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Nursing Practice Framework in Palliative Care

Consejo General de Colegios Oficiales de Enfermería de España

INSTITUTO ESPAÑOL DE INVESTIGACIÓN ENFERMERA

NURSING PRACTICE FRAMEWORK IN PALLIATIVE CARE

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TABLE OF CONTENTS

Definitions

1. DEFINITIONS

- **Specific Development Area:** Official training qualification provided and regulated by the Ministry of Health, as a sub-specialization within one or more specialties in the health sciences, in scientific and technological knowledge that requires adequate training for the acquisition of highly specialized skills, in order to improve the quality of care and health of patients who require this highly specialized care due to the complexity of their health problems.[1]

- **Person-centered care:** A holistic approach that provides respectful and individualized health care, based on the therapeutic relationship between professionals, people receiving care, and their families, who are empowered to be involved in their health decisions.[2]

- **Professional Development:** Training and awareness of health professionals throughout their training cycle in health promotion and prevention, from a comprehensive and multidimensional perspective.

- **Professional competence:** Ability of the health professional to integrate and apply the knowledge, skills, and attitudes associated with the best practices of their profession to solve the problems that arise.

- **Accreditation Diploma:** Official training credential provided and regulated by the Ministry of Health. It certifies that the healthcare professional has achieved the competencies and continuing education requirements established in a specific functional area for a specified period of time.[3]

- **NANDA-I:** Known until 2002 as the North American Nursing Diagnosis Association, it is currently known by its official brand NANDA International or NANDA-I. It is the international organization whose mission is to facilitate the development, improvement, dissemination, and use of standardized nursing diagnostic terminology.

- **Advanced practice:** Advanced level of professional practice that maximizes the use of specialized skills and disciplinary knowledge, in order to respond to people's health needs. This practice uses a model of care based on theoretical, empirical, and experiential knowledge of the domain of practice, with the aim of offering comprehensive and complete care. Evidence-based practice is at the core of advanced practice competencies.[4]

Scope of the Resolution and of the Framework Document

2

2. SCOPE OF THE RESOLUTION AND OF THE FRAMEWORK DOCUMENT

Since the approval of the Spanish Constitution and its Article 36, a legal reserve has been established regarding the regulation of the practice of licensed professions. This constitutional provision has not entailed a modification of the purposes and functions assigned to professional associations and their general councils by the Law on Professional Associations, but it does imply that the regulatory function of these associations must respect the essential regulatory framework of the profession. This regulatory framework reserved to the law includes the existence of a licensed profession, the requirements and qualifications necessary for its practice, and its scope, understood as the formal set of activities that comprise it.

Case law holds that the General Councils are empowered to regulate “secondary or auxiliary aspects,” that is, when “neither professional competencies nor the essence of the activity is affected.” Thus, matters that “have not been regulated by rules issued by other public authorities with superior jurisdiction” fall within what is considered auxiliary or secondary, provided that such regulation remains within the essential limits.

This objective is precisely the purpose of both the present framework document and the resolution that approves it, such that neither of them constitutes, in any way, a regulation of professional competencies. Furthermore, the document is structured in a manner that fully respects not only the nursing competencies established by the relevant regulations, but also the competencies of the other healthcare professions.

In this way, the present document is linked to the field of professional ethics and deontology, offering a standard of conduct that allows for the monitoring of deviations in professional practice, based on the expertise and experience of the professionals who form its corporate foundation.

Therefore, based on these premises, this framework document outlines a professional profile within a field of nursing practice that already exists today, with the aim of establishing professional, ethical, and educational criteria to ensure quality and professional competence and, consequently, to promote the right to health and improve healthcare services in accordance with current scientific standards.

Theoretical Framework

3. THEORETICAL FRAMEWORK

According to the definition based on the consensus of the International Association for Hospice and Palliative Care in 2020,[5] palliative care (PC) is the approach that improves the quality of life of patients and their families in the face of the problems associated with life-threatening conditions, through the prevention and relief of suffering through early identification, and the thorough assessment and treatment of pain and other physical, psycho-emotional, and spiritual problems.

PC increases the quality of life of people with advanced conditions and no options for curative treatment. The benefits are achieved through the management of symptoms—whether physical (such as pain, dyspnea, or vomiting) or emotional (such as fear, anger, sadness, or thoughts of hastening death). They also include care and support for caregivers and families, such as assistance with social or community resources and family interventions, as well as spiritual support, including helping individuals explore the meaning of life, their beliefs, values, and sense of transcendence. All of this is provided with shared care planning (SCP) in collaboration with the patient.[6,7]

In Europe, specialized PC services are organized in multi- and interdisciplinary teams, with advanced training and full dedication to the relief of suffering associated with life-threatening and/or end-of-life conditions. They are usually found at all levels of care where people with these needs are found.[7]

Despite the existing evidence on the effectiveness of PC, a recent study conducted by the ATLANTES Global Observatory of Palliative Care[8] estimates that only 41% of European countries have achieved high coverage of PC, which includes specialized palliative resources.

In Spain, despite the 2001[9] National PC Plan and the PC Strategy of the National Health System published in 2010-2014[10], more than 80,000 people who could benefit from PC do not receive it. According to the PC Strategy of 2014[11], about 1,200 people under age 20 die from life-limiting diseases annually, while about 13,000 suffer from a life-limiting disease, and about 6,000 need specific pediatric care at the end of life.

One of the most important structural reasons for this care deficit is the lack of recognition of a specific specialty or area of knowledge in PC.

This refers to specialized care provided during an advanced illness with an uncertain prognosis and at the end of life, aimed at addressing identified needs from a holistic perspective—considering both the individual and their family environment—regardless of whether they are at home (private or residential) or in a hospital, and responding to needs at any age.[7]

Although PC training is included in most European nursing schools, it is generally offered as a module within another subject. The exceptions are France, Austria, and Poland, where it is taught as a mandatory specific subject. Only seven countries offer the possibility of clinical internships in a specific PC unit within the Bachelor of Nursing. Only Hungary, Iceland, and Poland offer PC internships at all nursing schools in the country.[7]

All of the above increases the need to have a nursing profile to provide this type of care, since its development in the Bachelor of Nursing is not sufficient, as indicated in the European PC Atlas published in 2019[7]. In this same atlas, it is noted that 15 countries do not offer PC training in the Bachelor of Nursing and another 11 countries do not report whether it is included.

It is also worth mentioning the beginning of modern PC with the birth of the hospice movement in 1930 in the United Kingdom. In the hospice model, symptomatic control was adapted during advanced disease, and aggressive treatments and unnecessary hospital admissions were minimized in the final months of life, thus improving shared decision-making. This care must be provided regardless of the disease (oncological or non-oncological), age, where the patient lives, who they love, what their beliefs are, and their background, as promoted by the Worldwide Hospice Palliative Care Alliance.[12]

The National Health Service in the United Kingdom only funds a fraction of palliative services in the country. Specialized hospitalization units are mostly funded by non-governmental organizations. For example, Marie Curie Cancer Care and Macmillan Cancer Support are the largest providers of PC in the country and provide the infrastructure and operational funding for care in homes and centers. In these settings, nurses play a fundamental role, including through a figure known as the PC specialist nurse, who carries out interventions that help improve patient care and quality of life. Among the specialist's responsibilities is the prescription of medications and other products, an activity regulated by the Nurse Prescriber Form of 2003. This form provides a comprehensive list of authorized medications, among them some controlled drugs, such as morphine.[13]

The British National Formulary (BNF) allows nurses to prescribe within their area of expertise, and PC nurses highlight the following medications: buprenorphine, diamorphine, diazepam, transdermal fentanyl, lorazepam, midazolam, morphine sulphate, and oxycodone.[13]

Clinical nurse specialists provide support to people with cancer and other life-limiting diseases and their families. These specialists are nurses with specialized knowledge and competencies in cancer and PC. In addition to giving information and advice on pain control, symptoms, and psychological support, they provide information on the disease and its management, as well as planning future care, which would correspond to our SCP.[13]

Canada, follows a similar model to that of other English-speaking countries, recognizing the clinical nursing specialist in PC, who can coordinate with generalist nurses to offer advice and support in evaluating and treating complex symptoms, ethical challenges, family problems, psychological distress, etc.[13]

In Latin America, there is a lot of heterogeneity in the credentialing and certification of PC nurses. While some countries require specific certification to work in PC services, other countries have no formal recognition of this type of care, according to the Atlas of Palliative Care in Latin America 2020.

The World Health Organization (WHO) highlights that political will is a decisive factor in ensuring the adequate care of people with palliative or end-of-life needs, given that this responsibility cannot fall solely on families and on the vocation of some professionals.[14]

In Spain, the care model was outlined in the National PC Plan and clearly defined in the PC Strategy of the National Health System and culminated with the publication of the Pediatric Palliative Care Strategy of the National Health System in 2014.[10]

The model is based on two levels, basic and advanced, which cover care in the community and hospitalization. Both levels are fundamental to the success of care in

advanced disease and end-of-life care. PC needs can be grouped into three categories: non-complex, complex, and highly complex.[15]

Non-complex needs should be covered by basic care resources; complex needs should be analyzed by specific PC care teams who should decide if they need an advanced resource; and highly complex needs, according to the evidence consulted, should be met using advanced resources in PC.[15]

As we have shown, the objective of the PC is to improve the quality of life of people with palliative needs and their families. To provide this care, nurses carry out an ethical and humanized practice, promoting the best possible level of care, providing quality of life and a dignified and peaceful death process. Any intervention must always be carried out with respect for shared decision-making with the person receiving care.[13]

Various studies highlight the need for early PC during life-limiting illnesses, with care intensifying as the disease progresses and curative options are no longer available, continuing through the end of life with the aim of ensuring well-being.[16]

To carry out this care, PC is conceived in multi- and interdisciplinary teams composed of physicians, nurses, psychologists, and social workers, among others. Such teams make it possible to address the multidimensionality of the person. This type of care brings together science and art to give a structured response to human suffering related to the stage of life in which death and the process of dying enter our personal story.[16]

The nursing skills curriculum in PC should be part of the corresponding professional accreditation systems, as a way toward excellence in the professional practice of nursing.[13,17-19] We cannot forget that there is still no formal academic regulation of specific knowledge due to the relative newness of this care discipline. In this case, the premise is that academic regulation does not go hand in hand with social and health needs, there being a gap that is usually covered with continuous training.

Nursing interventions in PC share some key aspects, such as the promotion of self-care, the relationship of trust and security, emotional support, touch, listening, comfort,

compassion, respect, and presence, which have been called “invisible” care interventions. As a result, the positive effects of these interventions on patients are not acknowledged or attributed to the quality of nursing care. Furthermore, this lack of recognition hinders the visibility of nurses’ contributions in clinical settings, undermines their professional standing in society, and limits their representation in the media.[13]

In 2005 and early 2006, the SECPAL Nursing Collective made a series of significant changes in its organization, structure, and internal and external functioning, trying to modernize and give impetus to the development of the profession in PC. As a culmination of these efforts, Spain’s first specialized Nursing Conference on Palliative Care was held in Madrid on December 1, 2006. Organizers stressed the objective set in recent years for this discipline: the professional recognition and formalization of a specific competency area and regulated training, following the example of countries such as the United Kingdom, Canada, the United States, and Australia, where PC nursing has a specific and standardized body of knowledge.[13]

As a result of this effort to develop the area of knowledge and specific training, the Spanish Association of Nursing in Palliative Care (AECPAL) was founded, under the Spanish Society of Palliative Care (SECPAL). The AECPAL maintained, on the one hand, the autonomous character of the nursing profession, and on the other, the interdisciplinary character of PC.

Among the AECPAL’s primary objectives is the development of its own body of knowledge and a specific training curriculum for nurses who are experts in PC in Spain. This curriculum aims to offer a framework for the training of nurses in PC, which should be part of the corresponding professional accreditation systems, as a pathway toward excellence in professional nursing practice.

Currently, PC for all professionals on the interdisciplinary team faces the challenge of a lack of structured specific training.

However, there are already defined formulas that accommodate accredited training and demonstrable professional experience to ensure quality of care. The uniqueness of nursing care and the specific areas of nursing knowledge address both patients and their families. PC nursing is interconnected with the disciplines of palliative medicine, psychology, and social work, as well as with nursing specializations that care for people

with palliative needs.[17]

Regarding academic training in the Bachelor of Nursing, according to the data collected for 2016-2021 and published by the Ministry of Science, Innovation, and Universities, of the 118 Spanish universities that offer the Bachelor of Nursing (91 public and 37 private), 60% offer PC as a subject, and 48% include it as a degree requirement. As for the autonomous communities that offer the subject as either compulsory or optional, within a range of 3 to 6 ECTS credits, the trend has remained unchanged from 2016 to the present.[17]

Because access to PC training in the bachelor's degree is uneven across Spain, there has been a proliferation of postgraduate training, such as expert courses and master's degrees, which are often the only specific training channel open to professionals interested in PC. Many units and teams are working on research and development for specific methods and working models. Gradually, they are succeeding in establishing basic and advanced training opportunities that enable professionals to attain a solid level of preparation in PC. There is consensus regarding the need to incorporate this knowledge into curricula to prepare people wishing to work in this field.[17]

Finally, within the framework of the National Strategy for the Development of Palliative Care, the Quality Agency of the Ministry of Health, in coordination with the Interterritorial Council, has completed consensus documents such as the National Health System's Palliative Care Strategy and Pediatric Palliative Care Strategy. Legislative proposals with the same goal—advancing PC and ensuring equity—are also being discussed.[10,11]

Since its first deliberations, the technical committee found consensus between scientific societies and Spain's autonomous communities on the need for specific training of physicians, nurses, and psychologists in PC. This document has become a point of reference for all autonomous communities, setting out basic recommendations for the uniform and coordinated development of this discipline, with the aim of eliminating the existing territorial disparities. The document's objectives and recommendations establish that this training and experience is a requirement to fill positions of specific PC teams or support while an area of specific training is developed under the Law on the Regulation of Health Professions.[1,3,10,11]

The urgency in defining a body of knowledge in PC nursing has also been addressed by expert groups within the European Association for Palliative Care (EAPC)[19] and in

relation to the different levels of PC training, where it is recommended that the curriculum include training in this field in the Bachelor of Nursing, as a first level of PC training. A second level of training will be advanced specific training.[19]

In addition, if we consider that according to the WHO, this area of care is a central part of health services, we must review the specific role of the nurse as an advanced practice nurse in PC both in pediatrics and in adult care.[19] In Spain, the national strategy for PC recommends the training of future nurses in undergraduate and postgraduate training for professionals working in this field, but such training lacks a consensual competency map.

Rationale

4

4. RATIONALE

The nursing group dedicated specifically to PC has been a co-protagonist in the birth and development of this care modality since its beginnings in Spain in the 1980s.[13] Already at this time, nursing played a fundamental role in its development. It was nurses who identified the gaps in supportive care and appropriate treatment for individuals whose illness no longer responded to curative therapies, yet who were not receiving adequate symptom management. These patients were often undertreated by both the healthcare system and the professionals themselves. Nurses continue to promote the implementation of specific healthcare resources throughout the national health system.

It is no coincidence that the definitive impetus for PC came from a professional in England, Cicely Saunders, whose vision as a nurse must undoubtedly be highlighted, in addition to her training as a social worker and, later, as a physician. In the 1960s, she was able to catalyze all the initiatives aimed at implementing care structures for people in need of PC, initiating the hospice movement that still endures today. Due to the constant demand to meet these needs, the philosophy of PC is strengthened, as the nature and specificity of this type of care are essential to ensuring the quality of life of patients and their families. Within this care model, the family is actively included in the planning of care, becoming itself a focus of attention before, during, and after the patient's death. This is especially relevant in the pediatric setting.[13]

Many of Spain's pioneers in PC were trained in English hospice centers, and in 1992 they formed SECPAL as a multi-professional scientific society. The goal of SEPCAL was to highlight the interdisciplinary, collaborative teamwork necessary for the care of people with advanced and end-of-life disease, as well as their families.

On December 18, 2000, the Plenary of the Interterritorial Council of the National Health System approved the National Palliative Care Plan[9], establishing the foundations for its development. The goal was to guarantee the right to care for people with advanced and/or end-of-life conditions, in any place, circumstance, or situation. The general objective of the plan was to improve the quality of life of people in the situation and their families, in a rational, planned, and efficient way, guaranteeing PC according to the guiding principles of the National Health System:

- Offering coverage that responds to needs, preferably with public funding
- Promoting coordination between healthcare levels and available resources
- Ensuring equity, regardless of the type of disease or area of care
- Providing quality, effectiveness, and efficiency in the use of resources
- Achieving the satisfaction of patients, families, and professionals

In 2007, the Interterritorial Council approved the first Palliative Care Strategy of the National Health System. Between 2010 and 2014, the plan was updated because of a joint and consensual effort involving the Ministry of Health, Social Policy, and Equality and Spain's autonomous communities, scientific societies, and patient associations.[10] This strategy aimed to improve PC and strengthen the cohesion of Spain's health system for the benefit of its citizens. Specifically, the plan aimed to regulate the exercise of individuals' rights during the dying process, the duties of healthcare professionals caring for these patients, and the guarantees that healthcare institutions are obligated to provide throughout this process.

Ten autonomous communities have approved the Law on the Rights and Guarantees of the Person in the Process of Dying. The pioneer was Andalusia (Law 2/2010), followed by Navarre (Regional Law/2011), Aragon (Law 10/2011), the Canary Islands (Law 1/2015), the Balearic Islands (Law 4/2015), Galicia (Law 5/2015), the Basque Country (Law 11/2016), Madrid (Law 4/2017), Asturias (Law 5/2018), and the Valencian Community (Law 16/2018). [20]

Since its inception in 2005, AECPAL has embraced and promoted professional responsibility by advocating for the competencies required for the clinical practice of PC nurses, as the result of both theoretical training and clinical experience. This has involved constant feedback between education (undergraduate, specialist, and/or master's level) and PC practice, as well as professional growth through the application of these competencies in PC practice.

The PC nurse is an essential member of the multi- and interdisciplinary team who collaboratively integrates palliative practices throughout the person's disease process, promoting quality of life and contributing to reduce the fragmentation of care, as well as

intervene with the appropriate care and treatment for the comfort of people with advanced and/or end-of-life conditions and that of their relatives.

At the same time, this multidisciplinary approach must always be based on reciprocal respect for the competencies of all health professionals involved in the health care process, as stated in current Law 44/2003, of November 21, on the organization of health professions.[21]

Designation of Professional Profile

5. DESIGNATION OF PROFESSIONAL PROFILE

The PC nurse works with people who have advanced chronic conditions and a limited life expectancy, as well as their families, providing care at home, in nursing and residential facilities, in schools, and in hospitals.[22]

The nurse in the field of PC is integrated into and works within the framework of the principles of multidisciplinary and cross-disciplinary collaboration, with full respect for the competencies of each healthcare professional who makes up the team.

Accreditation Diploma in the Functional Area of Palliative Care regulated by Order SND/1427/2023, of December 26[22].

The Accreditation Diploma (AD) in the Functional Area of Palliative Care for nursing recognizes training completed to care for patients in complex situations across various health science fields, within a functional area that is notably transversal.

The added value that an AD in PC brings to the nursing discipline, compared to a bachelor's or specialty, should come from the experience and ongoing training the candidate has in symptom management, communication skills in complex situations, handling psychosocial conflicts, and making ethical-clinical decisions in the advanced stages of illness. It also stems from the holistic approach they apply to patient and family care through teamwork and shared decision-making, always respecting the values and preferences of patients and their families. The AD is valid for 5 years.

The specific competency domains that are established in the AD are:

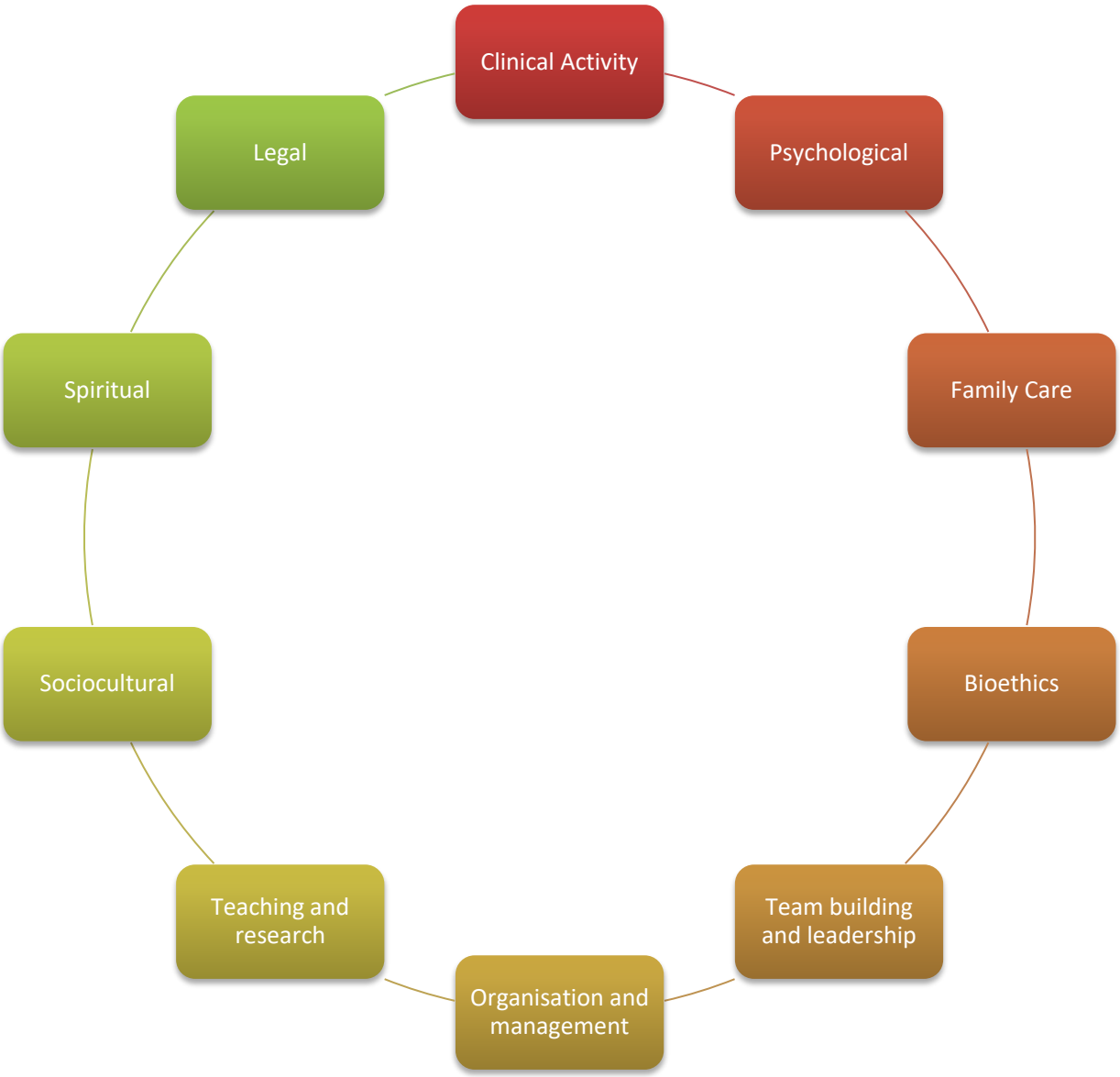

FIGURE 1. COMPETENCY DOMAINS OF THE NURSE IN PALLIATIVE CARE

Source: Authors.

The two possible access routes for obtaining an AD are as follows:

Exceptional procedure

The healthcare professional eligible for the diploma may exceptionally obtain the Accreditation Diploma in Palliative Care if, at the time this agreement comes into effect, they meet requirements A) and B):

A) Demonstrate, within the last ten years, a minimum of four years of full-time professional practice—corresponding at least to the standard working hours of statutory staff in public health services—in all tasks included within the competencies subject to accreditation, as part of their job role, with a positive performance evaluation duly certified by the corresponding healthcare institution within the National Health System according to its procedural regulations, or by an institution accredited by the autonomous community under the terms set out in Article 1.2 of Royal Decree 639/2015, of 10 July. Additionally, having worked in international health institutions will be valued.

- *If the activity is carried out on a part-time basis, an equivalent provision of services must be accredited.*
- *The professional practice must have been carried out in units or hospital or home-based PC support teams recognized by the responsible autonomous community or authorized PC units.*
- *Said certification will specify the dates on which the professional has satisfactorily performed the competencies subject to accreditation.*

B) Hold an official or university-awarded master's or expert degree in PC, offered by universities or healthcare centers that meet the conditions and requirements established by Organic Law 6/2001 of 21 December on universities, the regulations established by the autonomous community where they are located, and Royal Decree 640/2021 of 27 July on the creation, recognition, and authorization of universities and university centers, as well as the institutional accreditation of university centers.

Applications, addressed to the health administration where the applicant practices, may be submitted on a one-time and exceptional basis within six months following the publication by the responsible autonomous administration of the procedure for obtaining it, using the official form established for this purpose.

Ordinary procedure

The healthcare professional eligible for the diploma may obtain the AD in PC if they meet requirements A), B), and C):

A) Demonstrate, within the last ten years, a minimum of four years of full-time professional practice—corresponding at least to the standard working hours of statutory staff in public health services—in all tasks included within the competencies subject to accreditation, as part of their job role, with a positive performance evaluation duly certified by the corresponding healthcare institution within the National Health System according to its procedural regulations, or by an institution accredited by the autonomous community under the terms set out in Article 1.2 of Royal Decree 639/2015, of 10 July. Additionally, having worked in international health institutions will be valued.

- *If the activity is carried out on a part-time basis, an equivalent provision of services must be accredited.*
- *The professional practice must have been carried out in units or hospital or home-based PC support teams recognized by the responsible autonomous community or authorized PC units.*
- *Said certification will specify the dates on which the professional has satisfactorily performed the competencies subject to accreditation.*

B) Provide evidence of having acquired, within the last five years, the competencies defined in the AD in PC through various training activities accredited by the Continuing Education Commission for Health Professions or by accrediting systems recognized by the health scientific community, specifically related to the knowledge, skills, and attitudes outlined in the competency framework required for obtaining the AD. The minimum credits for each domain and profession must be met.

C) Provide at least two of the following types of evidence, from the last five years, demonstrating the acquisition of the competencies defined in the AD related to domain 7 (teaching and research), through various activities specifically linked to the knowledge, skills, and attitudes outlined in the competency framework required for obtaining the AD:

- *Teacher in accredited continuing education activities or in regulated training activities: 1 credit for every 10 hours of activity carried out.*
- *Tutor in refresher or training stays: 1 credit for each month completed.*

- *Participation in articles published in indexed journals, books, or monographs.*

    - *For each article published in an indexed scientific journal related to the activity: 0.5 credits.*
    - *For each article published in a non-indexed scientific journal that does not fall within the previous section, as well as articles from professional associations' journals: 0.05 credits.*
    - *For each scientific talk or poster, presented at a congress or scientific conference on a topic related to the category chosen, certified by the organizing body: 0.25 credits.*

- *Participation in research projects: 0.5 credits as principal investigator and 0.25 credits as collaborating researcher.*

Definition of Professional Profile

6. DEFINITION OF PROFESSIONAL PROFILE

In 2024, the expert group on nursing competencies in PC of the AECPAL proposed the definition of palliative nursing as a nursing training area that develops and provides PC to people of any age with advanced, complex chronic diseases and in end-of-life situations, also extending such care to their families and during the grieving process.

The main objective of palliative nursing is to prevent and relieve suffering through a humanized, holistic, and interdisciplinary approach to care, respecting each person's values, beliefs, and preferences, while considering their autonomy and human response to their life process.

Basic elements of the performance of PC nurses[13]

Identify multidimensional needs of the person and family

The proposed model of needs is based on their multidimensional nature, allowing for the exploration and identification of relevant aspects within each dimension. Multidimensional assessment facilitates the approach to needs and their prioritization, requiring revision adapted to the evolution of the process.

Practice a competent PC model

Once needs have been identified, it is advisable to apply a PC model of competence or excellence, based on basic competencies (clinical, communicative, ethical, planned care, continuous care and, finally, case management), responding to the person's core needs (spiritual and transcendent, dignity, respect and hope), incorporating the family and practicing appropriate activities and behaviors (empathy, congruence, trust, and honesty).

Develop a multidimensional and systematic therapeutic plan

Once the needs of each dimension have been identified and evaluated with greater or lesser complexity, elaborate the objectives for each one according to the values and preferences of the person and/or family.

Once the objectives for each dimension have been established, a systematic care plan can be implemented and follow-up can be initiated, with the necessary evaluation and monitoring.

Follow-up and review: This process is continuous and should be carried out as often as the situation requires.

a. Basic assessment and records

Assessment of the patient's condition: Both intensity/severity criteria and progression criteria must be considered, as they provide complementary perspectives; the former reflecting the seriousness of the condition, and the latter its dynamic evolution. Some assessment proposals would include:

1. Functional status:
    a. Karnofsky performance status
    b. Palliative performance status
    c. Barthel
    d. Evolution over time of the loss of activities of daily living (degree of functional autonomy)
    e. Lansky (< 16 years)
2. Nutritional conditions:
    a. Mini Nutritional Assessment (MNA)
    b. Subjective Global Assessment (GGA)
    c. Albumin
    d. Weight loss over time
    e. Weight/height ratio (percentile calculation) in pediatrics
3. Cognitive status:
    a. Mini-Mental Status
    b. Pfeiffer Test
4. Mood or emotional distress:
    a. Verbal Numerical Scale for Mood (VNS) 0–10
    b. Detection of Emotional Distress Scale

Symptom assessment: The Edmonton Symptom Assessment Scale (ESAS) is proposed. For daily assistive practice, verbal or categorical numerical scales are recommended. For pain and some symptoms, there are specific validated scales.

b. Basic questions, enabling identification of individuals' perceptions and concerns

In the pediatric setting, these questions can be posed to the child, with language adapted to their age and comprehension, provided that they are a cooperative patient. If not, we will speak with the child's parent(s)/legal guardian(s). These questions must be used in the context of a trusting therapeutic relationship. Some examples:

Information and understanding of the situation: "What do you think about your illness and its evolution?"

Concerns: "From what we have talked about the evolution and the future, what things are you most concerned about?" "What would you like us to know about you so we can help you better?"

Questions and pending issues: "From what we have talked about, do you have any questions?"

Expectations and requests: "What would you like us to do for you?" "How could we help you?"

c. Review of illness status and treatment

The condition of the illness, treatment goals, and indications for specific therapies, assessing:

Disease status: degree, stage, etc.

Predictable prognosis

Probability of response to specific treatment

Balance between effectiveness, response, toxicity, and tolerance to treatment

Predictable evolution: decompensation, crises, etc.

Review medication

Patient and family expectations

Identify values and preferences of the sick person:

Respect for the values and preferences of the person is a key requirement for making decisions. Ethics applied to clinical decision-making, respecting people's values and preferences. The advanced decision-making (ADM) process or the currently more commonly used concept of SCP is a voluntary, structured process of discussion about future care between the healthcare professional, the person, and their close circle, if applicable. Its purpose is to identify their values and preferences, establish agreed-upon and shared care goals, and adapt these to current needs and foreseeable future scenarios.

The objective of ADM is to work together with the sick person, caregivers (family members) and health professionals to develop a care plan consistent with the objectives, values, and preferences of the person.

It includes discussion about diagnosis, the prognostic situation, treatment preferences and care setting, the level of information the person wants, their desired degree of involvement in decisions and treatments, and which people they wish to have participate in this process.

To achieve this, it is necessary to have adequate communication skills, accurate information about the prognosis, as well as knowledge of and interest in the person's concerns, values, principles, and culture.

Involve family and primary caregiver

The family or emotional-relational support network should be considered as a unit of care and be involved in the care process, with their participation encouraged while avoiding feelings of excessive responsibility that could lead to burnout.

Perform case management, follow-up, continuous and urgent care, coordination, and integrated service actions

This process consists of including appropriate resource recommendations in the therapeutic plan for follow-up, with a focus on preventing the common crises that occur in people with advanced illnesses and limited life expectancy, as well as the coordination or integration of services to ensure appropriate care, quality, and efficiency.

The essential components are assessment, followed by the therapeutic plan and, finally, the follow-up plan. It is essential to make decisions and share information at all times with patients and caregivers.

Objectives for Palliative Care Nurses

7. OBJECTIVES OF THE NURSE IN PALLIATIVE CARE

a. General objective

- Provide, ensure, and administer the quality nursing care needed by a person in the advanced stages of illness and with a limited life expectancy, including the final days, aiming to achieve the highest possible quality of life for them and their family

b. Specific objectives

- Design, plan, implement, and evaluate evidence-based care programs and plans focused on supporting people with advanced illness and/or at the end of life, as well as their families
- Generate and promote the training of future nurses and experienced nurses and other health professions for the care of patients at the end of life, as well as their families
- Carry out and maintain different lines of research aimed at improving the care of people in this situation and their families
- Manage end-of-life processes in hospital, residential, nursing, and home settings
- Make and promote improvements in the management of the different devices and resources that serve people with advanced diseases and limited life expectancy and their families, to ensure their equity, efficiency, ethics, and orientation of care
- Guarantee the rights of people with advanced illness and/or at the end of life, with limited life expectancy, and their families to live at this final stage with the highest possible quality and comfort and with minimal suffering

Determination of professional profile

8. DETERMINATION OF PROFESSIONAL PROFILE

Both Annex VIII of Royal Decree 1093/2010, of September 3, which approved the minimum data set for clinical reports in the National Health System[23], and Royal Decree 572/2023, of July 4, which modifies it, specify the context in which nursing actions must be carried out using appropriate professional language, explicitly including the classifications of diagnoses relevant to this field.

We highlight the NANDA-I diagnoses of the thirteenth version and latest edition in English (2024-2026)[24] that are most common in the professional practice of nursing or in the field of PC. These NANDA-I diagnoses describe a need that requires nursing care and is also perceived by the patient and their family. Some are not exclusive to PC and therefore do not differ from those addressed in care management, with the complexity of the situation determining whether they should be managed within PC.

The most characteristic NANDA-I diagnoses in PC are indicated below. This list of diagnoses is not exhaustive, and there are many others related to the care of people in PC. In this regard, the AECPAL Care Plans Working Group published the third edition of a consensus document in 2021. Its aim was to provide a practical tool that facilitates the use of a common language through nursing taxonomy, unifying decision-making and actions to better fit clinical practice. It should serve as a reference for all nursing professionals who care for patients with PC needs. Moreover, it facilitates the evaluation of results to provide specific lines of research, quality monitoring in the care process and evidence-based practice, and safe and consensual practice.[25] Table 4 presents the diagnostic labels in NANDA Palliative Care edition 2024-2026:

TABLE 4. NANDA DIAGNOSTIC LABELS IN PALLIATIVE CARE-I[24]

Code	Diagnostic label
00128	Acute confusion
00132	Acute pain
00129	Chronic confusion
00235	Chronic functional constipation
00133	Chronic pain
00298	Decreased activity tolerance
00297	Disability-associated urinary incontinence
00497	Disrupted body image
00366	Excessive caregiving burden
00399	Excessive death anxiety
00477	Excessive fatigue burden
00390	Excessive fear
00026	Excessive fluid volume
00475	Excessive loneliness
00007	Hyperthermia
00091	Impaired bed mobility
00342	Impaired end-of-life comfort syndrome
00424	Impaired fecal continence
00344	Impaired intestinal elimination
00045	Impaired oral mucous membrane integrity
00380	Impaired physical comfort
00379	Impaired psychological comfort
00046	Impaired skin integrity
00052	Impaired social interaction
00454	Impaired spiritual well-being
00103	Impaired swallowing

00051	Impaired verbal communication
00421	Inadequate fluid volume
00325	Inadequate self-compassion
00538	Inadequate social support network
00031	Ineffective airway clearance
00032	Ineffective breathing pattern
00352	Ineffective dry mouth self-management
00372	Ineffective emotion regulation
00397	Ineffective fatigue self-management
00276	Ineffective health self-management
00384	Ineffective nausea self-management
00418	Ineffective pain self-management
00055	Ineffective role performance
00337	Ineffective sleep pattern
00405	Maladaptive coping
00373	Maladaptive family coping
00301	Maladaptive grieving
00175	Moral distress
00243	Readiness for enhanced emancipated decision-making
00185	Readiness to enhance hope
00173	Risk for acute confusion
00303	Risk for adult falls
00039	Risk for aspiration
00306	Risk for child falls
00299	Risk for decreased activity tolerance
00440	Risk for disrupted family interaction patterns
00374	Risk for excessive bleeding
00401	Risk for excessive caregiving burden
00335	Risk for excessive loneliness
00488	Risk for impaired human dignity
00247	Risk for impaired oral mucous membrane integrity
00047	Risk for impaired skin integrity
00491	Risk for impaired water-electrolyte balance

00407	Risk for ineffective sleep pattern
00004	Risk for infection
00302	Risk for maladaptive grieving
00482	Risk for situational inadequate self-esteem
00322	Risk for urinary retention
00481	Situational inadequate self-esteem

Nursing Practice Framework in Palliative Care

9. NURSING PRACTICE FRAMEWORK IN PALLIATIVE CARE

Organizational concepts to frame competency development

The actions and interventions of the nursing professional in this field are carried out within their scope of competencies, in accordance with their *lex artis*, framed by the principles and values contained in the legal and ethical regulations, and with full respect for the competencies of the other professionals involved in the entire care process.

It is necessary to consider interdisciplinarity with other health professionals involved in the field of PC, as we find ourselves with shared areas of expertise as recognized by current regulations. Therefore, PC nurses carry out their practice within a multidisciplinary context, sharing fundamental principles that underpin excellent PC.

According to Patricia Benner's model[26], nurses acquire skills throughout their professional development, becoming increasingly expert in a specific area within their scope of practice. In this case, these are nurses who have reached the highest level of proficiency in PC, based on scientific evidence, clinical judgment, and critical thinking. First, ten specific skills that the nurse must develop are described (fig. 1), as well as the necessary skills for said competencies.[22,27,28]

*1- **Critical and self-critical capacity:** Attitude to develop and use critical thinking based on scientific evidence of PC*

*2- **Empathy:** Cognitive ability to put oneself in the person's place and understand their feelings*

*3- **Active listening:** Ability to communicate and listen attentively to the person and their family members to positively influence their approach to the process*

*4- **Resilience:** Nursing competence in routine clinical practice that improves the ability to successfully face professional challenges despite adverse circumstances in the provision of PC*

*5- **Accessibility:** PC nurses must be accessible to people and responsive to their needs, providing timely care that supports the quality and sustainability of the healthcare system*

*6- **Teamwork:** Encourage joint work where all members of the multidisciplinary team are important for the health of the person*

*7- **Interpersonal skills:** Acquire skills for caregiving such as dexterity, self-confidence, the ability to build trusting relationships between people, and teamwork to improve the effectiveness of outcomes in PC within a transcultural nursing context with diverse individuals*

*8- **Ethical commitment:** Engage in the rational study of morality and the good life by providing PC aligned with the needs and beliefs of individuals*

*9- **Organizational skills**: Plan how time will be used at work to increase efficiency in PC*

The fundamental principles of PC nurses should also be considered. These principles are personal and professional qualities based on core values, communicated through attitudes and behaviors, which patients and families recognize as clear signs of commitment and excellent care:

Dignity

This practice consists of the application of a methodology of excellence in communication, focused on dignity and its promotion and recognition.

Spirituality

There are various instruments for the evaluation of aspects of values and beliefs, needs and intervention models.

Hope

The maintenance of hope is a key element for adaptation to the evolutionary process. It is a highly variable process, in which the objective of the intervention is to help reformulate the objectives and expectations and adapt them gradually and flexibly to the situation and the evolution of the process.

Autonomy

Whenever possible, we will try to anticipate decision-making, based on knowledge of the values, objectives, preferences, and decisions of the person in our therapeutic relationship, and systematizing their incorporation into decision-making, taking into account that it must always be updated in the face of a new situation. In pediatrics, parents are responsible for medical decisions when a child under 16 years of age (health age of majority) is involved. Whatever the patient's age, we should always listen to their opinion, preferences, and values.

Affection

In the advanced processes and end-of-life process, the family is the most important resource for the sick person and also as a unit to be cared for. The fundamental objectives of PC with respect to the family will be to provide support and education that allow the best emotional adaptation to change and loss, to train to care and respond to their emotional and practical needs, to promote communication and the functions of affect, and to provide the necessary means for their practical capacity to care. Signs indicating potential caregiver overload should be identified and monitored.

Other values

Hospitality, Empathy, Compassion, Commitment, Trust, Consistency, Presence and Honesty.

Regarding the **cross-cutting competencies** of PC nurses, these are the skills that any nurse should incorporate into their practice, with particular emphasis on teamwork and digital competencies. The most relevant characteristics for PC nurses are detailed below:

TEAMWORK

The transdisciplinary model, beyond coordination and cooperation among different professions, requires them to integrate with one another, blurring disciplinary boundaries in order to achieve common goals, while fully respecting the scope of practice of each profession. This is possibly the model most in line with PC, because it focuses on the needs of people in advanced disease processes and their families, and not on the tasks or functions of professionals, to:

- Provide the team with the identification of altered daily-living needs of the person and family in the process of advanced illness and end of life, so that decision-making can be as holistic and individualized as posible.
- Establish a comprehensive work plan as a team. The team is a learning space and a generator of knowledge.
- Encourage the participation of the team in the planning, design, establishment, development, and assessment of the team's objectives.
- Encourage team self-care with specific spaces and times as a tool to maintain the necessary balance to carry out interventions with individuals and families, as well as with the team members themselves.

DIGITAL TECHNOLOGIES

Within this framework, the conscious, safe, and critical use of information and communications technology (ICT) is necessary in the field of PC and requires an open mindset to fully understand the meaning of these care practices. In addition, it is essential in areas such as case management and telecare.

- Know the digital ecosystem and obtain the basic skills to properly and safely use the available digital devices and applications in the field of PC.
- Maintain a person-centered approach and use technologies as support, ensuring the personalization of care and humanized treatment.
- Know the different sources of health data and know how to process them to extract knowledge and results in real time that facilitate clinical decision-making in the field of PC.
- Manage the large amount of information generated by selecting valuable content and teaching people and families with advanced chronic conditions to be able to select information wisely.
- Use technologies, devices, and digital channels appropriately to enhance networking, communication, and remote training among healthcare professionals involved in PC.
- Implement ICT to facilitate and enhance research and scientific publication 2.0, as well as the design and production of digital health content on PC.
- Manage the digital tools and resources that facilitate the development of interdisciplinary projects and remote health care in collaboration with different health agents, including people and families with advanced chronic conditions.

Finally, we highlight the **specific competencies of the PC nurse** by presenting the classification of competencies based on the International Council of Nursing model, adapted to nursing practice in PC[29]:

RESPONSIBILITY, ETHICS, AND DEONTOLOGY

The PC nurse, within their professional responsibility, must be able to anticipate the outcomes of care and support and ethically justify their actions by developing the following competencies:

1. Responsibility, ethical and legal standards

- Be familiar with current legislation related to end-of-life care. Law 41/2002, of November 14, basic regulation of patient autonomy and rights and obligations regarding information and clinical documentation. Regional laws that develop it. Legal aspects related to the death of the patient and the ethical guidelines that affect the professional practice of PC.
- Understand the common service portfolio of the National Health System and the laws governing the healthcare system, including the interactions between its components relevant to PC, within the overall health policy of the State.
- Respect the values, lifestyle, and beliefs of the person, as well as sociocultural diversity at the end of life, throughout the care process; adapting care and fostering an environment where the person and their family can carry out their rites and customs (interculturality).
- Understand the social reflection on concepts related to suffering and pain at the end of life: dignified death, appropriate limitation of therapeutic effort, refusal of treatment, palliative sedation, futile treatment, and euthanasia.
- Be familiar with Organic Law 3/2021, of March 24, regulating euthanasia, in force since June 25, 2021, and the mechanisms it establishes for the exercise of conscientious objection.[30]

2. Ethical practice

- Apply the general ethical and deontological principles of the nursing profession related to decision-making, care activities, and the support of people at the end of life
- Participate in team decision-making by contributing the identification of altered daily living needs, recognizing the complexity of the situation experienced by the person with advanced and/or end-of-life illness, and the need for a multidisciplinary approach to ensure decisions are as holistic and individualized as possible

- Recognize the vulnerability and fragility of people with advanced illness and at the end of life and, consequently, the need to actively ensure respect for their fundamental rights.
- Avoid the influence that their own beliefs and values can have on the provision of care, respecting the autonomy and privacy of the person in daily care and in making decisions at the end of life.
- Recognize sociocultural diversity at the end of life, favoring an environment where the person and their family can carry out their rites and customs.
- Protect the person's right to make decisions by ensuring they have the necessary information throughout the care process, adapted to their needs, receptiveness, and clinical condition, using oral and/or written consent and the advance directives document.
- Provide support to the family in respecting the person's values, while also helping the person exercise their autonomy in relation to their emotional, family, and care environment.
- Give priority to the person's wish to be informed and respect their right to refuse a proposed treatment or care, while emphasizing their right to continue receiving attention, treatment, and care.
- Maintain the principles of privacy, confidentiality, and dignity with the body after death.
- Protect confidentiality and professional secrecy by recognizing that the owner of the information (diagnosis, prognosis, evolution, treatment, and care) is the person, and information will only be shared with prior consent and as provided for by law.
- Promote the expression of the person's wishes in anticipation of foreseeable cognitive decline that may prevent them from speaking for themselves, ensuring their preferences are documented in their medical record and/or through the completion and registration of an advance directives document, if they are of age.
- Ensure implicit and explicit consent in situations of change of therapeutic orientation and palliative sedation.
- Provide an environment that facilitates the maximum cognitive and emotional competence of the person or their representatives for decision-making, including refusal of treatment, favoring specialized help if deemed necessary.

- Support the person in clarifying their values and motives and possible consequences and obtain specialized assistance if considered necessary in the context of a request for euthanasia.

CARE DELIVERY AND MANAGEMENT

The nurse in PC must be able to support the person through their experience of advanced illness and/or end-of-life by developing, implementing, and managing an individualized care plan, carrying out the following actions within the nursing care process:

1. Essential principles of care delivery and management

- Establish a communication process that promotes the development of personal resources and the caregiving ability of the person and their family during the adaptation to the end-of-life situation.
- Organize the care plan by identifying health problems and establishing priorities focused on the quality of the interventions related to the person's daily life and well-being.
- Know, adjust, administer, and safely evaluate specific care and treatments.
- Identify and integrate the primary caregiver of the sick person into the care process.
- Establish a specific care plan for the needs of the family group.
- Act as a mediator between the family and the sick person, facilitating their adaptation to the end-of-life process.
- Promote continuity of care by managing available community resources and establishing communication channels between all the health teams involved.
- Participate in and promote teamwork as a tool to address the complexity of care and support for people at the end of life.
- Use the available scientific evidence and apply its results throughout the care process.
- Participate in and promote debate on innovations and changes in care for people with advanced illnesses and at the end of life.

2. Health promotion

- Include in the care plan the planning of health education interventions according to the person's clinical situation, knowledge, personal resources, and previous experiences.
- Promote healthy lifestyles as much as possible during end-of-life processes, supporting the autonomy and well-being of the person and their family for as long as possible, while respecting their habits and customs.
- Adapt the environment to the changing needs of the person at the end of life using social, family, environmental, and material resources.
- Provide knowledge and skills that help the person to have maximum autonomy in the management of their end-of-life process.
- Help the person delegate their care and support to significant others based on progressive functional and/or cognitive impairment at the end of life.

3. Assessment

- Systematically assess the clinical situation and emotional or social risk using specific criteria or indicators.
- Determine the degree of dependence and functional impact of health problems derived from the end-of-life process.
- Assess the level of information and understanding the person and their family have regarding the person's life situation and life expectancy prognosis.
- Systematically evaluate the caregivers' organizational, emotional, and self-care capacities.

4. Diagnosis and Planning

- Define and prioritize nursing diagnoses with the person and family.
- Identify critical situations and promptly refer the case to other professionals when it exceeds the nurse's scope of practice.
- Activate specific end-of-life care protocols—such as pain management, care for delirium, support during the last days, post-mortem care, and bereavement support—along with relevant procedures and techniques (discharge, referrals, routes of administration, etc.), tailoring them to the individual person and their situation.
- Define outcome criteria and establish the schedule of activities according to the complexity of the situation of the person with advanced illness at the end of life.
- Include in the clinical record the nursing care plan and activities related to cooperation issues.
- Record the activation of specific techniques, protocols, and procedures used, noting the outcome criteria.
- Prepare the indications of care and treatment to promote self-care and/or the participation of the main caregiver and prepare the necessary graphic documentation.

5. Implementation

- Act according to the established plan, adjusting the activities to the changing needs of the person at the end of life and their family.
- Provide the necessary information and documentation to ensure the highest possible level of participation of the person and their primary caregiver in the care.
- Document and record changes to the interventions.

6. Evaluation

- Evaluate and integrate the results of the care plan interventions in relation to the objectives set out in the multidisciplinary therapeutic plan.
- Use the results of the evaluation to further individualize the care plan.
- Evaluate the outcomes of delegated interventions, techniques, protocols, and procedures used.

7. Therapeutic communication and interpersonal relations

- Use the therapeutic relationship as a supportive tool in all interactions with the person and their family, being mindful of the person's emotional vulnerability given their life circumstances. In pediatrics, pay special attention to involving siblings in the illness and care process.
- Respond to information needs and requests, integrating bad news as part of the communication process with the person and family.
- Encourage the expression of feelings and emotions of the person and family, in the different stages of the processes of loss and grief, without fear of being judged.
- Create an intimate therapeutic context that fosters communication.
- Support the family after death by identifying specific needs in the grieving process.

8. Safe environment, comprehensive care, and resource management

- Prevent risk situations through early detection, communication, and reporting safety issues to the appropriate authorities.
- Promote a flexible organization that is adapted to changing care needs.
- Establish criteria to assign the most suitable and competent nurse for care delivery, considering their expertise and/or emotional readiness in relation to the complexity of the situation.
- Apply quality and risk management indicators—addressing both actual and potential risks—tailored to end-of-life care.
- Provide specialized support to meet the needs and requests of professionals and teams from other levels of care involved in supporting the person and family at the end of life.
- Design specific care plans to support nurses from other levels of care in caring for people at the end of life.
- Establish protocols and intervention criteria between the different levels of care involved in managing advanced illness and end-of-life situations.

PROFESSIONAL DEVELOPMENT

The nurse in PC must be able to contribute to the development of professional nursing practice in the field of PC:

1. Professional commitment

- Be a reference point in the field of PC.
- Manage and contribute nursing knowledge in PC at all levels of care and support.
- Identify and analyze the political and/or institutional situation related to the care needs of people during the end-of-life process.
- Implement the necessary changes at the professional, institutional, and political levels aimed at improving care for people at the end of life.
- Assume ethical and legal co-responsibility in the comprehensive care of the person/family in end-of-life situations throughout the care process.
- Contribute to the social understanding of the end of life as part of the life cycle.

2. Quality improvement

- Know, develop, and apply indicators and quality standards for care plans for people at the end of life.
- Participate in the processes of evaluating and improving the quality of care for people at the end of life.

- Incorporate criteria of effectiveness and efficiency that ensure the best care, optimizing the available resources.
- Generate resources to respond to specific care needs with quality criteria.
- Apply and disseminate the conclusions and improvement proposals emerging from the analysis of healthcare quality evaluation results.

3. Teaching and continuing education

- Lead the nursing learning process in PC.
- Apply reflective learning about one's own practice as an element of continuous learning.
- Participate in the identification of training needs and collaborate in the development, implementation, and evaluation of teaching programs in PC for all health professionals.
- Participate as a resource for educating others about caring for people during the end-of-life process.

4. Research

- Identify and apply the best scientific evidence in the practice of PC.
- Identify priority areas and those eligible under current regulations governing research processes and develop research networks locally, nationally, and internationally.
- Consider the ethical issues underlying research with human subjects that arise from the vulnerability inherent in the end-of-life process, ensuring respect for the rights of the person as a research participant.
- Acquire the capacity for leadership, collaboration, and commitment to disseminate the results of nursing research in PC, which will allow the generation of new scientific evidence locally, nationally, and internationally.

Definition of the Minimum Training Content for Palliative Care Nurses

10. DEFINITION OF THE MINIMUM TRAINING CONTENT FOR NURSES IN PALLIATIVE CARE

The situations that nurses may experience in PC are an ongoing challenge for the development of their competencies in the practical, relational, and moral dimensions of care. For this they need knowledge, training, guidance, and support to fulfil their role.[17]

To ensure the proper training of nurses in PC, the minimum clinical practice time with specific resources considered necessary in this field is at least one year of professional experience.

To ensure proper training for those who will take on this role, the following **specific content** should be included, in which the nurse in PC should acquire in-depth knowledge:

Functional training, Management, and Organization of PC

- Principles and philosophy of PC.
- Organization of the National Health System and the resources of each autonomous community's strategy.
- Coordination between levels of care, information management, quality management

Specific Clinical Training for Nurses in PC

- Knowledge of advanced and/or end-of-life illness in both oncological and non-oncological patients
- Basic nursing care
- Pain care
- Care for other symptoms: digestive, respiratory, urogenital, neurological, psycho-emotional, etc.
- Care for systemic symptoms (asthenia, fever, etc.)

- Skin care: malignant wounds, lymphedema, etc.
- Care in the final days of life (person/family): recognition of the dying phase, bereavement support, specific management of the subcutaneous route, prevention of complicated grief, etc.
- Competence in specific techniques: infusion pumps, care of non-invasive and invasive mechanical ventilation, paracentesis, care of central venous access devices, etc.
- Care in palliative emergencies: spinal cord compression, vena cava syndrome, massive hemorrhage, hypercalcemia, etc.
- Pediatric PC

Psycho-emotional Needs in PC

- Communication with the sick person and family: adaptation to advanced and end-of-life illness, conspiracy of silence, decision-making, handling bad news, etc.
- Psychological response to advanced and end-of-life illness: emotional reactions (fear, guilt, sadness, anxiety), loss of autonomy, treatment-resistant pain and symptoms, etc.
- Attitudes and responses of professionals: influence of values and beliefs, skills, impact on the team, burnout, compassion fatigue, etc.
- Grief and support: adaptation to loss, identification of early grief and pathological grief, support for family and professional team

Sociocultural Needs in PC

- Family and sick people as a unit of care
- Main caregiver
- Family participation in decision-making
- Family burnout

Bioethics

- Inclusion of the four principles (beneficence, non-maleficence, justice, autonomy)
- Informed consent, principle of double effect, sedation
- Advance directives/living will/SCP

Cooperative Work and Leadership Management in PC

- Multidisciplinary team
- Relationship of the nurse to the rest of the team
- Group dynamics, nurse leadership
- Management of meetings, objectives, and group procedures
- Negotiation and conflict resolution
- Burnout: prevention, early detection, improvement strategies

Training and Teaching in PC

- Teaching methodologies: design and development of teaching projects
- Preparation of clinical sessions
- Dissemination and presentation of training projects
- Bibliographic search and critical reading

Research in PC

- Application of evidence in the care of people in the PC program
- Research topics and trends in PC and related disciplines
- Ethical and legal dimensions of research: clinical practice guidelines
- Good practices, Declaration of Helsinki and complementary

Spiritual Needs in PC

- Individual spirituality, and what the illness and its life-threatening nature entail
- Ability to explore spiritual and transcendence needs
- Hope and PC, spiritual suffering

Legislation in PC

- Care at the end of life
- Regional and national PC plans, living will or advance directives, and SCP.
- Knowledge of the guidelines and codes of ethics
- Patient Autonomy Act
- Bureaucracy surrounding death, certificates, etc.

Challenges for Palliative Care Nurses

11. CHALLENGES OF THE NURSE IN PALLIATIVE CARE

PC is provided within a complex context that requires working with a multidimensional view of the person. Challenges include:

- Promoting the early identification of individuals in need of PC, recognizing their values and preferences, and making decisions that respect them; likewise, supporting their families by caring for them and designing and validating instruments that allow us to do so effectively and efficiently.

- Intervening in the drafting, development, and management of public policies with the aim of changing the conditions that produce inequality, given that politics is the most effective instrument nurses must regulate relations between citizens and especially establish the rights and responsibilities that derive from them.

- Promoting basic training in PC for nursing professionals from their undergraduate stage and for all professionals working in non-specialized PC settings and ensure intermediate and/or advanced training for professionals with partial or specific dedication to individuals and families with palliative needs.

- Promoting the creation and recognition of the figure of the PC nurse specialist, which will ensure excellent nursing care for people with advanced chronic illnesses and limited life expectancy and their families.

- Promoting the dissemination and equity of PC to people and families with palliative needs regardless of age, condition, or place of residence.

- Collaborating in the development of comprehensive PC policies and programs that respond to the needs of people with advanced chronic illnesses, from the early stages of their evolution, in all health and social services and responding to all their needs, including the psychological, social, and spiritual care of individuals and their families.

- Promoting PC as a fundamental human right, which includes multidimensional care, and which has as its fundamental objective to relieve suffering and provide support for all people with advanced illness, in all areas of care.

- Promoting the creation of a specific training area. As indicated in Order SND/1427/2023, of 26 December, which publishes the guidelines for the creation of an Accreditation Diploma in the Functional Area of Palliative Care[1].

Acronyms and Abbreviations

12. ACRONYMS AND ABBREVIATIONS

AD: accreditation diploma

ADM: advance decision-making

AECPAL: *Asociación Española de Enfermería en Cuidados Paliativos* (Spanish Association of Nursing in Palliative Care).

EAPC NVS: European Association for Palliative Care Numerical Verbal Scale

ESAS: Edmonton Symptom Assessment System

MNA: Mini Nutritional Assessment

PC: palliative care

SCP: shared care planning

SECPAL*: Sociedad Española de Cuidados Paliativos* (Spanish Society of Palliative Care)

SGA: subjective global assessment

TIC: information and communications technology

WHO: World Health Organization

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13

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Appendices

14

14. APPENDIX

RECOMENDACIONES PRÁCTICAS PARA LA IDENTIFICACIÓN Y LA APROXIMACIÓN PRONÓSTICA DE PERSONAS CON ENFERMEDADES CRÓNICAS AVANZADAS Y NECESIDADES PALIATIVAS EN SERVICIOS DE SALUD Y SOCIALES

NECPAL 4.0 PRONÓSTICO (2021)

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Càtedra de Cures Pal·liatives
UVIC·UCC
ICO - INSTITUT CATALÀ D'ONCOLOGIA

Con el apoyo de:

Generalitat de Catalunya
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Generalitat de Catalunya
Pla interdepartamental d'atenció i interacció social i sanitària

Figura 1. Instrumento NECPAL 3.1 «clásico»

Pregunta sorpresa (PS) (a/entre profesionales):
¿Le sorprendería que este paciente muriese a lo largo del próximo año?

▶ SÍ, me sorprendería → **NO es NECPAL** ▶ NO me sorprendería

"Demanda" o "Necesidad"	- Demanda: ¿Ha habido alguna expresión implícita o explícita de limitación de esfuerzo terapéutico o demanda de atención paliativa de paciente, familia, o miembros del equipo?
	- Necesidad: identificada por profesionales miembros del equipo
Indicadores clínicos generales de progresión - Los últimos 6 meses - No relacionados con proceso intercurrente reciente/ reversible	- Declive nutricional
	- Declive funcional
	- Declive cognitivo
Dependencia severa	- Karnofsky <50 o Barthel <20
Síndromes geriátricos	- Caídas - Úlceras por presión - Disfagia - Delirium - Infecciones a repetición
Síntomas persistentes	Dolor, debilidad, anorexia, digestivos...
Aspectos psicosociales	Distrés y/o Trastorno adaptativo severo
	Vulnerabilidad social severa
Multi-morbilidad	>2 enfermedades o condiciones crónicas avanzadas (de la lista de indicadores específicos)
Uso de recursos	Valoración de la demanda o intensidad intervenciones
Indicadores específicos de severidad/ progresión de la enfermedad	Cáncer, EPOC, ICC, y Hepática, y Renal, AVC, Demencia, Neurodegenerativas, SIDA, otras enfermedades avanzadas

Si presenta por lo menos 1 parámetro NECPAL: **NECPAL +**

INSTRUMENTO NECPAL VERSIÓN 4.0 2021

> *Checklist* de necesidades: Identificación de necesidades de atención paliativa para el enfoque paliativo situacional

1. Realizar una lista rápida de las dimensiones listadas.
2. Valorar si es necesario complementarlo con indicadores y parámetros más específicos o complejos.
3. Elaborar propuestas de mejora a corto plazo para responder a las necesidades detectadas.
4. Elaborar un plan terapéutico básico.

El resultado de este procedimiento nos permite identificar necesidades de atención paliativa y elaborar un plan terapéutico:

Acciones que se tienen que llevar a cabo para una atención integral a las personas identificadas

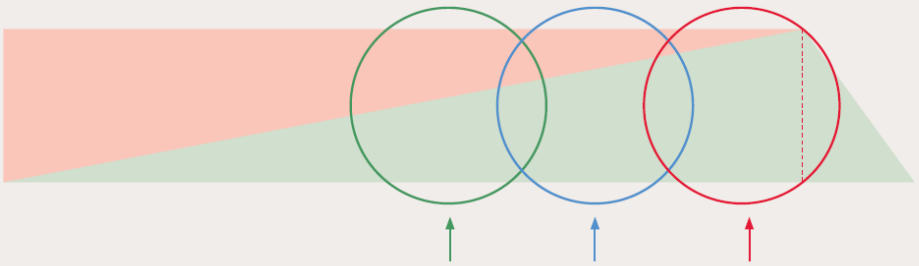
1. Llevar a cabo una evaluación multidimensional
2. Evaluar el estado de la enfermedad y de su posible evolución
3. Identificar los valores y preferencias e iniciar la planificación de decisiones anticipadas
4. Identificar y atender al cuidador principal
5. Identificar y ofrecer profesionales de referencia
6. Elaborar un plan terapéutico multidimensional
7. Gestionar los casos y llevar a cabo una atención integrada con otros servicios en el territorio

> *Checklist* situacional pronóstico:

• Identificación de riesgo • Pronóstico para enfoque • Pronóstico situacional

Enumerar los parámetros o factores positivos de valor pronóstico (necesidades paliativas identificadas, declive funcional, declive nutricional, multimorbilidad, aumento de uso de recursos y uso de los recursos específicos de enfermedad crónica). Consignar el número de parámetros afectados: 1-2, 3-4, o 5-6.

Estadio evolutivo: en función del número de parámetros pronósticos afectados, se pueden identificar 3 grandes grupos pronósticos o estadios evolutivos:



PS	Parámetros afectados	Estadio I	Estadio II	Estadio III
Pregunta sorpresa	• Necesidades identificadas • Declive funcional • Declive nutricional • Multimorbilidad • Aumento uso recursos • Indicadores específicos	• PS + 1-2 parámetros • Mediana: 38 meses	• PS + 3-4 parámetros • Mediana: 17.2 meses	• PS + 5-6 parámetros • Mediana: 3.6 meses

RECOMENDACIONES ADICIONALES

Metodología para la utilización asistencial

1. El pronóstico es uno de los elementos que conviene tener en cuenta. Siempre está asociado a las necesidades y demandas evaluadas.
2. El riesgo pronóstico se propone para grupos poblacionales que cumplen ciertos criterios. Hay que utilizarlo con prudencia aplicado a individuos, ya que desconocemos qué comportamiento pronóstico tendría en una sola persona perteneciente a un grupo.
3. Una vez establecido el riesgo pronóstico, dispondremos de un dato de carácter situacional evolutivo, que nos puede orientar para el enfoque terapéutico.
4. Es recomendable actualizarlo regularmente.

Beneficios y riesgos de la elaboración pronóstica individual

1. El beneficio más relevante de la evaluación pronóstica es contribuir al diagnóstico situacional y permitir redefinir algunos de los objetivos, activando, en su caso, un enfoque paliativo gradual.
2. Esta valoración debe ser compartida con el paciente y su familia, con el ritmo, intensidad y concreción que sean adecuados a la capacidad de adaptación.
3. El riesgo más relevante de la evaluación pronóstica consiste en la aplicación individual automatizada de un riesgo de carácter poblacional.
4. Se han contemplado otros riesgos, como las posibles pérdidas de oportunidades curativas, la estigmatización, etc., que han sido trabajados previamente con la implantación del NECPAL en fases iniciales.

Propuestas asistenciales relacionadas con las necesidades y el pronóstico de vida limitado

1. Llevar a cabo una evaluación multidimensional de necesidades: físicas, emocionales, sociales, espirituales, éticas y del final de la vida.
2. Evaluar el estado de la enfermedad y su posible evolución.
3. Identificar los valores y preferencias e iniciar la planificación de decisiones anticipadas.
4. Identificar y atender al cuidador principal.
5. Identificar y ofrecer profesionales de referencia.
6. Elaborar un plan terapéutico multidimensional.
7. Gestionar los casos y llevar a cabo una atención integrada con otros servicios en el territorio.

Edmonton Symptom Assessment Scale (ESAS) Tool

Name: _____

Phone Number: _____

Address: _____

Completed By:_____

Please circle a number that best describes how you feel

0	1	2	3	4	5	6	7	8	9	10
No pain										*Worst possible pain*
0	1	2	3	4	5	6	7	8	9	10
Not tired										*Very tired*
0	1	2	3	4	5	6	7	8	9	10
No nausea										*Very nauseous*
0	1	2	3	4	5	6	7	8	9	10
Not depressed										*Very depressed*
0	1	2	3	4	5	6	7	8	9	10
Calm										*Very anxious*
0	1	2	3	4	5	6	7	8	9	10
Not drowsy										*Very drowsy*
0	1	2	3	4	5	6	7	8	9	10
Normal appetite										*No appetite*
0	1	2	3	4	5	6	7	8	9	10
Best feeling of well-being										*Worst possible feeling of well-being*
0	1	2	3	4	5	6	7	8	9	10
No shortness of breath										*Very short of breath*
0	1	2	3	4	5	6	7	8	9	10
Other problem										

Adapted from: Cancer Care Ontario/ActionCancer Ontario. Available from: https://www.cancercareontario.ca/sites/ccocancercare/files/assets/CCOESAS-English.pdf

Mini Nutritional Assessment MNA®

Last Name _____First Name_____

Sex_____ Age _____Weight _____ Height _____ Date ____/_____/_____

Complete the screen by filling in the boxes with the appropriate numbers. Total the numbers for the final screening score.

Screening
A Has food intake declined over the past 3 months due to loss of appetite, digestive problems, chewing or swallowing difficulties? 0 = severe decrease in food intake 1 = moderate decrease in food intake 2 = no decrease in food intake
B Weight loss during the last 3 months 0 = weight loss greater than 3 kg (6.6 lbs) 1 = does not know 2 = weight loss between 1 and 3 kg (2.2 and 6.6 lbs) 3 = no weight loss
C Mobility 0 = bed or chair bound 1 = able to get out of bed / chair but does not go out 2 = goes out
D Has suffered psychological stress or acute disease in the past 3 months? 0 = yes 2 = no
E Neuropsychological problems 0 = severe dementia or depression 1 = mild dementia 2 = no psychological problems
F1 Body Mass Index (BMI) (weight in kg) / (height in m)^2 0 = BMI less than 19 1 = BMI 19 to less than 21 2 = BMI 21 to less than 23 3 = BMI 23 or greater

If BMI is not available, replace question F1 with question F2. Do not answer question F2 if question F1 is already completed.

F2 Calf circumference (CC) in cm 0 = CC less than 31 3 = CC 31 or greater ☐

Screening score
(max. 14 points)

12-14 points:	Normal nutritional status At
8-11 points:	risk of malnutrition
0-7 points:	Malnourished

Adapted from:

Vellas B, Villars H, Abellan G, et al. *Overview of the MNA® - Its History and Challenges*. J Nutr Health Aging 2006;10:456-465.

Rubenstein LZ, Harker JO, Salva A, Guigoz Y, Vellas B. *Screening for Undernutrition in Geriatric Practice: Developing the Short-Form Mini Nutritional Assessment (MNA-SF)*. J. Geront 2001;56A: M366-377.

Guigoz Y. *The Mini-Nutritional Assessment (MNA®) Review of Literature - What does it tell us?* J Nutr Health Aging 2006; 10:466-487.

Kaiser MJ, Bauer JM, Ramsch C, et al. *Validation of the Mini Nutritional Assessment Short-Form (MNA®-SF): A practical tool for identification of nutritional status.* J Nutr Health Aging 2009; 13:782-788.

Subjective Global Assessment Form

Patient name: _____ Date: ____/ ____ / _____

NUTRIENT INTAKE

1. ❒ No change; adequate
2. Inadequate; duration of inadequate intake _____

❒Suboptimal solid diet ❒Full fluids or only oral nutrition supplements ❒Minimal intake, clear fluids or starvation

3. Nutrient Intake in the past 2 weeks*
❒ Adequate ❒Improved but not adequate ❒No improvement or inadequate

WEIGHT

Usual weight _____ Current weight _____

1.Non fluid weight change past 6 months Weight loss (kg) _____

❒<5% loss or weight stability ❒5-10% loss without stabilization or increase ❒>10% loss and ongoing

If the above is not known, has there been a subjective loss of weight during the past six months?

❒ None or mild ❒Moderate ❒Severe

2. Weight change past 2 weeks* Amount (if known) _____
❒ No change❒Increased ❒Decreased

SYMPTOMS

(Experiencing symptoms affecting oral intake)

1.❒Pain on eating ❒Anorexia ❒Vomiting ❒Nausea ❒Dysphagia ❒Diarrhea❒Dental problems ❒Feels full quickly ❒Constipation

2. ❒ None ❒Intermittent/mild/few ❒Constant/severe/multiple

Symptoms in the past 2 weeks*

❒ Resolution of symptoms ❒Improving ❒No change or worsened

FUNCTIONAL CAPACITY

(Fatigue and progressive loss of function)

1.No dysfunction ❒

2.Reduced capacity; duration of change _____
❒Difficulty with ambulation/normal activities ❒Bed/chair-ridden

3.Functional Capacity in the past 2 weeks*
❒ No change❒ Improved ❒Decrease

METABOLIC REQUIREMENT

High metabolic requirement ❒ Yes ❒No

PHYSICAL EXAMINATION

Loss of body fat ❒No ❒ Mild/Moderate ❒Severe

Loss of muscle mass ❒No ❒ Mild/Moderate ❒Severe
Presence of edema/ascites ❒No ❒Mild/Moderate ❒Severe

SGA RATING

❒ A Well-nourished	❒B Mildly/moderately malnourished	❒C Severely malnourished
Normal	Some progressive nutritional loss	Evidence of wasting and progressive symptoms

Adapted from:

Duerksen DR, Laporte M. and Jeejeebhoy K. Evaluation of Nutrition Status Using the Subjective Global Assessment: Malnutrition, Cachexia, and Sarcopenia. Nutrition in Clinical Practice, 2021;36:942-956. https://doi.org/10.1002/ncp.10613

Baker JP, Detsky AS, Wesson DE, Wolman SL, Stewart S, Whitewell J, Langer B, Jeejeebhoy KN. Nutritional assessment: a comparison of clinical judgement and objective measurements. N Engl J Med. 1982;306(16):969-72. https://doi.org/10.1056/NEJM198204223061606.

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