POLICY AND PRACTICE FRAMEWORK FOR NURSES IN THE CONTEXT OF PALLIATIVE CARE

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POLICY AND PRACTICE FRAMEWORK FOR NURSES IN THE CONTEXT OF PALLIATIVE CARE

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1. Theoretical framework

According to the definition agreed by the International Association for Hospice and Palliative Care - IAHPC - in 2020, Palliative Care (PC) is defined as the approach which improves the quality of life of patients and their families facing the difficulties associated with potentially terminal illnesses, by means of the prevention and relief of suffering through the early identification, evaluation and excellence in the treatment of pain and other problems: physical, psychosocial and spiritual.

PC increases the quality of life of people with advanced illnesses with no option for remedial treatment. Benefits are obtained through the control of symptoms, which may be physical (pain, dyspnea, vomiting, etc.), or emotional (fear, anger, sadness, a desire to hasten death, etc.); as well as social support (management of social and/or community support, family involvement, etc.); and spiritual support (the meaning of life for each person and their significance, beliefs and values,etc.); taking into account prior planning of the attention to be given to the person.

Despite proven evidence of the effectiveness of PC, every year, according to data from Eurostat, in general only 50% of people in Europe who need PC, have access to it.

In Spain, in spite of the National PC Plan, initiated in 2001, and the most recent PC Strategy within the National Health System, published for the period 2010 - 2014, (yet to be updated), we are dealing with more than eighty thousand people eligible to receive PC, but not receiving it. According to the 2014 PC Strategy, among the under 20 Spanish population, in one year, around 1,200 children die from terminal illnesses, some 13,000 suffer illnesses which limit their lifespans, and around 6,000 of these need answers to their specific questions at a pediatric age about the end of life.

One of the most important structural reasons for this deficit in care is the lack of recognition of a speciality or area of specific knowledge in PC. Specific attention must be directed to the processes of advanced illness, uncertain prognosis and to the end of life, which seeks to satisfy needs identified by an integrated focus, on the person as well as their family, wherever they find themselves, either in their homes (individual or shared) or in hospital, and answers given to their current needs in whatever stage of life they find themselves.

In Europe, services specializing in PC are organized in multi- and interdisciplinary-teams, have advanced training, and complete dedication to the relief of suffering associated with potentially life-threatening pathologies, and/or the end of life. In general, they are found at all levels of care, wherever the person with these needs finds themselves.

Although in most European countries, training in PC is given, such teaching is not as a separate unit in most schools of Nursing, but rather is included as a module within another unit, except in France, Austria and Poland where it is taught as a specific compulsory subject. Only seven countries offer the possibility of clinical practice in a specific PC unit within the degree. Only Hungary, Iceland and Poland report having practical training in all the schools of Nursing in their countries.

All of this emphasizes the need to have a nursing profile to give this sort of attention, since its development during the degree studies is not sufficient as indicated by the PC European Atlas published in 2019. In this atlas it was pointed out that 15 countries do not offer teaching in this area during Nursing training and another 11 countries did not give information about their situation.

It is worth mentioning too that the beginning of modern PC came with the birth in the United Kingdom of the "Hospice" movement in 1930. This event marked the beginning of awareness of the importance of adequate symptomatic control for many people with advanced illnesses, the minimizing of aggressive treatments and unnecessary hospital admissions in the last months of life, and so improving the taking of shared decisions. Such attention must be given independently of the nature of illness, oncological or non-oncological, without consideration of age, place of residence, personal relationships, beliefs or background as laid down by the Worldwide Hospice Palliative Care Alliance (WHPCA, 2021).

The National Health Service (NHS) in England finances only a fraction of the palliative services in the United Kingdom, and the specialized admission units are largely financed by Non-Government Organizations (NGOs), for example Marie Curie Cancer Care and MacMillan Cancer Support, among others, which comprise the biggest support collective for PC in the country, as well as providing infrastructure and funding for care in centers or in homes. In these settings, nurses play a key role, being PC specialist nurses who carry out procedures which facilitate attention to and quality of life, including the prescription of medications and products according to the Nurse Prescriptor Form 2003, as well as a further list which as well as these medications includes a number of controlled drugs such as morphine.

The British National Formulary (BNF) allows nurses to prescribe within their area of specialization, and in the case of PC nurses point to the following medications: buprenorphine, diamorphine, diazepam, transdermal fentanyl. lorazepam, midazolam, morphine sulfate and oxycodone.

Clinical Nurse Specialists (CNS) or clinical nursing specialists in PC lend support to people who are suffering from cancer and other life-limiting illnesses as well as to their families. These specialists are nurses with specialized knowledge and competence in cancer and PC. As well as giving information and advice on pain control, symptoms and psychological

support to patients, they also provide information on the illness and its management, as well as planning future attention, which would correspond to our Shared Attention Planning.

In other countries, such as Canada, they take similar steps to those in the English speaking environment. recognizing Clinical Nurse Specialists (CNS) in PC, allowing them to coordinate with graduate nurses (GN), offering guidance, assistance in evaluating and treating complex symptoms, ethical challenges, family difficulties, psychological anxiety, etc., acting as specialists in these kinds of needs.

In Latin America, there is a great deal of heterogeneity in the degree structure and certification of nurses in PC. While some countries award specific certification in PC, and require this to be able to work with palliative resources, other countries have no no register of this type of care, according to the Atlas of Palliative Care in Latin America, 2020.

The World Health Organization (WHO) makes it clear that political will is a decisive element in guaranteeing adequate attention for people with palliative or end of life needs, given that this responsibility can not fall only upon families and the personal calling of some professionals.

In the Spanish setting, the model of care was profiled in the PC National Plan and clearly defined in the PC Strategy of the National Health System which culminated with the publication of the Strategy for Pediatric Palliative Care by the National System of Health in 2014.

The model is based on two levels, basic and advanced, covering attention within the community and hospitalization. Both levels are fundamental and the keys to success in caring in advanced illness and end of life cases. The need for palliative care can be categorized into three levels: not complex, complex and highly complex. Non-complex needs can be met from basic care resources, complex needs must be analyzed by specific PC care teams who decide whether advanced resources are required; and if so, according to available evidence, must be met with advanced PC resources.

As we have shown, the objective of palliative care is to improve the quality of life for people with palliative needs and their families. To provide such care, nurses carry out humane and ethical practices, fostering the best possible level of care, contributing to quality of life and to a dignified peaceful death. Every intervention must be carried out with regard to the taking of shared decisions about the care for the person.

Several studies have shown the need for early PC, during the process of pathologies with the prognosis of death, intensifying care as the disease advances with no possibility of cure, and this must be maintained until the end of life with the objective of guaranteeing wellbeing.

To carry out this attention, PC is conceived as comprising a multi and interdisciplinary team, made up of professionals in Medicine, Nursing, Psychology and Social Work, among others. And it is in this way, through such teams, that the multidimensionality of the patient suffering the illness can be addressed. This level of care brings together science and a humanistic approach to give a structured response to human suffering related to that stage of life which makes up our experience of the process of dying.

The curriculum of nursing competence in PC should form part of the corresponding accreditation system for professionals, as a path to excellence in the professional practice of Nursing. We cannot forget that there is still no formal academic regulation of specific knowledge due to this discipline of care being in its early stages. In such a case, it is clear that academic regulation is not in step with social and health needs, and there is a discrepancy which must be met with continuous training.

There are core aspects which comprise the essence of nursing intervention in PC such as the fostering of self-care, the link with trust and security, emotional support, tact, listening, comfort, compassion, respect and presence, which have been identified as acts of invisible care. This means that the impact of these actions on the person is not recognized and fostered as good nursing practice, and is neither recognized in nursing work in the clinical setting, nor in social standing and representation, nor in communication media.

During 2005 and the beginning of 2006, the nursing guild SECPAL made a series of significant changes in their organization, structure and internal and external functioning, with the aim of modernizing and promoting the development of the profession in this field. As a result, in Madrid, on the 1st of December, 2006, the first Monografic Nursing Conferences were held in Spain. Emphasis was given to the objective set out for this discipline in recent years: professional recognition and the formalizing of a specific area of competence and regulated training, following the example of countries advanced in the development of PC such as: the United Kingdom, Canada, the United States and Australia where PC Nursing has a specific and standardized body of doctrine.

As a result of this effort to develop the area of knowledge and training, the Spanish Association of Palliative Care Nursing (AECPAL) federated with SECPAL was founded, maintaining on the one hand the autonomous character of the nursing profession, and on the other the interdisciplinary nature which characterizes palliative care.

Among the essential objectives promulgated by the AECPAL, was the necessity to develop their own body of doctrine and a training program specifically for nurses to become experts in PC in Spain. This curriculum would seek to offer a curricular outline for the training of nurses in PC, which should form part of the corresponding accreditation of professionals, as a path to excellence in the professional practice of Nursing.

Currently, palliative care by all the professionals of the interdisciplinary team, faces the difficulty of a lack of organized, specific training. However, there are defined formulas which can accommodate accredited training and demonstrated professional experience to be able to assure quality service.

The singularity of caring and area of specific nursing knowledge encompasses the both patients and their families, is articulated within disciplines allied with palliative medicine, with psychology and social work, as well as actual nursing specialities applied to the typology of those with palliative needs.

With reference to academic training in Nursing Degrees, according to information available between 2016 and 2021, and published by the Ministry of Science, Innovation and Universities, of the 118 Universities which teach Nursing Degrees, 91 public and 37 private, 60% offer Palliative Care as a subject, and is compulsory in 48%. With respect to those autonomous communities which teach the subject as either compulsory or as an elective, within a range of 3 to 6 ECTs, the trend in 2016 has remained without modifications.

The unequal and inconsistent access to training in PC in nursing degrees has generated an increase in post-graduate courses such as expert training and Masters degrees throughout the country as the only specific training for those professionals interested in palliative care. There are many units and teams who work tirelessly in research and in updating methodologies and specific working models and who, step by step, manage to find a space for basic and advanced training which give professionals the opportunity to reach some level of training in PC. There is total consensus on the need to incorporate such knowledge in curriculums for those who wish to work in this field.

Finally, and in the framework of the National Development Strategy for PC, the Evaluation and Quality Agency in the Health Ministry, in coordination with the Interterritorial Council have drawn up documents of consensus, such as the PC Strategy in the National Health System and the Pediatric Strategy of the NHS and are discussing legal initiatives in the same sense: developing PC and ensuring fairness.

Since its first deliberations, the Technical Committee has found consensus between the scientific community and the Autonomic Communities (ACs) over the need for specific training of medical professionals, nurses and psychologists in PC. This document has become a reference for all the ACs in which basic recommendations for the uniform and coordinated development of this discipline are established, with a view to eliminating the currently existing territorial inequalities. Included in the identification of objectives and recommendations is that this training and experience should be required to take up positions in determined teams or in support while an Area of Specific Training or Diploma of Training is developed under the auspices of the Law on the Organization of Health Professionals.

The pressing need for the definition of a body of doctrine in PC Nursing has also been taken up by groups of experts within the European Association for Palliative Care (EAPC) in relation to the differing levels of training in PC, recommending that instruction in this field be included in the training program for Nursing Degrees, as a first level of preparation. A second level would comprise specific advanced training.

Furthermore, if we consider that this area of care is, as determined by WHO, one of the central columns of health services, there is a need to examine the specific role of the nurse in the advanced practice of Palliative Care (EPACP) in pediatric as well as adult care. In Spain, the PC National Strategy recommends the training of future nurses at degree and postgraduate education for those who work in this field; however, to date, there is no consensus on a roadmap to competence.

2. Justification

The nursing community specifically dedicated to PC have been co-protagonists in the birth and development of this modality of care since its beginnings in Spain in the 1980s. Already in these beginnings, nursing played a key role in its growth. Nurses were those who detected shortcomings in support and adequate treatment for whose illnesses did not respond to remedial treatment without receiving adequate management of their symptoms and were generally undertreated by the health system and by their own professional carers. From the outset until now, nurses continue being promoters of the inclusion of specific caring resources in all fields of national health.

It is no coincidence that the definitive boost for PC came at the hands of an English professional, Cicely Saunders, about whom we certainly must underline her vision as a nurse, as well as her training as a social worker and later as a doctor. In the sixties, she knew how to catalyze all the initiatives directed to implanting care structures for those people who were in need of palliative attention, initiating the "Hospice" movement which continues to this day.

Given the constant demand to meet such needs, the philosophy underpinning PC has been strengthened, since the particularity and specificity of this care is fundamental to guarantee quality of life for ill people and their families. From this healthcare model, the family environment is included decisively in the planning of care, and they are also the targets of care themselves before, during and after the patient's death. This is especially relevant in a pediatric context.

In Spain, many of the pioneers received their training in English hospices and in 1992 they established the Spanish Society of Palliative Care (SECPAL), a multiprofessional scientific association. Through this, they wanted to emphasize the importance of interdisciplinary, collaborative teamwork, necessary for the care of those with advanced illnesses and at the end of their lives, as well as their families.

On the 18th of December, 2000, the plenary session of the Interterritorial Conference on the National Health System approved the National Palliative Care Plan and the rules for its development. The aim was the guaranteeing of the right to care for those suffering from advanced illness and/or facing the end of life, whatever their location, circumstances or situation. The general objective of the plan was to improve the quality of life of such people and their families in a rational, planned and efficient wa, guaranteeing PC according to the governing principles of the National Health System:

- The offering of a coverage which responds to needs, preferably funded by public finance.
- Promoting coordination between care levels and available resources.

- Assuring equality, without regard to the type of illness or the care setting.
- Providing quality, efficacy and efficiency in the use of resources.
- Obtaining patient, family and professional satisfaction.

In 2007, the Interterritorial Council approved the first Strategy for Palliative Care within the National Health System. From 2010 to 2014 an update was carried out as a result of critical reflection and the combined cooperative efforts made by the Ministry of Health, Social Policy and Equality, the Autonomic Communities, the scientific community and Patient associations. This strategy aimed to improve PC and the connection with our health system for the benefit of the population. With the objective of standardizing the exercising of patients' rights during the process of dying and the duties of health professionals who attend to these ill people, as well as the guarantees which health institutions are obliged to furnish with regard to this process.

Ten Autonomic Communities have passed the Law Governing the Rights and Guarantees of people in the process of dying. The pioneer was Andalucia (Law 2/2010), followed by Navarra (Navarran Law/2011), Aragon (Law 10/2011), The Canary Islands (Law 1/2015), The Balearic Islands (Law 4/2015), Galicia (Law 5/2015), Basque Country (Law 11/2016), Madrid (Law 4/2017), Asturias (Law 5/2018), and Valencia (Law 16/2018).

From its beginnings, The Spanish Association of Palliative Care Nursing (AECPAL) has accepted and fostered professional responsibility, standing up for the competence and and ability to exercise care by the palliative nurse as a result of their theoretical training and clinical practice; constant feedback between training (degree and/or expert and/or Masters) and palliative care, as well as professional progress through the application of these abilities in such practice.

The PC nurse is an indispensable member of the multi-interdisciplinary team and a key element who combines palliative care through the person's course of illness, in a collaborative way, promoting quality of life and contributing to reducing treatment fragmentation, as well as taking part in the care and treatment suitable for the comfort of people with an advanced illness and/or at the end of life, and their families.

Furthermore, this multi-discipline must always be considered from the point of view of reciprocal respect for the care exercised by all the health professionals involved in the process of health care, as stipulated by the applicable Law 44/2003, dating from november 21, the Regulation of Health Professionals.

3. Definition

The nurse working in the field of PC takes part in the control of symptoms, guarantees care, insures respect for the autonomy and the rights of the person, offers personal attention, respect for values and lifestyles, respects the person's singularity, fosters wellbeing, quality of life, continuity of care and teamwork. To achieve this, they focus on all aspects of the patient as a person, understanding that they have individual, particular and specific needs, in the end of life process, which are in continual change, evolution and varying level of complexity, as well as caring for the family during the entire course of the illness and even after death, during the process of mourning.

4. Basic elements of nursing standards of practice in Palliative Care

4.1 Identifying the multidimensional needs of the person and their family

The proposed model of needs is based on the multidimensional character of such needs, allowing the exploration and identification of relevant aspects of each dimension.

Such multidimensional evaluation facilitates the approach to patient needs and their prioritization, specifying reviews adapted to the evolution of the process.

4.2 Implanting an impeccable model of palliative care

Once needs are identified, it is opportune to apply an impeccable model of palliative care, based on basic skills (clinical, communicative, ethical, planned care, continual care, and finally, management of the case), responding to the individual needs of the person (spiritual and significant, dignity, respect and hope), involving the family and adopting appropriate attitudes and behavior (empathy, coherence, trust and honesty).

4.3 Devising a multidimensional systematic therapeutic plan

Once the needs of each dimension - with greater or lesser complexity - are identified and evaluated, set out the objectives for each one according to the values and preferences of the patient.

Having established the objectives for each dimension, a Plan of Systematic Care can be implemented and follow-up initiated, including any evaluation and monitoring which may be required.

Follow-up and review: this process is repeated whenever necessary, at a frequency determined by the situation.

a. Basic Explorations and recording: the basic aspects of exploration and recording are:

- Evaluation of the patient's condition: it is necessary to take into account the criteria of intensity/severity and of progression, which together contribute a measure of the gravity and dynamic respectively, to the evaluation. Some proposals for evaluation would be:

    1. Functional state:
        a. Karnofsky Performance Status
        b. Palliative Performance Status
        c. Barthel

d. Time scale of loss of daily activities (level of functional autonomy)
e. Lansky (<16 years of age)

2. Nutritional state:
    a. Mini Nutritional Assessment (MNA)
    b. Global Subjective Evaluation (GSE)
    c. Albumin
    d. Weight loss over time
    e. Weight/height ratio (percentage figure) in pediatric cases
3. Cognitive State:
    a. Mini-mental Status
    b. Pfeiffer Test
4. Mood or emotional disturbance:
    a. Numerical Verbal Mood Scale (ENV 0-10)
    b. Emotional Disturbance Detection Instrument (EDD)

- Evaluation of Symptoms: The Edmonton Symptom Assessment Scale (ESAS) is proposed. For the normal practice of care, the numerical verbal scales or categories are recommended. For pain and certain symptoms there are particular valid scales.

b. Basic questions: These allow the identification of the perceptions and worries of the person. In the pediatric field, such questions can be asked directly of the patient, in a way adapted to their age and comprehension level, as long as the patient is cooperative. If not, we should speak to the child's parents or legal guardian. This must be done in an atmosphere of a trusting therapeutic relationship. Some examples would be:

1. Information on and understanding of the situation: "How do you regard the illness and its evolution?"
2. Worries: "Among the things we have talked about regarding the evolution of the illness and the future, which issues worry you the most?" "What would you like us to know about you so we are able to be of more help to you?"
3. Questions and remaining issues: "Regarding the things we have discussed, is there anything you are not sure about?"
4. Expectations and requests: "What would you like us to do for you?" "How can we help you?"

c. Review of the stage of the illness and treatment

The stage of the illness, objectives and indications for specific treatments, assessing:

1. The stage of illness: level, state, etc.
2. Foreseeable prognosis
3. Probability of a response to specific treatment
4. Balance between efficacy, response, toxicity and tolerance to the treatment

5. Foreseeable evolution: imbalance, crisis, etc.
6. Review of medication
7. Patient and family expectations

4.4 Identifying the patient's values and preferences

Respect for the person's values and preferences is an ineluctable requirement in the taking of decisions. An ethical approach to the taking of clinical decisions is necessary, respecting the person's values and preferences.

The objective of SCP is to work together with the patient, (family) carers and health professionals to develop a care plan, consistent with the patient's objectives, values and preferences.

The discussion must include the diagnosis, prognosis, treatment preferences and care setting, the level of information which the person wishes to have, and the extent of their involvement in decisions and treatment, as well as which people they wish to take part in this process.

To achieve this, adequate communication skills, exact information on the prognosis, as well as knowledge and interest in the patient's anxieties, values, principles and culture, are all indispensable.

4.5 Involving the family and the principal carer

The family, or affective-relational environment, must be regarded as a unit to take into account, and they must be involved in the process of care, encouraging their participation in caring while avoiding any excessive feelings of responsibility which may provoke their burnout.

4.6 Carrying out case management, follow-up, continuing and urgent care, coordination and integrated service activities

This consists in including within the Therapeutic Plan, adequate levels of resources for follow-up, with a focus on preventing evolutionary crises, common among those suffering from advanced illnesses and a limited life prognosis, and the coordination of integrated service actions to ensure appropriate care, quality of care and efficacy. The essential components are Evaluation, following the Therapeutic Plan, and finally, the Follow-up Plan. It is essential to always make decisions and to share them together with patients and their carers.

5. Designation

The Palliative Care Nurse has as their sphere of activity those with advanced chronic conditions with reduced life expectancy and their families, in a home setting as well as in social health centers and nursing homes, schools and hospitals.

In the context of palliative care, the nurse becomes involved with and works within the principles of a multi-disciplinary framework, with absolute respect for the abilities of each of the health professionals who make up the working group.

6. Nursing objectives in Palliative Care

- Provide and administer nursing care at the level of quality needed by someone in an advanced phase of illness with reduced life prognosis and in an end of life situation, achieving the best possible quality of life for them and their families.
- Design, plan, carry out and evaluate care programs and plans centered on evidence based care as applied to people in a situation of advanced illness and/or end of life, and their families.
- Generate and foster the training of future expert nurses and other health professionals in the care of patients in the end of life process and their families.
- Conduct and continue different lines of research with the aim of improving care for people in this situation and their families.
- Manage the end of life processes in the contexts of hospitals, nursing homes, social health centers and in the home.
- Carry out and foster improvements in the management of different mechanisms and resources required by people with advanced illnesses and a limited life prognosis and their families, to guarantee equity, efficacy, and ethics in their orientation.
- Guarantee the rights of those in a situation of advanced illness and/or at the end of life or with a limited life prognosis and their families, so that they may go through this end of life process with the maximum quality and comfort as well as the minimum suffering.

7. Determination of Competency Profile

The Royal Decree 1093/2010, September 3, which determined the minimum set of data required in clinical reports in the National Health System, specifies in annex VIII the context in which the activity of nursing must be carried out in its own particular language, expressly setting out diagnoses, interventions and results: NANDA-1, NIC and NOC (International Nursing Diagnoses, Nursing Intervention and Outcome Criteria).

We want to highlight the most usual NANDA diagnoses in nurses' exercising of their profession in the context of palliative care. These NANDA diagnoses, which are a statement of the requirements of nursing care and are also perceived as such by the patient and their family, are not exclusive to Palliative Care, and therefore are no different as regards developments in the field of the management of care, since it is the complexity of the situation which determines if they will be adopted in palliative care.

DIAGNOSES

00071 Defensive coping mechanisms
00074 Committed family coping mechanisms
00069 Ineffective coping
00053 Social isolation
00147 Anxiety on contemplating death
00120 Low situational self-esteem
00061 Carer fatigue
00083 Decisional conflict
00128 Acute confusion
00129 Chronic confusion
00124 Desperation
00051 Deterioration of verbal communication
00103 Swallowing deterioration
00046 Deterioration of skin quality
00045 Deterioration of oral mucus quality
00052 Deterioration of social interaction
00091 Deterioration of mobility in bed
00214 Discomfort
00132 Acute pain
00133 Chronic pain
00136 Mourning
00011 Constipation
00026 Retention of liquids
00093 Tiredness
00007 Hyperthermia

00014 Bowel incontinence
00020 Urinary incontinence
00095 Insomnia
00092 Intolerance to activity
00125 Impotence
00134 Nausea
00072 Ineffective denial
00032 Ineffective breathing pattern
00039 Risk of aspiration
00153 Risk of situation low self-esteem
00062 Risk of carer fatigue
00174 Risk to commitment to human dignity
00147 Risk of deterioration of skin quality
00172 Risk of complications in mourning
00152 Risk of impotence
00206 Risk of bleeding
00261 Risk of dryness in the mouth
00040 Risk of disuse syndrome
00054 Risk of loneliness
00066 Spiritual suffering
00175 Moral suffering
00148 Fear
00118 Altered body image

NOC

0303 Self- care: eating
0308 Self- care: oral hygiene
0309 Self- care: medication by injection
0310 Self- care: using the toilet
1205 Self-esteem
1300 Acceptance: state of health
1308 Adaptation to physical disability
1302 Coping with the problem
1402 Self-control of anxiety
1403 Self-control of distorted thinking
1404 Self-control of fear
1614 Personal autonomy
1615 Self-control of ostomy
2600 Coping with family problems
3121 Self-control: lymphedema
2508 Well-being of the principal carer
2002 Personal well-being

2000 Quality of life
0900 Cognitive functioning
1638 Patient engagement
0902 Communication
1215 Self-awareness
1601 Compliance behavior
1804 Knowledge: energy conservation
1851 Knowledge: dementia management
1843 Knowledge: pain management
1862 Knowledge: stress management
3207 Knowledge: management of lymphedema
1803 Knowledge: the illness process
1806 Knowledge: health resources
1813 Knowledge: therapeutic regime
0204 Consequences of immobility: physiological
0250 Consequences of immobility: psychological
002 Energy conservation
0500 Bowel control
0502 Urinary control
1605 Pain control
1618 Control of nausea and vomiting
1902 Risk control
1935 Risk control: breathing
1937 Risk control: dehydration
1608 Symptom control
1700 Beliefs about health
1704 Beliefs about health: the perception of threats
0003 Rest
1206 Desire to live
1501 Role performance
2101 Pain: damaging effects
0601 Body water balance
0907 Preparation of information
0501 Bowel elimination
1204 Emotional stability
1201 Hope
2008 State of comfort
2009 State of comfort: surroundings
2010 State of comfort: physical
1010 Swallowing status
0912 Neurological status: consciousness
0914 Neurological status: sensory/motor medullary function
1008 Nutritional state: ingestion of food and liquids
0403 Breathing state: respiration

2208 Stress factors in family care
1502 Social interaction skills
0602 Hydration
1200 Body image
1503 Social involvement
2603 Family integrity
1101 Tissue integrity: skin and mucous membrane
1305 Psychosocial adjustment: change of life
0208 Mobility
2007 Comfortable death
1307 Dignified death
1211 Level of anxiety
0916 Delirium level
1208 Level of depression
0920 Level of dementia
2102 Pain level
0007 Level of tiredness
2109 Level of discomfort
2604 Family normalization
0901 Cognitive orientation
1606 Participation in decisions about health
0203 Body position: self-initiated
2202 Experience of in home family carer
2204 Relationship between main carer and patient
2205 Efficiency of main carer: direct care
2206 Efficiency of main carer: indirect care
2608 Family resilience
1309 Personal resilience
2210 Resistance to the role of carer
1304 Grief resolution
2301 Response to medication
2506 Emotional health of principal carer
2001 Spiritual health
2507 Physical health of principal carer
1100 Dental health
3009 Patient/user satisfaction: psychological care
3016 Patient/user satisfaction: pain management
3008 Patient/user satisfaction: protection of their rights
2107 Severity of nausea and vomiting
0413 Severity of blood loss
0603 Severity of fluid overload
1203 Severity of loneliness
1504 Social support
0004 Sleep

0800 Thermoregulation
0906 Decision making

NIC
4420 Agreement with the patient
2210 Administration of analgesics
2300 Administration of medication
7040 Support for the principal carer
7140 Support for the family
5270 Emotional support
5250 Support in decision making
5420 Advice
5440 Increasing support systems
1800 Help with self-care
1804 Help with self-care: urination/defecation
4640 Help with anger management
0840 Change of position
0844 Change of position: neurological
5480 Clarification of values
5260 Care in the dying moments
5330 Mood control
0410 Care of bowel incontinence
0610 Care of urinary incontinence
0408 Care of ostomia
3520 Care of bedsores
7260 Respite care
5310 Giving hope
5820 Anxiety reduction
4020 Reduction of bleeding
4024 Reduction of bleeding: epistaxis
5616 Teaching: prescribed medication
5602 Teaching: the process of illness
4410 Setting shared objectives
4920 Active listening
5426 Fostering spiritual growth
5290 Fostering mourning
5300 Fostering the expression of feelings of guilt
7170 Fostering the presence of the family
7560 Fostering visits
7110 Encouraging family involvement
8340 Encouraging resilience
1720 Encouraging dental health

7330 Cultural mediation
6480 Environment management
6482 Environment management: comfort
4350 Behavior management
0180 Energy management
1450 Nausea control
2380 Medication control
1710 Maintaining oral health
0180 Energy management
2260 control of sedation
3140 Airway management
6440 Delirium control
6460 Management of dementia
1410 Pain control: acute
1400 Pain control: chronic
0450 Management of constipation/fecal retention
4120 Control of liquids
4250 Shock management
4976 Improving communication: speech deficits
5220 Improving body image
5230 Improving coping mechanisms
1850 Improving sleep
4130 Monitoring of liquids
7400 Guidance in the health system
5390 Increasing self-awareness
5400 Increasing self-esteem
5370 Role enhancement
5100 Socialization enhancement
3200 Precautions to avoid inhaling foreign matter
5340 Presence
6490 Prevention of falls
4010 Prevention of bleeding
3540 Prevention of bedsores
7460 Protection of the patient's rights
1730 Re-establishing oral health
1860 Swallowing therapy
3740 Fever treatment
3590 Skincare

8. Policy framework for Palliative Care nurses

8.1 Organizational concepts to demarcate competence development

Actions and interventions by the professional nurse in this field are developed in their area of competence, in accordance with their "lex artis", within the framework of the principles and values set out in the legal and deontological regulations and with absolute respect for the responsibilities of the other professionals who take part in the total care process.

Having regard to the interdisciplinarity of the other health professionals who are involved in the area of palliative care, is indispensable, since there will be shared areas of competence as the current regulations state. Therefore, the PC nurse carries out their function in a multidisciplinary context sharing core principles to provide excellent palliative care.

These core principles are personal and professional qualities based on values which are demonstrated through attitudes and and behavior and which taken together express such values and are perceived by the patient and their family the determining signs of excellence in commitment and care:

- Dignity: In practice, this consists in the application of a methodology of excellence in communication, centered on the fostering and recognition of dignity.
- Spirituality: There are various ways of evaluating aspects concerning values and beliefs, needs, and models of intervention.
- Hope: The maintaining of hope is a key element in adaptation to the evolving process. This is a highly variable process in which the aim of the intervention consists in helping to reformulate objectives and expectations and adapt them gradually and flexibly to the situation and the evolution of the process.
- Autonomy: Wherever possible, we must try to anticipate the taking of decisions, taking as a base the awareness of values, objectives, preferences, and the patient's decisions in our therapeutic relationship, as well as standardizing their inclusion in the taking of decisions, bearing in mind that one must always be up to date when facing a new situation. In pediatrics, parents are those responsible for taking medical decisions where this concerns a person under 16 (age of majority in health care). Whatever the age of the patient, we must always listen to their opinion, preferences and values.
- Affect: In advanced conditions and the end of life process, the family constitutes the most important resource for the ill person and also the main care unit. The fundamental objectives of palliative care with respect to the family consist in giving help, courtesy, and support which will allow the best possible emotional adaptation to the evolution and attendant losses, capacity to look after and respond to their emotional and practical needs, foster communication, and affective functions, and make available the means necessary for their practical caring ability.

They must be able to identify and monitor those signs which may indicate carer overload.
- Finally, other values to take into account are: Hospitality, Empathy, Compassion, Commitment, Trust, Coherence, Presence and Honesty.

Regarding the PC nurse's transversal competences, they are just those which every nurse must include in their practice, highlighting teamwork and digital skills.

- Teamwork

The interdisciplinary model, as well as requiring coordination and cooperation between different professions, also requires that they mutually integrate, blurring interdisciplinary divisions and boundaries so as to achieve shared objectives, with maximum regard to the field of competence of each of them. This is possibly the model which best accords with palliative care, since it is centered on the needs of people in the advanced stages of illness and their families and not on the tasks and functions of the professionals so as to:

- Bring to the team the detection of needs in the altered daily lives of the person and their family in the process of advanced illness and end of life, such that decisions taken are the most holistic and individual as possible.
- Establish an integrated work plan for the team. The team is a place of learning and a generator of knowledge.
- Foster the participation of the team in the planning, design, establishing, development and evaluation of the team's objectives.
- Promote team "self-care" in specific places and times as a tool to maintain the necessary balance to carry out interventions with people and families, as well as with team members.

- New technologies

In this field, the sensible, secure and critical use of IT is indispensable for Palliative Care and requires an open mind to understand its significance in such care. Furthermore, it is essential in areas such as the management of cases and tele-care.

- Knowledge of the digital ecosystem and the acquiring of basic skills to appropriately and safely use the various devices and digital applications in the field of Palliative Care.
- Maintaining the focus on the person and using technologies as a support guaranteeing the individualization of care and humanized treatment.
- Knowing the various sources of health information and being aware of how to deal with them so as to extract knowledge and results in real time which will facilitate the taking of clinical decisions in the field of Palliative Care.

- Managing the large amount of information which is generated, selecting content of value and instructing people and families going through advanced illness such that they too know how to select information.
- Managing technologies, devices and digital channels in an appropriate way to improve internet connections, communication and distance learning among health workers related to PC.
- Implementing IT to facilitate and strengthen research and scientific publications 2.0, as well as the design and production of health digital content as related to PC.
- Managing digital tools and resources which foster the development of interdisciplinary projects and distance health care in cooperation with different health personnel, including those people and families with chronic advanced illnesses.

Finally, we want to underline the specific competences of PC nursing, showcasing the classification of such competences based on the International Council of Nursing (ICN), adapted to the practice of PC nursing.

- Responsibility, ethics and deontology

Within their professional responsibility, the PC nurse must be able to anticipate the results of care and attention, and be able to justify ethically through developing the following capacities:

1. Responsibility, ethical and legal guidelines

- Being aware of current legislation within the end of life framework. Law 41/2002, November 14, is the basic regulatory guideline as applied to patient autonomy, as well as the rights and obligations relating to clinical information and documentation together with laws decreed by autonomic governments. Legal aspects related to patient death and deontological guidelines as they apply to the professional exercise of PC.
- Knowledge of the range of shared services within the national system of health and the laws which govern the health system, the interactions between their components as they relate to PC, within the global State health policy.
- Respecting the values, lifestyle, and beliefs of the patient and their socio-cultural diversities at the end of life, during the care process; adopting such care practices and fostering an environment where the person and their family can carry out their rites and rituals (interculturalism).

Knowledge of social themes surrounding concepts about suffering and pain at the end of life: dignified death, adaptation of the therapeutic effort, rejection of treatment, palliative sedation, futile treatment and euthanasia. Knowledge of Organic Law 3/2021, March 24, rules governing euthanasia, in effect June 25, 2021, and guidlines which this sets out for the exercise of conscientious objection.

2. Ethical practices

- Applying the general ethical and deontological principles contained in the profession of nursing relating to the process of decision making, care activities and attention to people at the end of life.
- Participating in team decision making, bringing the awareness of needs in an altered daily life, recognizing the complexity of the situation a person with advanced illness and/or the end of life is facing, and the necessity of a multidisciplinary approach so that the taking of decisions is as holistic and individual as possible.
- Recognizing the vulnerability and fragility of the person suffering from advanced illness and/or facing the end of life, and consequently, the need to actively safeguard respect for their fundamental rights.
- Avoiding the influence that one's own beliefs and values may have in the giving of care respecting the autonomy and intimacy of the person under daily care and in the taking of decisions at the end of life.
- Recognizing sociocultural diversity at the end of life, fostering an environment where the person and their family can carry out their rites and customs.
- Protecting the person's right to decide, making sure they have the necessary information during all the caring process, adapted to their needs, receptivity and clinical status, utilizing verbal and/or written consent and any document of anticipated wishes.
- Giving support to the family in respecting the person's values and at the same time assisting that person to exercise their autonomy in a loving, familiar and supportive environment.
- Prioritizing the wish of the patient to be informed and respecting their right to reject any proposed treatment or care program, emphasizing their right to continue being cared for, treated and looked after.
- Maintaining the principles of intimacy, confidentiality and dignity of the corpse after death.
- Protecting confidentiality and professional secrecy recognizing that the owner of the information (diagnosis, prognosis, evolution, treatment and care) is the individual themself, and this information can only be shared with their previous consent and in those cases governed by law.
- Encouraging the expression of the person's wishes, in anticipation of foreseen cognitive deterioration, where they are not able to express such wishes themselves, registering their preferences in their clinical history and/or with the drawing up and registering of a document of anticipated desires in the case where the person has reached the age of majority.
- Ensuring implicit and explicit consent in situations where there is a change in therapeutic orientation and palliative sedation.
- Trying to create an atmosphere which encourages the maximum cognitive and emotional involvement of the person or their representatives in the taking of decisions including the rejection of treatment, favoring specialized assistance, should it be considered necessary. Accompanying the person in clarifying their

values, motives and consequences, and in obtaining specialized assistance, if thought necessary in a request for euthanasia.

- Provision and management of care

The PC nurse must be able to accompany the person going through the process of advanced illness and/or end of life putting into place and managing an individualized care plan, developing the following activities within the framework of nursing care:

1. Essential principles in the provision and management of care

- Establish a process of communication which fosters the development of personal resources and the caring capacity of the person and their family in the process of adaptation to the end of life situation.
- Organize a care plan identifying health problems and establishing priorities based on the quality of the interventions in the daily life and wellbeing of the person.
- Know, adjust, administer and confidently evaluate the specific care and treatment.
- Identify and involve the principal carer of the person being looked after.
- Establish a plan of specific care for the needs of the family group.
- Act as a mediator between the family and the ill person, fostering their adaption to the end of life process.
- Foster the continuation of care managing the available community resources and establish channels of communication between all the health teams who are implicated.
- Participate in and foster teamwork as an instrument to approach the complexity of the care and attention given to people at the end of life.
- Use the available scientific evidence and apply it during all the process of care.
- Participate in and promote debate about innovations and changes in care for those in the process of advanced illness and the end of life.

2. The promotion of health

- Include in the care program the planning of health education according to the clinical situation, knowledge, personal resources and previous experience. Promote healthy lifestyles where possible within the end of life process, maintaining the person's autonomy and wellbeing for the maximum possible time as well as that of the family, respecting their habits and customs.
- Adapt the surroundings to the changing needs of the person a t the end of life using social, family, environmental and material resources. Bring knowledge and abilities which help the person to to retain maximum autonomy in the management of their end of life process. Help the person to delegate their care and attention to according to their progressive functional and/or cognitive deterioration at the end of life.

3. Evaluation

- Systematically evaluate the clinical situation and the emotional or social risk through specific criteria or indicators.
- Determine the level of dependence and functional repercussion on health problems deriving from the end of life process.
- Evaluate the person's and family's level of information and knowledge about the living situation and prognosis.
- Systematically evaluate the organizational, emotional and self-care capacity of those in the carer's surroundings.

4. Planning

- Define and prioritize the nursing diagnosis with the person and their family.
- Identify critical situations and activate the early involvement of other professionals according to the limits of their professional activities.
- Activate specific protocols for end of life care (assistance with pain, help to people with delirium, situation of final days, post-mortem care, help in mourning...); procedures and methods (discharge, outcomes, administration methods...), individualizing them according to the person and the situation.
- Define results criteria and establish an activities timeline according to the complexity of the situation of the person with advanced illness and facing end of life.
- Include the clinical history in the planning of nursing care and activities related to problems of cooperation.
- Register the activating of methods, protocols and specific procedures used, indicating results criteria.
- Prepare instructions for care and treatment to foster the self-care and/or the participation of the principal carer and draw up the necessary graphic information.

5. Execution

- Act in accordance with established planning, adjusting activities to the changing needs of the person and their family in the end of life situation.
- Provide the information and documentation necessary to ensure the highest level of participation possible of the person and principal carer.
- Document and register any changes in their interventions.

6. Evaluation

- Evaluate and include the results of interventions within the care plan in relation to the set objectives of the multidisciplinary therapeutic program.
- Use the results of the evaluation to deepen individualization in the care plan.

- Evaluate the results of delegated interventions, techniques, and protocols and procedures used.

7. Therapeutic communication and interpersonal relationships

- Use the therapeutic relationship as a way of helping in all the interactions with the person and their family, taking into account the emotional fragility of their life situation. In pediatric cases, pay special attention to including siblings in the process of illness and care.
- Respond to the needs and requests for information, including bad news as as part of the process of communication with the person and their family.
- Encourage the expression of feelings and emotions by the person and their family in the different stages of loss and mourning, without fear of being judged.
- Create an intimate therapeutic context which fosters communication.
- Be with the family after death watching for specific needs in the mourning process.

8. A safe environment, integrated care and management of resources

- Prevent situations of risk through early detection, communication and the recording of problems of security to the relevant authorities.
- Foster flexible organization adapting to changing care needs.
- Draw up criteria which allow the assigning of the most suitable nurse, able to give care and attention, taking into account their knowledge and/or emotional response to the complexity of the situation.
- Use quality indicators and current or potential risk management adapted to the end of life situation.
- Give specialized support to the needs and requirements of other professionals and teams at other levels of the care and attention to the person and their family at the end of life.
- Design specific care plans as support to nurses at other levels of care and attention to the person at the end of life.
- Establish circuits and criteria for intervention between the different assistance levels involved in care in the case of advanced illness and also the end of life.

- Professional development

The PC nurse must be able to contribute to the development of the exercise of nursing in the context of PC:

1. Professional commitment

- Be a reference in the field of palliative care.
- Manage and bring knowledge of PC nursing to all levels of assistance and care.

- Become aware of the political and/or institutional situation relative to the care needs of people in the end of life process.
- Implement necessary changes at a professional, institutional and political level aimed at the improvement of care for people in the end of life situation.
- Accept ethical and legal co-responsibility in the comprehensive care of the person/family in the end of life situation during all the care process.
- Contribute to social understanding of the end of life as part of the life cycle.

2. Improve quality

- Be aware of, prepare and apply quality indicators and standards to the quality of care plans for people at the end of life.
- Participate in the processes of evaluation and improvement in the quality of care for people at the end of life.
- Incorporate criteria of efficacy and efficiency which guarantee the best care, optimizing available resources.
- Generate resources to respond to specific care needs with quality criteria.
- Apply and disseminate conclusions and proposals to improve the analysis of results and the evaluation of the quality of care.

3. Teaching and training: lead the process of learning for nursing in PC

- Apply reflective learning correct practice as an element of continuous learning.
- Participate in the detection of training needs and cooperate in the preparation, implementation and evaluation of teaching programs in PC to all professionals in the field of health.
- Participate in society as an educative element in the care of people at the end of life.

4. Research

- Identify and apply the best scientific evidence in the practice of Palliative Care.
- Identify priority and sensitive lines of research from the regulations in force which control research processes at the local, national and international level.
- Evaluate ethical questions in research on human beings as regards the situation of vulnerability in the end of life process, guaranteeing respect for the person's rights as a subject of research.
- Acquire the abilities of leadership, cooperation, and commitment in the dissemination of PC nursing research results, allowing the production of new scientific evidence at the local, national and international level.

9. Determination of minimum content in the training of Palliative Care nurses

The situations in which PC nurses find themselves are a continuing challenge to the development of their skills in the practical, relational and moral dimensions of care. That is why they require knowledge, training, orientation and support to carry out their functions.

The minimum time of clinical practice in specific areas considered necessary for PC to guarantee sufficient training for nurses in this field would be a minimum of one year's professional experience.

For adequate training of those who are going to fulfill this role, the following specific content must be included:

Functional Training, Management and Organization of Palliative Care with thorough knowledge of:

- The principles and philosophy of PC
- The organization of the National Health System (NHS) and the resources of each Autonomous Community (AC)
- The National Strategy
- Coordination between levels of care
- Information control
- Quality control

Clinical nursing Training specific to PC with thorough knowledge of:

- Knowledge of the advanced illness and/or end of life of oncological and non-oncological patients
- Basic nursing care
- Pain relief and care
- Care in other symptoms: digestive, respiratory, urogenital, neurological, psycho-motor, etc.
- Care in systemic symptoms (asthenia, fever,etc.)
- Skin care: tumorous lesions, lymphedema, etc.
- Care during the final days (person/family): identification of the phase of dying, support during mourning, specific subcutaneous management, prevention of complications during mourning, etc.
- Specific technical skills: infusion pumps, management of invasive and non-invasive mechanical ventilation, paracentesis, central perfusion vials, etc.
- Care in palliative emergencies: medullary compression, Vena Cava syndrome, heavy bleeding, hypercalcemia, etc.
- Pediatric Palliative Care

Psycho-emotional requirements in PC with thorough knowledge of:

- Communication with the ill person and their family: adaptation to the advanced illness and end of life, conspiracies of silence, taking decisions, managing bad news, etc.
- Psychological responses to advanced illness and the end of life: emotional reactions (fear, guilt, sadness, anxiety), loss of autonomy, pain and symptoms refractory to treatment, etc.
- Attitudes and responses of professionals: the influence of values and beliefs, skills, impact in the team, burn-out, compassion fatigue, etc.
- Mourning and accompanying: adaptation to loss, identification of anticipated and pathological mourning, support to the family and the professional team.

Sociocultural requirements in PC with thorough knowledge of:

- The ill person and their family as a unit to be looked after
- The principal carer
- Family participation in the taking of decisions
- Family breakdown

Bioethics with thorough knowledge of:

- Inclusion of the 4 principles (beneficence, non-maleficence, fairness and autonomy)
- Informed consent
- Double-acting principle, sedation
- Anticipated wishes/ living will/Shared care planning

Cooperative work and Leadership Management in PC with thorough knowledge of:

- Multidisciplinary teams
- The relationship of the nurse with other members of the team
- Group dynamics, leadership in nursing
- Management of group meetings, objectives and procedures
- Negotiation and resolution of conflict
- Burn-out: prevention, early detection, strategies for improvement
- Training and Teaching in PC with thorough knowledge of:
- Teaching methodology: design and preparation of teaching projects
- Preparation of clinical sessions
- Dissemination and presentation of training projects
- Literature searches and Critical Reading

Research in PC with thorough knowledge of:

- The application of evidence in the care of people in the PC program
- Research themes and trends in Palliative Care and related disciplines
- Ethical and legal issues in research: Guides to Clinical Practice
- Good practice, the Helsinki Declaration and related issues
- Spiritual Needs in PC
- Individual Spirituality, the implications of the illness and its threats to life
- The ability to explore spiritual and transcendental needs
- Hope in Palliative Care
- Spiritual suffering

Legislation related to PC with thorough knowledge of:

- End of life care
- Regional and National Palliative Care plans
- Living wills or anticipate wishes and shared care planning
- Knowledge of deontological guides and regulations
- The law governing Patient Autonomy
- Bureaucracy at death, certificates, etc.

10. Contribution of Palliative Care nurses to the health system

Recent decades have seen a significant transformation of society at all levels with a major impact on the health of the population and on the Health System.

We find ourselves faced with an aging population, increased life expectancy, an increase in chronic illnesses, rising comorbidity as well as illnesses related to lifestyle, factors which have led to an explosion in health costs.

At the same time, we live in an increasingly well-informed society, with changes in the roles of carers, and a non-acceptance of death, which contribute to a greater use of health resources.

Among the contributions that PC nurses can make to the social-health system, we can highlight the following:

- Centering the health process on a cross-curricular, open, interdisciplinary team into which each professional brings their vision and abilities.
- Managing necessary resources according to the state of health and situation of each person, from a holistic standpoint.
- Fostering changes in the care paradigm by the carer
- Fostering the abandoning of the paternalistic model such that each person is able to self-manage their own illness, empowering people and guaranteeing their autonomy at every moment, knowledge of their state of health and responsibility for their own health.
- Encouraging the step from reactive care to proactive care
- Promoting a model of care centered on the person, in which continual care is guaranteed through the removal of barriers between the different levels of care and adequate management of the person according to their needs.

PC nurses find themselves within a model of integrated care in complex cases, based on teamwork, and by taking advantage of the synergies generated by health resources. This means a model of proactive, individualized, intensive and continual care of the person and their family, making efficient use of resources.

11. Nursing challenges in Palliative Care

Palliative care is put into practice in a complex context in which it is necessary to work within a multidimensional view of the person. Among the challenges are:

- Fostering the early identification of people needing palliative care, identifying their values and preferences and taking decisions based on these, as well as taking care of their families, designing and validating instruments which allow this in an efficacious and efficient way.
- Participating as nurses in the development of methods which must be implemented in health and social services to attend to them, in the development of territorial organizational models, and in planning and legislative measures to be incorporated into the system, involving the whole of society such that they change their attitudes and so promote active volunteering.
- Encouraging basic training in PC for professionals in Nursing from their degree stage and for all professionals who perform duties in areas not confined to PC, and ensure intermediate and/or advanced training for those professionals working part or full time with people and their families with palliative needs.
- Promoting the creation and recognition of the figure of the specialist nurse in PC, which guarantees excellence in nursing care for people with advanced chronic illnesses and limited life expectancy, and their families.
- Fostering the dissemination and equity of palliative care for people and their families with palliative needs, independently of their age, pathology or place of residence.
- Cooperating in the development of policies and integrated programs of palliative care which respond to the needs of those with advanced chronic conditions from the initial phases of their evolution, in all Health and Social Services and which respond to all their needs, including psychological, social and spiritual care of people and their families.
- Promoting palliative care as a fundamental human right which includes all aspects of care, and which has as its fundamental aim the relief of suffering, and the accompanying of people with advanced illnesses, in all the services provided.

12. Glossary

AC: Autonomous Community

AECPAL: Spanish Association of Palliative Care Nursing

AIHPC: International Association for Hospice and Palliative Care

EAPC: European Association for Palliative Care

EDP: Early Decision Planning

ESAS: Edmonton Symptom Assessment System

GSV: Global Subjective Valuation

IBN: International Board of Nursing

ICT: Information and Communication Technologies

MNA: Mini Nutritional Assessment

NHS: National Health System

NVS: Numerical Verbal Scale

PCU: Palliative Care Unit

SCP: Shared Care Planning

SECPAL: Spanish Society of Palliative Care Nursing

WHPCA: Worldwide Hospice Palliative Care Alliance

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14. Annexes

Annex 1 NECPAL CCOMS-ICO Version 4.0

PRACTICAL RECOMMENDATIONS FOR IDENTIFYING AND ESTABLISHING PROGNOSTIC APPROACH OF PEOPLE WITH ADVANCED CHRONIC CONDITIONS AND PALLIATIVE CARE NEEDS IN HEALTH AND SOCIAL SERVICES

NECPAL 4.0 PROGNOSTIC (2021)

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Figure 1. NECPAL instrument 3.1 "classic"

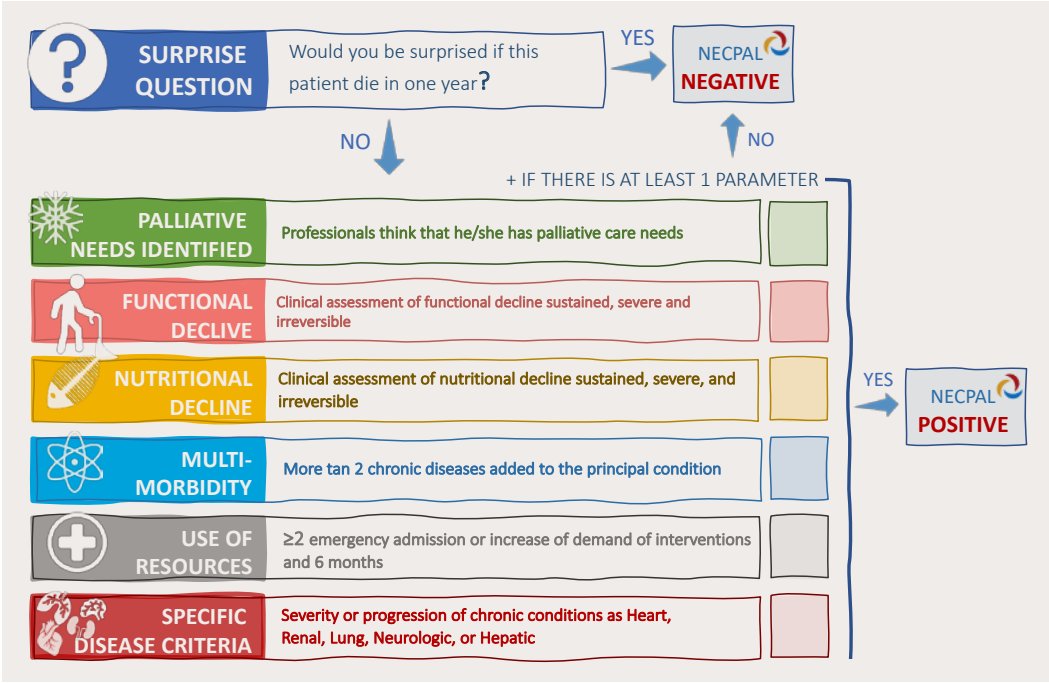
Surprise question (SP) (to and between professionals):
Would it surprise you if the patient died during the coming year?

▶ **YES,** it would - NOT NECPAL ▶ **NO,** it wouldn't

"Request" or "Need"	- Has there been an implicit or explicit expression of limitations in the therapeutic effort or a request for palliative care from the patient, family or members of the team?
	- Need: identified by professional members of the team
General clinical indicators of progression **- In the last 6 months** **- Not related to the recent/reversible intercurrent process**	- Nutritional decline
	- Functional decline
	- Cognitive decline
Severe dependence	- Karnofski <50 or Barthel <20
Geriatric Syndromes	- Falls - Bedsores - Dysphagia - Delirium - Repeated infections
Persistent symptoms	Pain, weakness, anorexia, digestive…
Psychosocial aspects	Distress and/or severe adaptive disorder
	Severe social vulnerability
Multi-morbidity	> 2 illnesses or chronic advanced conditions (from list of specific indicators)
Use of resources	Evaluation of the need for or the intensity of interventions
Specific indicators of severity / progression of the illness	Cancer, EPOC, ICC, Hepatic and Renal, AVC, Dementia, Neurogeneration, AIDS, other advanced illnesses.

If at least one parameter is present NECPAL: NECPAL +

NECPAL TOOL VERSION 4.0 2021



> Checklist of needs: identification of palliative care needs in a situational palliative approach

1. Draw up a quick itemization of the listed dimensions
2. Decide if it is necessary to add to it with more specific or complex indicators and parameters
3. Prepare short term improvement proposals to respond to perceived needs
4. Make a basic therapeutic plan

The results of this procedure will allow us to identify palliative care needs and prepare a therapeutic plan:

Actions which must be carried out for the integral care of the identified people

1. Carry out a multidimensional evaluation
2. Evaluate the stage of the illness and its possible evolution
3. Identify values and preferences and initiate the planning of early decisions
4. Identify and attend to the principal carer
5. Identify and make available experienced professionals
6. Prepare a multi-therapeutic plan
7. Manage the cases and carry out integrated care with other services in the territory

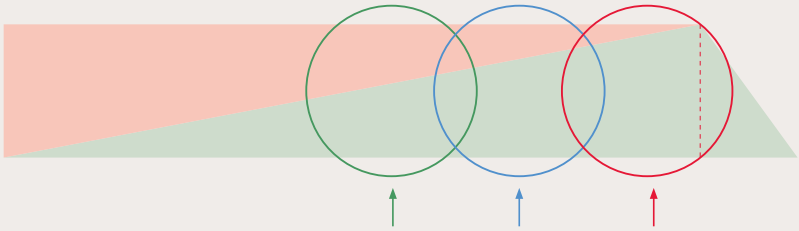
> Situational prognostic checklist:

- **Identification of risk**
- **Focused prognostic approach**
- **Situational prognosis**

Enumerate the parameters and factors of prognostic value (identified palliative needs, functional decline, multimorbidity, increase in use of resources, and use of resources specific to the chronic illness).

Assign numbers to the indicated parameters: 1-2, 3-4, or 5-6.

Evolutionary study: depending on the number of prognostic parameters implicated, 3 large prognostic groups or evolutionary stages can be identified:



PS	Indicated parameters	Stage 1	Stage 2	Stage 3
Surprise question	• Identified needs • Functional decline • Nutritional decline • Multimorbidity • Increase in use of resources • Specific indicators	• PS + 1-2 parameters • Average 38 months	• PS + 3-4 parameters • Average 17.2 months	• PS + 5-6 parameters • Average 3.6 months

ADDITIONAL RECOMMENDATIONS

Methodology of care utilization

1. The prognosis is one of the elements which should be taken into account. It is always related to the evaluated needs and requests.
2. There is a prognostic risk for population groups who fall under different criteria. This must be applied with caution when applied to individuals, since we do not know which prognostic behavior an individual belonging to a group would show.
3. Once the prognostic risk is established, evolutionary situational information will be available which will guide us to the therapeutic approach.
4. It should be updated regularly.

Benefits and risks of preparing individual prognoses

1. The most relevant benefit of prognostic evaluation is its contribution to situational diagnosis and allows the redefining of some of the objectives, activating, where appropriate a gradual palliative focus.
2. This evaluation should be shared with the patient and their family at the rate, intensiveness and concision adequate to the capacity for adaptation.
3. The most relevant risk in prognostic evaluation is its automatic individualized application of risk derived from a characteristic population risk.
4. Other risks should be taken into account, such as the loss of curative opportunities, stigmatization, etc., dealt with previously during the application of NECPAL during the initial phases.

Proposals for care related to needs and the prognosis of limited life

1. Carry out a multidimensional evaluation of needs: physical, emotional, social, spiritual, ethical, and end of life.
2. Evaluate the stage of the illness and its possible evolution.
3. Identify values and preferences and initiate the planning of early decisions.
4. Identify and attend to the principal carer.
5. Identify and employ experienced professionals.
6. Prepare a multidimensional therapeutic plan.
7. Manage the cases and carry out integrated care with other services in the territory.

Annex 2 The Edmonton Symptom Assessment System

No pain	0	1	2	3	4	5	6	7	8	9	10	The worst pain imaginable
No fatigue	0	1	2	3	4	5	6	7	8	9	10	The most fatigued imaginable
No drowsiness	0	1	2	3	4	5	6	7	8	9	10	The drowsiest imaginable
No nausea	0	1	2	3	4	5	6	7	8	9	10	The worst nausea imaginable
No loss of appetite	0	1	2	3	4	5	6	7	8	9	10	The worst loss of appetite imaginable
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	The worst shortness imaginable
No depression	0	1	2	3	4	5	6	7	8	9	10	The worst depression imaginable
No anxiety	0	1	2	3	4	5	6	7	8	9	10	The most anxiety imaginable
Fall asleep perfectly	0	1	2	3	4	5	6	7	8	9	10	The most difficulty in sleeping
Perfect feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	The worst feeling possible
No_____ Other problems (e.g. dryness of the mouth)	0	1	2	3	4	5	6	7	8	9	10	The worst possible

Source:
https://www.researchgate.net/publication/259144031_Version_espanola_del_Edmonton_Symptom_Assessment_Sytem_ESAS_un_instrumento_de_referencia_para_la_valoracion_sintomatica_del_paciente_con_cancer_avanzado/link/5a6060dca6fdcc21f487c528/download

Annex 3 Mini Nutritional Assessment

Last name: First name:

Sex: Age: Weight, kg: Height, cm: Date:

Complete the screen by filling in the boxes with the appropriate numbers.
Add the numbers for the screen. If score is 11 or less, continue with the assessment to gain a Malnutrition Indicator 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 3kg (6.6lbs)
1 = does not know
2 = weight loss between 1 and 3kg (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 ☐

F 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 ☐

Screening score (subtotal max. 14 points) ☐☐
12-14 points: ☐ Normal nutritional status
8-11 points: ☐ At risk of malnutrition
0-7 points: ☐ Malnourished
For a more in-depth assessment, continue with questions G-R

Assessment

G Lives independently (not in nursing home or hospital)
1 = yes 0 = no ☐

H Takes more than 3 prescription drugs per day
0 = yes 1 = no ☐

I Pressure sores or skin ulcers
0 = yes 1 = no ☐

J How many full meals does the patient eat daily?
0 = 1 meal
1 = 2 meals
2 = 3 meals ☐

K Selected consumption markers for protein intake
- At least one serving of dairy products (milk, cheese, yoghurt) per day yes ☐ no ☐
- Two or more servings of legumes or eggs per week yes ☐ no ☐
- Meat, fish or poultry every day yes ☐ no ☐

0.0 = if 0 or 1 yes
0.5 = if 2 yes
1.0 = if 3 yes ☐.☐

L Consumes two or more servings of fruit or vegetables per day?
0 = no 1 = yes ☐

M How much fluid (water, juice, coffee, tea, milk...) is consumed per day?
0.0 = less than 3 cups
0.5 = 3 to 5 cups
1.0 = more than 5 cups ☐.☐

N Mode of feeding
0 = unable to eat without assistance
1 = self-fed with some difficulty
2 = self-fed without any problem ☐

O Self view of nutritional status
0 = views self as being malnourished
1 = is uncertain of nutritional state
2 = views self as having no nutritional problem ☐

P In comparison with other people of the same age, how does the patient consider his / her health status?
0.0 = not as good
0.5 = does not know
1.0 = as good
2.0 = better ☐.☐

Q Mid-arm circumference (MAC) in cm
0.0 = MAC less than 21
0.5 = MAC 21 to 22
1.0 = MAC greater than 22 ☐.☐

R Calf circumference (CC) in cm
0 = CC less than 31
1 = CC 31 or greater ☐

Assessment (max. 16 points) ☐☐.☐
Screening score ☐☐.☐
Total Assessment (max. 30 points) ☐☐.☐

Malnutrition Indicator Score

24 to 30 points	☐	Normal nutritional status
17 to 23.5 points	☐	At risk of malnutrition
Less than 17 points	☐	Malnourished

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1. Vellas B, Villars H, Abellan G, *et al.* Overview of the MNA® - Its History and Challenges. *J Nutr Health Aging*. 2006; **10**:**456**-465.
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For more information: www.mna-elderly.com

Source:
https://www.researchgate.net/figure/Figura-1-Hoja-de-evaluacion-del-test-MNA-Mini-Nutritional-Assessment_fig1_267920670/download

Annex 4 Subjective Global Assessment Form (SGAF)

(Select the appropriate category with a tick, or a numerical value where indicated with "#")

A. History

1. Weight change
   Overall weight loss over the last six months: = #_____ kg: % loss = #_____
   Changes in the last two weeks:_____ increase _____ no change _____ loss.
2. Change in nutrient intake (relative to the normal)
   _____ No change
   _____ Changes _____ duration = # _____ weeks.
   _____ Type: _____ suboptimal solid intake _____ liquid intake.
   _____ High calorie liquids _____ inanition.
3. Gastrointestinal symptoms (lasting >2 weeks)
   _____ none _____ nausea _____ vomiting _____ diarrhea, anorexia.
4. Functional capacity
   _____ no dysfunction (i.e. total capacity).
   _____ Dysfunction _____ duration = #_____ weeks.
   _____ Type: _____ working suboptimally.
   _____ Outpatient.
   _____ Bed ridden.
5. Illness in relation to nutritional requirements.
   Primary diagnosis (specify)
   Metabolic load (stress): _____ no stress _____ low stress
   _____ moderate stress _____ high stress.

B. Physical changes (specify): 0 = normal, 1+ = slight, 2+ = moderate, 3+ = profound).
   # _____ subcutaneous fat loss (triceps, thorax)
   # _____ muscular atrophy (quadriceps, deltoids)
   # _____ ankle edema
   # _____ sacral edema
   # _____ ascites

C. VGS classification (select one)
   _____ well nourished
   _____ moderate (or suspicion of being malnourished)
   _____ seriously malnourished

Source:
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