results monitoring and social involvement of patients, health care system and carers,

## 6. Specialized literature and organizations related to the palliative care in Spain

After the application of World Health Organization Program about palliative care in Catalonia in 1989 several guideline have been developed about the most important aspects of palliative care, such as the National Program about Palliative Care (Plan Nacional de Cuidados paliativos) and National Strategy about Palliative Care (Plan Nacional de Cuidados Palliativos) promoted by the National Health System. The main organization to promote and improve the application of palliative care in Spain are:

- Organización Mundial de la Salud, [www.who.int](http://www.who.int)

- Programa de las Naciones Unidas para el SIDA, [www.UNAIDS.org](http://www.UNAIDS.org)
- Fundaciones Princesa de Gales Memorial Fund, [www.theworkcontinues.org](http://www.theworkcontinues.org)
- Robert Woods Johnson Foundation, [www.rwjf.org](http://www.rwjf.org)
- International Association for Hospice and Palliative care, [www.hospicecare.com](http://www.hospicecare.com)
- International Association for the Study of Pain, [www.iasp-pain.org](http://www.iasp-pain.org)
- Help the Hospices, UK Forum for Hospice and Palliative Care Worldwide, [www.helpthehospices.org.uk](http://www.helpthehospices.org.uk)
- Sociedad Española de Cuidados Paliativos, [www.secpal.com](http://www.secpal.com)
- WHO Collaborating Centre, Wisconsin, USA, [www.medsch.wisc.edu/painpolicy](http://www.medsch.wisc.edu/painpolicy)
- Asociación Latino americana de Cuidados Paliativos, [www.cuidadospaliativos.org](http://www.cuidadospaliativos.org)
- Sociedad Española del Dolor, secretaria@sedolor.es. Documento de la SED sobre el uso de opioides, [www.sedolor.es](http://www.sedolor.es)
- Sociedad Vasca de Cuidados Paliativos, [www.sovpal.org](http://www.sovpal.org); [sovpal@sovpal.org](mailto:sovpal@sovpal.org)
- Fundación ADESTE, [fundacionadeste@terra.es](mailto:fundacionadeste@terra.es)
- Canarias Sahel, <http://www.cmcsahel.org/quienes.html> .Cooperación Médica con África
- Web Andaluza de Anestesiología, Reanimación y tratamiento del dolor, <http://www.anestcadiz.com>

National and international journals about palliative care considered of high interest in Spain are:

- Cancer Pain Release, [www.WHOcancerpain.wisc.edu](http://www.WHOcancerpain.wisc.edu)
- Hospice Information, [www.hospiceinformation.info](http://www.hospiceinformation.info)
- IAHPC, [www.hospicecare.com](http://www.hospicecare.com)
- World Hospice Palliative Care Online, [avril@hospiceinformation.info](mailto:avril@hospiceinformation.info)
- Palliatif (en francés), [irzpalli@vtx.ch](mailto:irzpalli@vtx.ch)
- Medicina Paliativa, [www.secpal.com/medicina\\_paliativa/index.php](http://www.secpal.com/medicina_paliativa/index.php)
- Revista de la Sociedad Española del Dolor, [revista.sedolor.es](http://revista.sedolor.es)

Handbook generally used by medical students and health care professional to train in palliative care among the most important in Spain:

- Doyle D, Woodruff R. Manual for palliative care, [www.hospicecare.com/manual/IAHPCmanual.htm](http://www.hospicecare.com/manual/IAHPCmanual.htm)

- Sociedad Española de Cuidados Paliativos. Guía de Cuidados Paliativos, [www.Secpal.com](http://www.Secpal.com)
- Sociedad Vasca de Cuidados Paliativos: varios libros en PDF, [www.sovpal.org](http://www.sovpal.org)

Training program available in Spain for medical and biomedical students and health professionals about palliative care are frequent, but doesn't exist an official resident program related to palliative care, for that reasons health professional or other interested to a training program they can choose among masters degree available in medical school, training program offered by public health care institution:

1) multi-discipline curses available for all kind of health professionals involved in palliative care

- Universidad Autónoma de Madrid: máster en Cuidados Paliativos y Tratamiento de Soporte del Enfermo con Cáncer  
[http://www.uam.es/ss/Satellite/es/1242654675830/1242656616884/estudiopropio/estudioPropio/Master\\_en\\_Cuidados\\_Paliativos\\_y\\_Tratamiento\\_de\\_Soporte\\_del\\_Enfermo\\_con\\_Cancer.htm](http://www.uam.es/ss/Satellite/es/1242654675830/1242656616884/estudiopropio/estudioPropio/Master_en_Cuidados_Paliativos_y_Tratamiento_de_Soporte_del_Enfermo_con_Cancer.htm)
- Universidad de Valladolid: máster en cuidados paliativos  
<http://www.enclaveformacion.com/master-paliativos/>
- Universidad de La Rioja: máster universitario en cuidados paliativos pediátricos:  
<http://www.unir.net/master-cuidados-paliativos-pediatricos.aspx>
- <http://www.masterunir.com/salud/master-en-cuidados-paliativos-pediatricos/>
- Universidad de Barcelona: máster de atención y cuidados paliativos (Univ Barcelona):  
[http://www.ub.edu/web/ub/es/estudis/oferta\\_formativa/master\\_universitari/fitxa/A/M280C/index.html](http://www.ub.edu/web/ub/es/estudis/oferta_formativa/master_universitari/fitxa/A/M280C/index.html)
- Universidad Autónoma de Barcelona: máster en Atención Paliativa Integral a Personas con Enfermedades Avanzadas (Univ Autónoma Barcelona):  
[http://www.uab.cat/web/postgrado/master-en-atencion-paliativa-integral-a-personas-con-enfermedades-avanzadas/informacion-general-1206597472083.html?param1-3144\\_es?param2-2008/](http://www.uab.cat/web/postgrado/master-en-atencion-paliativa-integral-a-personas-con-enfermedades-avanzadas/informacion-general-1206597472083.html?param1-3144_es?param2-2008/)
- Universidad Pontificia de Comillas: máster Universitario en Cuidados Paliativos (Univ Pontificia de Comillas):  
<http://www.euef.upcomillas.es/es/postgrado/sanitaria/master-universitario-en-cuidados-paliativos>

- Máster Propio en Cuidados Paliativos (Centro Universitario de Enfermería San Juan de Dios y el Centro de Formación Permanente de la Universidad de Sevilla): <http://www.mastercfc.us.es/cuidadospaliativos/es-es/inicio.aspx>
- Máster en Cuidados Paliativos (Univ. Camilo José Cela): <https://www.ucjc.edu/estudio/master-en-cuidados-paliativos/>
- Tratamiento de soporte y cuidados paliativos en el enfermo oncológico (Univ de Salamanca): <http://www.usal.es/webusal/node/350>.
- Atención y Cuidados Paliativos (Univ de Vic – Univ central de Barcelona): <http://www.uvic.cat/es/estudi/atencio-i-cures-palliatives---icouvic-ucc>
- Master especialista universitario en cuidados paliativos (San Juan de Dios y Univ del País Vasco): <http://www.hospital-sanjuandedios.es/cas/master-especialista-universitario-en-cuidados-paliativos.html>
- Máster en Cuidados Paliativos (medical practice group): <http://www.mpg.es/master-y-executive/master-en-cuidados-paliativos>
- Cuidados continuos. Tratamiento de soporte y cuidados paliativos. (Fundación Instituto Catalán de oncología). <http://www.e-oncologia.org/cursos/cuidados-continuos-tratamiento-de-soporte-y-cuidados-paliativos/#.VV3VSShBfO4>
- Principios y práctica de los cuidados paliativos. (Fundación Instituto Catalán de oncología). <http://www.e-oncologia.org/cursos/principios-y-practica-de-los-cuidados-paliativos/#.VV3V5yhBfO4>

## 2) Nurses

- Máster universitario en enfermería en cuidados paliativos (Univ. de Navarra): <http://www.universia.es/estudios/unav/unav-master-universitario-enfermeria-cuidados-paliativos/st/193269#>
- Enfermería en los Cuidados Paliativos. Hospitalización Domiciliaria (Escuela de Ciencias de la Salud. Centro adscrito a la UCM). <http://www.emagister.com/enfermeria-cuidados-paliativos-hospitalizacion-domiciliaria-cursos-2576225.htm>
- Cuidados Paliativos. (Fundación Instituto Catalán de oncología).
- Enfermería en cuidados paliativos. (Hospital Centro de cuidados Laguna).

---

<sup>1</sup> Oriol I, Gómez M, Gándara A, Herrera E (2014). Informe de la situación actual de Cuidados Paliativos. AECC. [consultado 19 junio 2015]. Disponible en: [https://www.aecc.es/Investigacion/observatoriodelcancer/Estudiosrealizados/Documents/Informe\\_SituacionActualCuidadosPaliativos.pdf](https://www.aecc.es/Investigacion/observatoriodelcancer/Estudiosrealizados/Documents/Informe_SituacionActualCuidadosPaliativos.pdf)



- 
- <sup>2</sup> Real Academia Española. Diccionario de la Lengua Española, 23<sup>a</sup> ed. Disponible en: [www.rae.es](http://www.rae.es)
- <sup>3</sup> Fallowfield L, Jenkins V. Communicating sad, bad, and difficult news in medicine. *Lancet* 2004;363:312-319.
- <sup>4</sup> Old J. Communicating bad news to your patient. *Fam Pract Manag* 2011;18:31-35.
- <sup>5</sup> Sweeny K, Shepperd JA, Han PKJ. The goals of communicating bad news in health care: do physicians and patients agree? *Health Expect* 2011;16:230-238.
- <sup>6</sup> Hammond I, Franche RL, Black DM, Gaudette S. The radiologist and the patient: breaking bad news. *Can Assoc Radiol J* 1999;50:233-234.
- <sup>7</sup> Fujimori M, Uchitomi Y. Preferences of cancer patients regarding communication of bad news: a systematic literature review. *Jpn J Clin Oncol* 2009;39:201-216.
- <sup>8</sup> Baile W, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES - A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist* 2000;5:302-311.
- <sup>9</sup> Fellowes D, Wilkinson S, Moore P. Communication skills training for health professionals working with cancer patients, their families and/or carers (Cochrane Review). In: *The Cochrane Library*, 2003, Issue 2. Oxford:Update Software.
- <sup>10</sup> Mack JW, Cronin A, Taback N, et al. End-of-life care discussions among patients with advanced cancer: a cohort study. *Ann Intern Med*. 2012;156:204-210.
- <sup>11</sup> Leung JM, Udris EM, Uman J, Au DH. The effect of end-of-life discussions on perceived quality of care and health status among patients with COPD. *Chest*. 2012;142:128-133.
- <sup>12</sup> Zhang B, Wright AA, Huskamp HA, et al. Health care costs in the last week of life: associations with end-of-life conversations. *Arch Intern Med*. 2009; 169(5):480-488
- <sup>13</sup> Emanuel EJ, Fairclough DL, Wolfe P, Emanuel LL. Talking with terminally ill patients and their caregivers about death, dying, and bereavement: is it stressful? is it helpful? *Arch Intern Med*. 2004;164:1999-2004.
- <sup>14</sup> Back AL, Young JP, McCown E, et al. Abandonment at the end of life from patient, caregiver, nurse, and physician perspectives: loss of continuity and lack of closure. *Arch Intern Med*. 2009;169:474-479.
- <sup>15</sup> Chadi M. *Redes sociales en el trabajo social*. Buenos Aires: Espacio Editorial, 2000
- <sup>16</sup> Mystakidou K, Tsilika E, Parpa E, Katsouda E, Galanos A, Vlahos L. Assessment of anxiety and depression in advanced cancer patients and their relationship with quality of life. *Qual Life Res*. 2005;14:1825-1833.
- <sup>17</sup> Breitbart W, Rosenfeld B, Pessin H, et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA*. 2000;284:2907-2911
- <sup>18</sup> The National Cancer Institute. When Someone You Love is Being Treated for Cancer. U.S. National Institutes of Health. Acceso el 19 junio 2015. Disponible en: <http://www.cancer.gov/publications/patient-education/when-someone-you-love-is-treated.pdf>
- <sup>19</sup> Goodwin PJ. Support groups in advanced breast cancer. *Cancer*. 2005;104:2596-2601
- <sup>20</sup> Jones LW, Demark-Wahnefried W. Diet, exercise, and complementary therapies after primary treatment for cancer. *Lancet Oncol*. 2006;7:1017-1026
- <sup>21</sup> Valois C. *Redes de apoyo psicosocial al duelo*. En: Astudillo W, Pérez M, Ispizua A, Orbegozo A, eds. *Acompañamiento en el duelo y medicina paliativa*. San Sebastián: Sociedad Vasca de Cuidados Paliativos; 2007.
- <sup>22</sup> Given BA, Sherwood P, Given CW. Support for Caregivers of Cancer Patients: Transition After Active Treatment. *Cancer Epidemiol Biomarkers Prev* 2011;20:2015-2021.
- <sup>23</sup> Rabow MW, Hauser JM, Adams J. Supporting family caregivers at the end of life: "they don't know what they don't know". *JAMA*. 2004;291:483-491.



- <sup>24</sup> Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist*. 1980;20:649–655.
- <sup>25</sup> Ferrell, B.; Mazanec, P. Family Caregivers. In: Hurria, A.; Balducci, L., editors. *Geriatric Oncology: Treatment, Assessment, and Management*. New York: Springer; 2009. p. 135-155.
- <sup>26</sup> Schulz R, Beach SR. Caregiving as a risk factor for mortality: The caregiver health effects study. *JAMA*. 1999;282:2215–2219.
- <sup>27</sup> Garlo K, O’leary JR, Van Ness PH, Fried TR. Caregiver burden in caregivers of older adults with advanced illness. *J Am Geriatr Soc* 2010;58:2315-2322.
- <sup>28</sup> Grant M, Sun V, Fujinami R, Sidhu R, Otis-Green S, Juarez G, et al. Family caregiver burden, skill preparedness, and quality of life in non-small-cell lung cancer. *Oncol Nurs Forum* 2013;40:337-346.
- <sup>29</sup> Douglas S, Daly B. Effect of an integrated cancer support team on caregiver satisfaction with end-of-life care. *Oncol Nurs Forum*. 2014;41: E248–E255.
- <sup>30</sup> Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW. Interventions with Family Caregivers of Cancer Patients: Meta-Analysis of Randomized Trials. *CA Cancer J Clin*. 2010;60:317–339.
- <sup>31</sup> Given BA, Given CW, Sherwood PR. Family and Caregiver Needs over the Course of the Cancer Trajectory. *J Support Oncol*. 2012;10:57–64.
- <sup>32</sup> Censos de Población y Viviendas. Instituto Nacional de Estadística (INE) (in Spanish)
- <sup>33</sup> Population Figures at 1 January 2015, Instituto Nacional de Estadística (INE) (In Spanish)
- <sup>34</sup> Anuario Estadístico de España 2008. Instituto Nacional de Estadística (INE) (in Spanish)
- <sup>35</sup> Registered Health Professional Statistic 2014. Instituto Nacional de Estadística (INE)
- <sup>36</sup> Observatorio del Cáncer AECC. Informe de la situación actual de Cuidados Paliativos. Madrid: Asociación Española contra el Cáncer (AECC); 2015. Disponible en: [https://www.aecc.es/Investigacion/observatoriodelcancer/Estudiosrealizados/Documents/Informe\\_SituacionActualCuidadosPaliativos.pdf](https://www.aecc.es/Investigacion/observatoriodelcancer/Estudiosrealizados/Documents/Informe_SituacionActualCuidadosPaliativos.pdf)
- <sup>37</sup> Defunciones según la causa de muerte en 2012. Instituto Nacional de Estadística (INE) (In spanish)
- <sup>38</sup> Constitución Española de 1978 (In Spanish)
- <sup>39</sup> Ley 2/2010, de 8 de abril, de Derecho y Garantías de la Dignidad de la Persona en el Proceso de la Muerte (In Spanish)
- <sup>40</sup> Ley 10/2011, de 24 de marzo, de derechos y garantías de la dignidad de la persona en el proceso de morir y de la muerte (In Spanish)
- <sup>41</sup> Ley Foral 8/2011, de 24 de mazo, de derechos y garantías de la dignidad de la persona en el proceso de la muerte (In Spanish)
- <sup>42</sup> Ley 41/2002, de 14 de noviembre, básica reguladora de la autonomía del paciente y de derechos y obligaciones en materia de información y documentación clínica (In Spanish)
- <sup>43</sup> Centeno Cortés C. Panorama actual de la medicina paliativa en España. *Oncología* 1995; 18(4): 173-183
- <sup>44</sup> Sanz Ortiz J, Barceló JR. Rendimientos de una Unidad de Cuidados Paliativos en un Hospital Universitario. *Oncología* 1989; 12(10): 504-508
- <sup>45</sup> Sanz Ortiz J. El paciente en enfermedad terminal. Los intocables de la medicina. *Medicina Clínica* 1985; 84(17): 691-693
- <sup>46</sup> Sanz Ortiz J. Historia de la medicina paliativa. *Medicina Paliativa* 1999; 6(2): 82-88

- 
- <sup>47</sup> Fernández Abellán P. Plan Integral de Cuidados Paliativos en el Servicio Murciano de Salud 2006-2009. Ed. Consejería de Sanidad y Consumo de la Región de Murcia: 2009
- <sup>48</sup> Lynch T, Connor S et al. Mapping Levels of Palliative Care Development: A Global Update. *Journal of Pain and Symptom Management* 2012; 54(6): 1094-106
- <sup>49</sup> Palliative Care in Spain. February 2013. Available in [www.ehospice.com](http://www.ehospice.com) (Accessed 05/28/2015)
- <sup>50</sup> Ministerio de Sanidad Política e Igualdad Ed. Estrategia Nacional de Cuidados Paliativos. Actualización 2010-2014. Madrid: 2011
- <sup>51</sup> Directorio de Recursos SECPAL 2013. Available in [www.secpal.com](http://www.secpal.com) (Accessed 05/28/2015)
- <sup>52</sup> Núñez Olarte JM, Gracia Guillén D. Cultural Issues and Ethical Dilemmas in Palliative and End-of-Life Care in Spain. *Cancer Control* 2001; 8(1): 46-54
- <sup>53</sup> Díez Fernández JA. Patients' autonomy and doctors' duties according to the Andalusian bill of "dignified dead". *Cuadernos de Bioética* 2010; 21(71): 51-60
- <sup>54</sup> Gomez –Batiste X, Paz S, et al. Principios básicos, definiciones y conceptos en la organización de programas de servicios públicos de cuidados paliativos. Observatorio "Quality"/ Centro colaborador de la OMS para programas Públicos de cuidados paliativos. Instituto Catalán de Oncología 2009
- <sup>55</sup> Gomez-Batiste X, Espinosa J, et al. Equipos de soporte domiciliarios de cuidados paliativos en España. *Medicina Paliativa* 2010; 135(2): 83-89
- <sup>56</sup> Espinosa J, Gómez-Batiste X, et al. Modelo de Atención, organización y mejora de la calidad para la atención de los enfermos en fase terminal. *Medicina Clínica* 2010; 135(2):470-47
- <sup>57</sup> Lacasta Reverte MA, Rocafort Gil, et al. Intervención psicológica en Cuidados Paliativos. Análisis de los servicios prestados en España. *Medicina Paliativa* 2008; 15(1): 39-44
- <sup>58</sup> Vega T, Arrieta E, et al. Atención sanitaria paliativa y de soporte de los equipos de atención primaria en domicilio. *Gaceta Sanitaria* 2011; 25(3): 205-210
- <sup>59</sup> Astudillo Alarcón W, Díaz-Albo E, et al. Cuidados paliativos y tratamiento del dolor en la solidaridad internacional. *Revista de la sociedad española del dolor* 2009; 16(4):246-255