

Executive summary:

Current problems, elements for improvement and future challenges for palliative care in the population with cancer



asociación
española
contra el cáncer

INDEX:

- 01. Introduction**
- 02. What is palliative care?**
- 03. National regulatory framework**
- 04. Comprehensive care**
- 05. Population with cancer and with palliative needs, place of demise and access to palliative care**
- 06. The Spanish Association Against Cancer and Palliative Care**
- 07. Recommendations**

Introduction

Understanding how people with cancer spend the final stages of their life in Spain is essential for the Spanish Association Against Cancer, as it is the first step towards ensuring that this population has all its needs covered in a comprehensive and multidisciplinary manner.

Of the 493,776 people who passed away in Spain in 2020, 183,119 were eligible for palliative care (PC). Nearly 62% would be cancer patients. But did they receive palliative care? If they did, was it comprehensive and multidisciplinary? Were all their and their families' needs met? Were their wishes to decide where to die respected?

According to the European Society for Palliative Care, the optimal number of specialised palliative care resources for an adequate care is 2 per 100,000 inhabitants, one in hospital and one at home. On average, Europe has 0.8 and Spain 0.6. These figures clearly indicate that people with cancer and with palliative needs have not been receiving the care they needed. What would it take to guarantee such care? What are the implications of not receiving it? What do we need to do to ensure that people with cancer at the end of their life receive comprehensive, multidisciplinary care that meets their needs and those of their families?

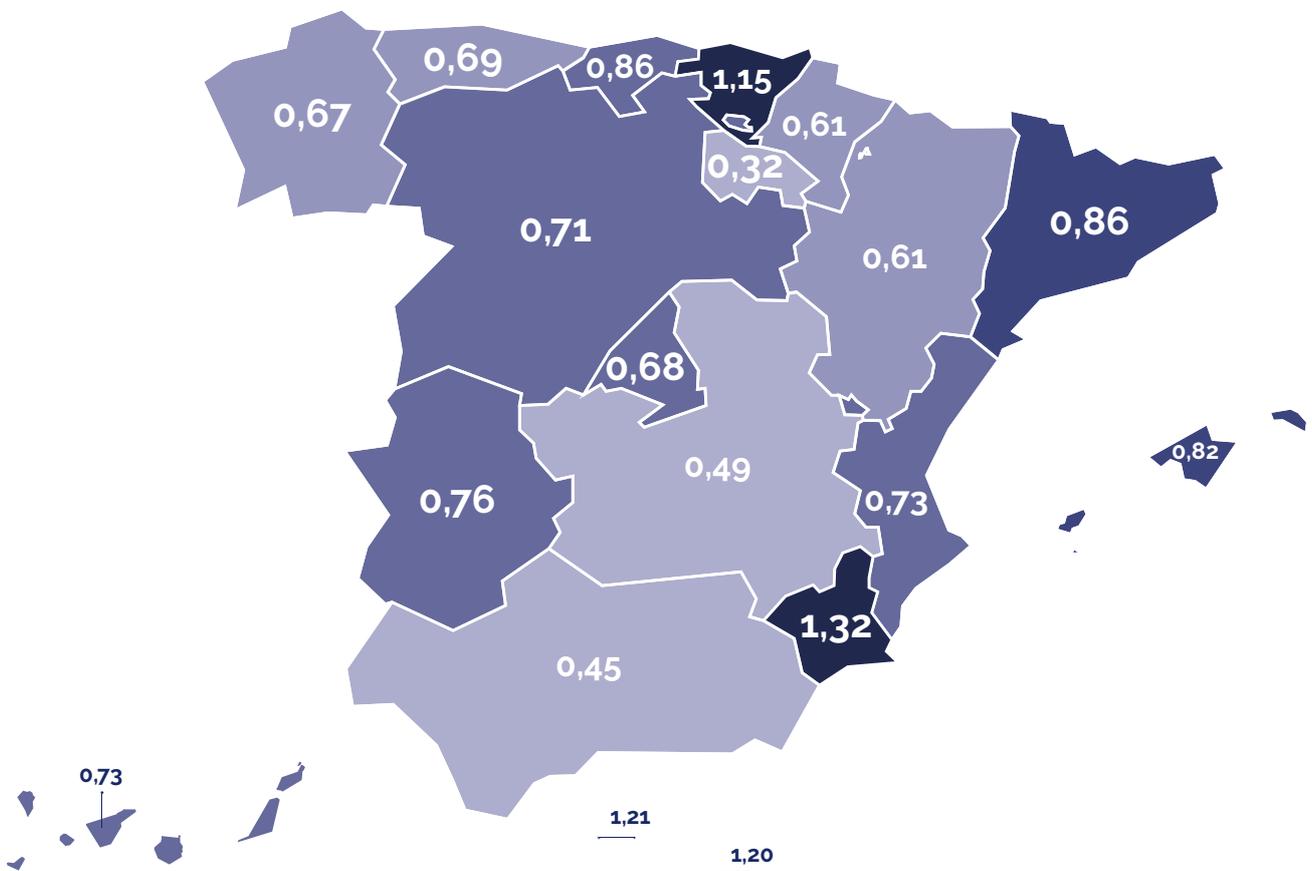


Figure 1. Rate of specific palliative care resources for adults per 100,000 inhabitants by autonomous community Source: SECPAL. Palliative care resource geodirectory. December 2017.

Lastly, the European Union has a particular interest in palliative care, as in February 2022 the European Parliament passed a resolution on strengthening Europe in the fight against cancer: towards a comprehensive and coordinated strategy, that stresses the importance of palliative care by calling on Member States, among other measures, to provide comprehensive and multidisciplinary services for people with cancer; to develop child-specific palliative care; and to address this type of care in their national cancer programmes.

This study aims to address the current problems, elements for improvement and future challenges for palliative care in the population with cancer.

02 /

What is palliative care?

Palliative care does not help patients to die, but to live right up to the end. It provides quality of life for both the patient and their family. The following golden rules describe what such care is and means.

-  1. The right of people with advanced life-threatening illnesses to receive care.
-  2. Comprehensive, individualised and continuous care for both patients and their families.
-  3. Intended to prevent and alleviate the physical, emotional, social and spiritual suffering of the patient and their family
-  4. Integrated into patient care once palliative needs are identified, as a complement to treatment.
-  5. Care continues beyond death, accompanying the family and loved ones through the grieving process.
-  6. Focused on the patient, respecting their life story, values, principles and preferences that they want to be taken into account in how they would like to receive such care.
-  7. Provided by an interdisciplinary team made up of medical, nursing, psychology, social work and spiritual counselling professionals who are specifically trained to deliver such care.
-  8. Can be received in any care setting, at home, in hospital and/or a residential facility.
-  9. Includes coordination and cooperation with other professionals (primary care, specialist care, community health), and the community, to help the patient and their family.
-  10. Involves enhanced sensitivity, training and awareness among professionals, society at large and government about the value of caring.

03 /

National regulatory framework

Since 1995, palliative care for end-of-life patients has been included in Spanish National Health System (SNS) provision, reflecting the viewpoint of healthcare professionals and organisations,

such as the Spanish Association Against Cancer, which highlighted the need to address care for people facing this final stage of their life.

In 2001, the regulatory framework for palliative care in Spain was established, based on the approval of the "National Palliative Care Plan", which urged the Spanish regions, or Autonomous Communities (ACs), to develop measures to improve the quality of life of people with terminal palliative needs and their families, by guaranteeing palliative care according to the guiding principles of the SNS.

Subsequently, Act 16/2003, of 28 May 2003, on the cohesion and quality of the National Health System, included palliative care for the terminally ill within the scope of primary care (Article 12) and specialist care (Article 13). In addition, Article 8 provides that the listed health provision is to be effected through the portfolio of common services.

Royal Decree 1030/2006 of 15 September, establishing the portfolio of common services of the National Health System and the procedure for updating them¹⁶, further develops the content of this provision in Table 2:

ANNEX II. Portfolio of common services in primary care	ANNEX III. Portfolio of common services in specialist care
Article 7. Palliative care for the terminally ill.	Article 6. Palliative care for the terminally ill.
<p>This includes comprehensive, individualised and continuous care for people with a disease at an advanced stage who would not respond to treatment with a curative aim and have a limited life expectancy (generally less than 6 months), as well as for those close to them. Its therapeutic goal is to improve their quality of life, with respect for their belief system, preferences and values.</p> <p>Such care is particularly humanised and personalised, and is provided at the patient's home or at a healthcare centre, if necessary, establishing the necessary mechanisms to guarantee continuity of care and coordination with other resources, and in accordance with the protocols established by the corresponding health service. It includes:</p>	
<ol style="list-style-type: none"> 1. Identification of the terminally ill according to diagnostic criteria and natural history of the disease. 2. Comprehensive assessment of the needs of patients and caregivers and establishment of a written care plan, including preventive measures, hygienic-dietary recommendations, symptom management and general care. 	
<ol style="list-style-type: none"> 3. Frequent assessment and monitoring of physical and mental symptoms, indicating pharmacological and non-pharmacological treatment of pain and other symptoms. Patient information and support at various stages of the process. 	<ol style="list-style-type: none"> 3. Frequent assessment and monitoring of physical and mental symptoms, performing the necessary examinations and diagnostic procedures, and indicating pharmacological and non-pharmacological treatment of pain and other symptoms. Patient information and support at various stages of the process.
<ol style="list-style-type: none"> 4. Information, health advice, counselling and support for those related to the patient, especially the primary caregiver. 	
<ol style="list-style-type: none"> 5. In situations where this is necessary, and particularly in complex cases, care is provided by healthcare and/or social support structures or by specialised services, both at medical appointments and at the patient's home or through hospitalisation, where appropriate. 	

Since then, there have been several attempts in different legislatures to pass a state law on palliative care, which remained fruitless by the time this report went to press.

Some of Spain's autonomous communities have gone a step ahead of central government by providing a greater range of guarantees, passing laws in their regions to ensure all have access

to such provision. This is the case in 10 regions: Andalusia, Aragon, Asturias, Balearic Islands, Canary Islands, Valencia, Galicia, Madrid, Navarre and the Basque Country. However, it would be desirable to move towards national legislation to harmonise the various regional regulatory developments in this regard in order to guarantee fully equitable access to palliative care throughout Spain.

The latest “SNS Palliative Care Strategy” has been inadequately implemented in most of the Autonomous Communities (ACs), resulting in territorial inequality in access to this type of care. The causes range from a lack of recognition of palliative specialist status to a lack of resources or specific training in palliative care.

04 /

Comprehensive response in palliative care

The needs of people with cancer in their final stage of life vary greatly, and the care they receive must therefore be comprehensive and multidisciplinary. In Spain, the composition of palliative care teams is highly uneven due to the lack of an equitable and structured model to handle such provision. Two types of team have been identified:

	Full PC Team
Basic PC team <ul style="list-style-type: none"> • Medical • Nursing 	<ul style="list-style-type: none"> • Medical • Nursing • Psychology • Social work

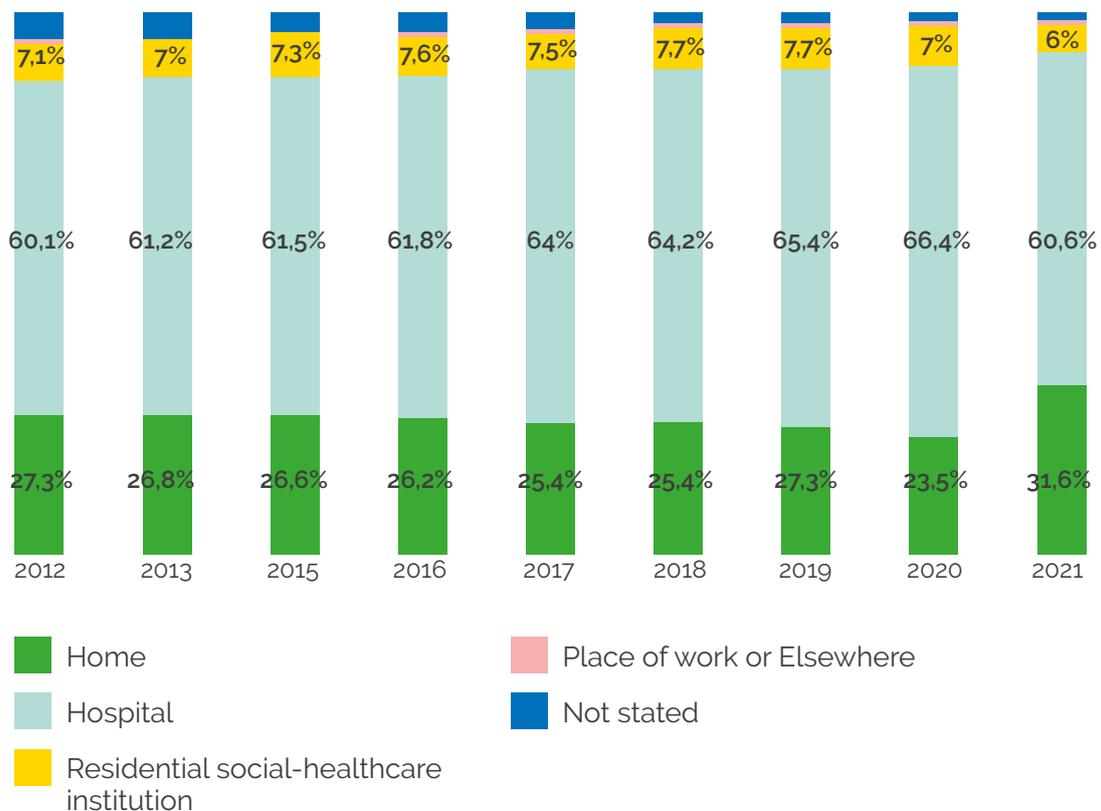
Out of all palliative care teams in Spain, only 25% have psychologists and social workers, and they spend less than 50% of their working hours providing such care. This means that psychosocial professionals are not systematically integrated into palliative care teams. This deficit leads to dependency on the Hospital Care mental health service; dependency on the training of health professionals in psychosocial matters, and on agreements with the charitable sector (Spanish Association Against Cancer, la Caixa Foundation).

The lack of a comprehensive approach to palliative care has an impact on patients and families, but also on professionals. Lack of information and tools to cope with the final phase of life; lack of communication with PC professionals or misinformation about available rights and resources are some of the consequences suffered by families. In terms of professionals, the consequences are of a different nature, such as difficulty in drawing up personalised treatment plans, lack of communication with the family, or lack of information regarding the social system.

Cancer patients with palliative needs, place of demise and access to PC

By 2020, 62% of the population eligible for palliative care were cancer patients (according to the McNamara basic model). But according to the latest data available from SECPAL, only 49.2% received this. Lack of resources, lack of information, uneven implementation of the “SNS Palliative Care Strategy” in the different regions or lack of multidisciplinary teams are the main causes.

One indicator of the quality of a palliative care and end-of-life support system is respect for the wishes of the patient as to where they choose to die. According to a European study, 66% of people with cancer in Spain would like to die at home. According to the Spanish Association Against Cancer, only 31.6% did so in 2020. As shown in the graph, the percentage of deaths at home due to cancer decreased systematically between 2012 and 2019, and subsequently grew substantially in 2020. It should in this regard be stressed that this growth is explained by the significant impact of the global emergency caused by Covid-19 on the health system.



Percentage of deaths by place (cancer patients).

¹SECPAL (2016). Analysis and evaluation of Palliative Care resources in Spain (p. 92)

²Gomes, B., Higginson, I. J., Calanzani, N., Cohen, J., Deliens, L., Daveson, B. A., Bechinger-English, D., Bausewein, C., Ferreira, P. L., Toscani, F., Meñaca, A., Gysels, M., Ceulemans, L., Simon, S. T., Pasman, H., Albers, G., Hall, S., Murtagh, F., Haugen, D. F., Downing, J., ... PRISMA (2012). Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. *Annals of oncology official journal of the European Society for Medical Oncology*, 23(8), 2006–2015. <https://doi.org/10.1093/annonc/mdr602>

One of the main barriers in accessing PC is the lack of continuity in care. Referral to palliative units usually occurs late, causing such care to begin near the end of life, which is at odds with the very nature of PC, required when treatment for curative purposes no longer has the desired effect, but there is still plenty of life left.

Lack of care coordination	Delayed referral of patients for PC
<ul style="list-style-type: none"> • Unevenness in the PC care process • Unevenness in the referral process • No key figure on PC teams responsible for coordination between primary care, specialist care and PC teams • No communication channel between different healthcare levels • Lack of interoperability of shared clinical history between primary care, oncology and PC teams 	<ul style="list-style-type: none"> • Lack of care coordination. • Lack of resources in primary care to identify palliative needs • High care burden on primary care and PC due to growing demand for this type of care • Reluctance of specialist care professionals to refer their patients • Reluctance of patients/relatives due to the impact of switching to palliative treatment • Unfamiliarity among healthcare professionals with the portfolio of palliative care services (belief that only end of life is addressed). • Lack of training in PC in primary and specialist care

In addition to the above, coordination between the PC units and the social system is not recorded in protocols, and ongoing care services are not implemented in home and residential PC.

Absence of coordination protocols between PC and care homes	<p>The coordination model varies according to: structure/capacity of the teams at care homes, the AC and the reference hospital.</p> <p>2 predominant models:</p> <ul style="list-style-type: none"> • Care homes comprising multidisciplinary teams trained to offer home PC to residents. • Homes with fewer human resources that are forced to refer residents with palliative needs to hospitals
Lack of coordination between PC and social services	<p>Most common in basic palliative care teams (see composition on page 20) where coordination work is carried out by healthcare roles.</p> <p>This means that timely access to social resources cannot be ensured:</p> <ul style="list-style-type: none"> • Support requested from social services usually has a longer resolution time than patients' life expectancy.
Inaccessibility of shared information systems	<p>Care homes do not have access to shared information systems mainly due to:</p> <ul style="list-style-type: none"> • Different information system in the social system (dependent on the regional social services departments) which prevents access <p>Psychologists external to PC teams do not have access to the shared clinical history of the health system.</p>

This situation is compounded by the citizens lack of knowledge about palliative care and their right to receive it, for different reasons:

Patient unaware of own prognosis	Social taboo of the process of dying
<ul style="list-style-type: none">• Tendency among families to hide end-of-life prognosis from patients (especially elderly) in order to prevent psychological impact.• As a result, it is generally the family who are involved in making decisions regarding palliative care (where to pass away / receive care, etc.)• This oath of silence makes it difficult in particular to manage psychological and social needs.	<ul style="list-style-type: none">• There is these days a widespread social invisibility of death, in a process of denial as to the possibility that it could occur in the future.• This phenomenon means that the set of issues regarding death, such as, among others, palliative care, are not addressed prior to the diagnosis of a cancer, nor in the palliative care process itself by relatives, patients and, on occasion, healthcare professionals.

06 /

The Spanish Association Against Cancer and PC

The Spanish Association Against Cancer laid the foundations for home care and was the first social organisation to launch multidisciplinary home palliative care units for cancer patients and their families in Spain, in 1991. It set up as many as 62 units nationwide. In 2007 it began a process of progressive transfer of these units to the National Health System, but continues to provide psychological and social support, and volunteering, to patients and families.

The Association maintains its psychological, social and volunteering care services for people at the end of their lives, and their families.

Recommendations

Receiving end-of-life care is an inalienable right of the individual.

End-of-life care is a comprehensive, individualised and continuous care process in which the patient and their family must be given an active role in planning decisions in advance, with full respect for the patient's autonomy and dignity.

Both the patient and their family lie at the heart of this care, and must have the peace of mind that their needs will be taken care of, both physical (pain control and symptoms), emotional, social or spiritual.

Spain needs to further improve the care that the national health system provides to people with palliative needs. Furthermore, it must be guaranteed that equal access to palliative care covers 100% of the population in need, both adults and children and teenagers, without any form of discrimination.

In order to help improve care for cancer patients with palliative needs, the Spanish Association Against Cancer sets out the following recommendations:

- 01.** Ensure equity and quality of comprehensive care for people with palliative needs by passing state legislation on rights and guarantees in end-of-life care.
- 02.** Provide accessible information so that citizens understand what palliative care is and how it is accessed.
- 03.** Define unified criteria, processes, protocols, care circuits and information systems within the SNS to identify and offer an early response to patients with palliative needs.
- 04.** Ensure ongoing training in palliative care for health and social care professionals caring for patients in this situation (dedicated palliative care teams, home support units and teams, emergency services, care home professionals, etc.).
- 05.** Design and implement targeted palliative care training accessible from different degree, postgraduate and specialist courses.
- 06.** Respect the patient's preferences if they wish to be cared for at home, and provide the necessary means to guarantee this, if their conditions and those of their family environment so allow. It should be borne in mind that about 70% of people with cancer want to stay at home^[1].
- 07.** Increase specific palliative care resources, both in hospital and at home, and at medium-/long-term residential centres, and strengthen them with psychology and social work professionals.
- 08.** Create residential centres specialising in palliative care for people with palliative needs and difficulties in accessing such care at home due to various social problems (solitude, inadequate housing, etc.).

- 09.** Promote multi- and inter-disciplinary work, as well as appropriate coordination of professionals who provide relief and care in all dimensions of the quality of life of the patient and their family (physical, emotional, social and spiritual).
- 10.** Ensure availability of targeted palliative care 24/7 for patients in the final stage of their life, and their families.
- 11.** Establish fast-track access to social provision and support for people with palliative needs.
- 12.** Facilitate the participation of patients and caregivers in the care process.
- 13.** Provide the primary caregiver with the necessary training and support resources to improve both the quality of life of their sick relative and their own, including the necessary social and occupational protection to facilitate them to care for the patient.
- 14.** Foster social solidarity in accompanying people at the end of their life through appropriately trained volunteers.
- 15.** Ensure the availability of bereavement care so as to promote continuity of care for the family unit.
- 16.** Provide psychological support to palliative care professionals to prevent the burnout syndrome.
- 17.** Establish processes and procedures for collaboration with non-profit organisations working on care and support for people with palliative needs.
- 18.** Identify and promote good practices in end-of-life care.
- 19.** Promote research into palliative care.
- 20.** Carry out and publish regular assessments and audits, both of palliative care plans, strategies and programmes, and of compliance with the various regional laws, in the interest of due transparency and social accountability as to the provision of palliative care and equal access for all those who need it.

¹ Gomes B, Higginson IJ, Calanzani N et al. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. *Annals of Oncology*, 2012; 23(8): 2006-2015. Disponible en <https://www.sciencedirect.com/science/article/pii/S0923753419381098>



asociación
española
contra el cáncer