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PALLIATIVE CARE SERVICES: GUIDE TO QUALITY CRITERIA

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PALLIATIVE CARE QUALITY CRITERIA GUIDE

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In our country, palliative care has experienced a progressive development over the last years, with an ever-increasing number of care providers interested in a comprehensive treatment of terminal patients.

The Spanish Society of Palliative Care intends through this document to establish and agree on the main quality and good practice criteria in Palliative Care. The objective of this paper is that these quality criteria may serve as a guide to those centres and institutions interested in their development. These basic guidelines try to establish a commitment with professional care quality in Palliative Care, in order they may be useful both to these care providers and as a base for the innovation and development in this knowledge area.

I. DEFINITIONS

I.1. Palliative Care Definition

(1) Palliative Care is defined as the integral, individualised and continued care to the patients with an advanced and terminal disease, as well as to their families. This kind of disease is characterised by the presence of multiple and changing symptoms, with a high emotional, social and spiritual impact, thus creating an important need and demand of attention. This demand is competently attended, focusing the therapeutic objectives to the improvement of comfort and quality of life. These parameters are defined by patients and their families according to and respecting their … preferences and values …

I.2. Objectives and tools

(2) The main objective of Palliative Care … is to improve the quality of life and comfort, as defined by patients and their families.

(3) The tools that are used to fulfil this goal must be individualised and include :

- Symptom control and relief
- Emotional support and communication
- Promotion of the emotional adjustment of Patients and families
- Supporting and improvement of the caring family structure
- Change in the organisation, oriented towards patient’s needs and demands

I.3. Principles and values

(4) These objectives are based on .... principles and values in Palliative Care .... that may be summarised as follows:

- Comprehensive care of the patient with an advanced terminal disease and their family
- Autonomy and dignity promotion ....
- Active and rehabilitative conception of care
- Deep respect for the objectives and values of the patients and their families
- Inter-disciplinary Team organisation
- Efficacy and efficiency
- Social responsibility in answer to the health and social rights of persons

I.4. Palliative Care .... dimensions

(5) Among the many factors included in Palliative Care ... quality, ... as relevant activity areas, the following may be highlighted:

- Clinical or direct care
- Relationship, acquaintance and information to patients and families
- respect for Patients and family rights ...
- Appropriate environment and resources
- Organisation model
- Coordination with other levels of health an social care.

I.5. Patients and needs typology

(6) Palliative Care patients distinguish themselves by a high need and high demand pattern, that is defined by their clinical condition and whose profile is the following:

- Incurable, advanced and progressive disease
- With a poor chance of response to specific treatments
- With a fluctuating evolution and frequent needs crisis
- With a strong emotional and familiar impact
- After-effects on the caring structure, and
- a limited life prognosis

(7) According to this definition of needs, patients with evolutionary advanced and/or terminal diseases such as cancer, AIDS, dementia, geriatric conditions, or other types of advanced chronic diseases, need to be cared with the Palliative Care principles, in coordination with other services and attention levels.

(8) Need's crisis is the term applied to those severe situations for family unit characterised by the presence of physical, psychological, social, or spiritual concrete needs that can reduce the patient life comfort and quality. It also modifies the emotional stability of their families and requires a specific intervention to be resolved.

I.6. Resources typology

(9) Resource typology in Palliative Care may comprise the following care areas:

- Home
- General units admission
- Specific units admission
- Out-patients .../consultation
- Day hospitalisation

(10) Use and availability of these resources will be made according to the situation, structure and complexity of the equipment, patients typology and integration and/or coordination with other specialised resources in an integral system.

(11) General measures are those that can be recommended at all .... levels of the health care system , specially when high proportions of advanced and/or terminal patients are seen. Their launching is highly significant in order to reach a wide coverage of good quality **....** . Services and resources of primary care oncology, geriatrics, internal medicine, general surgery, ENT and infectious diseases are characterised by a high prevalence of advanced and terminal patients.

(12) Some of these measures are: specific training in palliative care, spaces and timeframes more specifically dedicated to the attention of patients with advanced diseases and their families, establishment of protocols of most prevalent situations, an increase in availability and improvement of team work, use of opioids, and training and practicing of clinical ethics.

(13) Symptoms with a poor prognosis or with an important emotional impact, difficulties in familiar organisation and adaptation, particularly in need crisis, conform a pattern of needs and high demands that usually require specific teams to intervene, with the ability to resolve these problems.

(14) Palliative Care specific teams are those who have a specific structure (based upon an interdisciplinary team), an advanced ability to intervene in complex care situations, a specific dedication to the attention of advanced, terminal patients (with an assistance volume that guarantees their experience and training), being identified and acknowledged as such by users and organisations..

(15) Basic organisation models in palliative care can be summarised in:

- General measures
- Specific nurses
- Support teams (in the community, hospital, social health centres or comprehensive system)
- Specific units
- Comprehensive care systems (integrated resources in a sector, with integrated action)

(16) Specific teams intervention models will depend on several factors:

- On the environment (needs, demands, resolution degree of the other resources and implementation of general measures in that sector,…)
- On the complexity of the situation: a generic classification may include several kinds of situations (complex, chronic, acute, agonising).
- Complexity of the Intervention

(17) Palliative care specialised intervention may acquire high complexity degrees (control of resistant symptoms, high emotional impact situations, familiar adjustment situations), depending on the training and experience, available resources and their coordination.

(18) Evolutionary trends that have been observed in recent years seem to direct towards:

- Flexible intervention patterns
- Early interventions
- Complexity-based interventions
- Shared care between specialist and general services
- Cooperation, establishment of protocols, and respect
- Integrated care in systems or networks

II. STRUCTURE AND ORGANISATION

II.1. Human resources

(19) The Palliative Care professional team will be an interdisciplinary one and will be formed by physicians and nurses, with the cooperation .... of psychologists and social workers, and other relevant professionals whose dedications will be quantified according to specific needs of attention. One of these professionals will be the team responsable.

(20) A Basic team is the one that includes a physician and nurse(s), with the cooperation of social work and psychology professionals; a complete team is the one that includes social work and psychology professionals, as well as others (physical therapist, occupational therapist, others); and a reference team is the one that performs reference functions in assistance complexity, associated to university advanced training and research.

(21) The number of professionals that will form each team will be established according to the resource where they work, the patient typology and their activity indicators.

(22) The need of “monographic” teams (in cancer, AIDS, geriatrics, or other specialities) will always be established according to the number of patients in this area and the support degree of reference services in this ..... area.

(23) The Palliative Care professional team will always have an advanced training that guarantees their competence and that can be proved.

(24) Palliative Care teams will preferably be located in structures that allow a better support to be given to both patients and their families. Thus, they may be located in hospitals, social health centres, and community resources or as a part of an ... comprehensive system..

(25) Palliative Care support teams, when performing a support activity and combining direct care activities, support of other teams , interdisciplinary work and resource’s connection, do not necessarily require specific .... units or structures, although location, identification and access are needed.

(26) The team will dedicate its time to the patient care activities, both directly and as a reference consulting body, supporting other professional teams. These activities will be performed under an interdisciplinary work scheme. Their competences – further to direct assistance – include resource connection, quality assessment activities, continued training and research in the areas where they perform their tasks.

(27) Training, functions and responsibilities of each team member will be established formally. Further to a brief definition of the jobs and responsibilities

of each professional, it is suggested to include the continued training activities and assessment criteria to be used in periodic evaluations of their capacity and fulfilment.

II.2. Material resources

(28) Palliative Care necessary resources for attending people's needs are:

- Assistance structures (equipped consultation, unit with admission beds, day area, etc.)
- Physical structure for management and team activities (management area, consult office and meeting room / classroom)
- Interpersonal communications (phone, beeper, fax, e-mail)
- Files
- Access to support services of the organisation where they are located (secretary, archive, admissions, library, management and general services, computer, training resources and research)
- Access and connection to the different resources of the system.

(29) The necessity of resources will be adapted to the number of professionals in the team as well as to the activities that must be performed (admission, ... consultation, day unit, consultant) and will depend upon the development structure of the team (basic, complete, reference).

(30) Physical spaces devoted to communication and acquaintance with patients and their families should allow those patients and families to feel their intimacy, confidentiality and safety are being respected. The hospitalisation unit should be organised in such a way that it allows the permanent presence of the family and is perceived by them as a warm and human environment.

(31) Palliative Care teams should have a specific physical structure for teamwork, where files, secretary and basic clinical material can be kept, further to allowing regular interdisciplinary meetings.

(32) The working space must have accessible personal communication systems (phone, automatic answer machine, fax, e-mail, and beepers) in order to facilitate assistance continuity, consulting with patients and families and resource connection tasks.

III. PROCESSES

(33) Processes that are considered in this Quality Criteria Guide include:

- Patients and families care
- Team work
- Assessment

III.1. Patients and families attention

(34) As attention processes to patients and families, the following are considered:

- Assessment of patients and families needs
- Establishment of therapeutic objectives
- Comprehensive and continued care to patients and families
- Education of patient and family

III.1.a. Needs assessment

(35) The patient has physical, emotional, spiritual and social needs that must be assessed when the clinical history and the physical examination are made.

(36) A periodic need's assessment of all patients will be done, which allows therapeutic objectives to be defined, as well as to establish a follow-up and evaluation of health results.

(37) Establishing a needs profile and designing a plan with individualised therapeutic objectives will require to evaluate, on each patient, the following aspects:

- Evolution time of his or her disease
- Location, strength, frequency and radiation of pain and other symptoms
- Basic characteristics of the present disease
- Frequency and intensity of crisis
- Physical impact and dependency
- Emotional impact
- Emotional relationships
- Religious believing and value system
- Attitudes and fears towards death
- Previous dispositions
- Family and social resources
- Family needs
- Information

- Disease impact
- Adjustment model, relevant aspects of the experience of facing disease and treatment.

(38) The initial and complete evaluation of patient and family needs will be done by means of a guide that establishes the protocol and directions to be taken.

(39) The evaluation of needs will be registered in writing on the patient's Clinical Chart

III.1.b. Therapeutic objectives

(40) Once the global evaluation of needs of the patient and his or her family has been established, according to the interdisciplinary clinical history and physical examination, a care planning should be determined. This planning should include priorities in needs and establish therapeutic objectives for both the patient and his or her family.

(41) These therapeutic objectives, once they have been established and agreed upon by the interdisciplinary team, should cover and attend physical, emotional, social and spiritual needs of the patient and his or her family.

(42) A supporting plan shall be determined for the family or caring people, very specially for primary careers in order to attend their needs. This plan will be given in writing and will be periodically reassessed.

(43) One of the therapeutic objectives of the attention will consist of the detection of needs and the active promotion of specific education to the patient and his or her family / care-provider related to the cares the patient should receive.

(44) Therapeutic objectives will be periodically reassessed according to the times established in the relevant guides and that are decided by the interdisciplinary team, with deep respect for the values and preferences of patients.

III.1.b. Patient and family attention

(45) Direct attention of patients and their families is the main and most important activity of Palliative Care teams that will be regulated by defined principles and values.

(46) The patient should have a space of his or her own and sufficient time will be granted for him or her to express his or her emotions, to receive information and support, solving questions or worries. An adequate climate of cooperation will preside these meetings, which are highly significant for the patients

emotional and spiritual spheres. Practical topics should also be considered in this life ending process.

(47) The patient and his or her family will be granted a space, availability and time that are adequate to allow a good relationship and communication.

(48) Access to these facilities will be granted to the family in appropriate ways and times.

(49) From the beginning of assistance, a main care-provider or attendance reference will be identified. The primary career is the person who performs most of the care , is responsible for the support activities and acts as the principal responsible for patient's care

(50) A plan will be established for the family to receive the continued and specific education and support to benefit and support the patient.

(51) The team will take care for the early detection and treatment of crisis of emotional failure and the appearance of new stress situations in the family or care-providers. Special interest should be placed on last days situations at home.

(52) A special program of bereavement care, including access mechanisms, risk cases identification and intervention protocols.

III.1.c. Patient and family education

(53) From the first contact with the Palliative Care team, this will analyse and detect educational needs of the patient and his or her family.

(54) Specifically, education and support necessities of the family will have as objectives those of training for an adequate care of the patient, promoting emotional adaptation and preventing pathological bereavement and grief.

(55) The family needs to re-adapt itself during the patient's terminal phase and to restore itself after the death of their loved one. Thus, the team will assess and systematically compile on a specific file the situation, structure, impact and needs of the family.

(56) Both the patient and his or her family will always receive written information; the pharmacological treatment to be administered will be explained in order to facilitate therapeutic comprehension, adherence and effectivity.

(57) Other educational aspects to be included will be the nutritional needs of the patient, information and communication, emotional care and practical care training.

(58) The patient and his or her family will always be informed on how to localise the team or alternative options in case of an emergency, by means of a continued ... system or agreements with emergency care systems.

III.2. Team work

(59) Within this section, the following is considered::

- Team work systems
- Team care and support
- Continued training and research
- Coordination between levels and services

III.2.a. Team work

(60) The global assessment of patients and their families needs, as well as the therapeutic approach in Palliative Care requires a work performed by a team of interdisciplinary professionals.

(61) It is advisable that every patient and his or her family have at least one person in the team to serve as an care personalised reference,.... . Among the functions to be performed by this assistance reference, further to his or her professional duties, he or she will have to manage the established care program and to support the patient and the family, thus facilitating a fluid communication and information exchange.

(62) Team work is essentially based on interdisciplinary meetings, with at least weekly periodicity.

(63) Objectives of these interdisciplinary meetings are:

- Multidimensional evaluation of needs
- To discuss and agree upon therapeutic objectives
- To create an comprehensive and integrated therapeutic program
- Result's assessments
- To identify the needs and supports of the team.

(64) The methods to be applied in these interdisciplinary meetings include a professional assessment, agreements based upon values and contributions, and a systematisation of the work protocols.

(65) The work team in Palliative Care has to base their relations and coordination upon professionalism, respectfulness, communication and support of each other, establishing a good interdisciplinary working environment and cooperation among his members.

(66) Since the needs of the patient change with time, the Palliative Care team must meet periodically to reassess the established care program, deciding which modifications have to be made.

(67) The reassessment of the patient and family needs, care and results will take place within the weekly interdisciplinary meetings.

(68) In order to minimise the variability of its assistance interventions, written protocols and policies will be defined for assistance and inner and outer organisation.

(69) Protocols including the following aspects should be available:

- Admission and assistance priority
- Clinical protocols on frequent symptomatology (symptom control, attention in emergency situations)
- Admittance, accompaniment and follow-up of the bereavement
- Prevention protocols (emergency, emotional failure prevention)
- Last days protocol
- Derivation to other resources (must include the documentation that has to accompany the patient)
- Team access mechanisms
- Intervention criteria with regard to urgent situations and waiting lists
- Home attention
- Family education

III.2.b. Team care and support

(70) The team has the necessity to take care of itself, preventing its burnout and helping its members to face it, should it appear. This need has to be taken into account from the very beginning of training and its activity.

(71) The team will establish formal methods to prevent burnout (for instance, monthly meetings, mental health support, etc.) that serve as a support, training and early detection of this situation. Among informal methods, personal and professional respect attitudes are to be promoted and practiced by all its members.

III.2.c. Continued training and research

(72) A continued training program will be available for the team members, adapted to the needs of quality improvement of attention and to individual demands. This program will be yearly reassessed and will be included in the yearly targets.
(73) Each member of the team should have a basic competence training. More than 50% of them should have an intermediate-advanced training, according to the recommendations or Palliative Care training of SECPAL[1].

(74) Each team will elaborate a written program of continued training sessions. This training program will include at least a monthly session and periodical exchanges with other teams or units.

(75) For an efficient use of the resources and as a quality guarantee of the services, the Palliative care team is responsible of contributing evidence of efficacy, efficiency, effectiveness and cost-effectiveness of its interventions. Thus, teams will develop individualised or cooperative clinical research programs whenever it is possible.

(76) Reference teams should promote the organisation and coordination of investigative studies, as well as of advanced training activities.

(77) The development of research programs is recommended in every palliative care area, including aspects such as symptoms description, evaluation and control, clinical trials of drugs, program effectivity and functioning, training results, bioethics, quality assessment, psychological aspects and social research.

(78) In order to contribute to the development of a solid knowledge base, it is recommended that these research results be published.

III.2.d. Levels and services coordination

(79) Assistance continuity means performing prevention, diagnosis, treatment and prognosis in the most coordinated way that is possible, in the place that offers more satisfaction to the patient and his or her family.

(80) A connection with other necessary resources will be established within the team reference health area, in order to cover in the best possible way the patient needs and that of his or her family. The patient's continued assistance will be guaranteed, particularly with the specialised or general resources that share their attention and those that may be required in special and/or emergency situations (palliative radiotherapy, specific pain management techniques, emergency services):

[1] "Docencia y Formación en Postgrado". In "Recomendaciones básicas de la Formación en Cuidados Paliativos". Sociedad Española de Cuidados Paliativos document from march 6, 1999 (accesible at the web page www.secpal.com).

- Health and social primary care
- Mental health resources
- Reference hospital
- Hospital / day centre
- Rehabilitation
- Related specialities (oncology, haematology, geriatrics)
- Voluntary network
- Social services
- Other support resources

(81) In order to guarantee such a continuity, stable connections will be established with the patient's origin teams. Resource connections, and cooperation with Palliative Care specific teams are aspects that improve assistance continuity and an integrated action.

(82) Such connections must include the planning of common clinical sessions, training activities and research.

(83) Home attention resources will require formal connections with admission services. In order to secure these relationships:

- Written working protocols will be available between these units.
- The documentation that allows the patient's assistance continuity will be determined.

(84) The support team will serve as a consultant of the assistance resources, channelling the upgrading to the professionals of those specialities the efficient assistance of the patient should be coordinated with.

(85) In order to guarantee the attention continuity, there will be written admission criteria for patients in specific resources of Palliative Care. These criteria will establish the responsibility delimitation of the patient in every moment and will be registered on the clinical documentation.

(86) In those places where several palliative care specific resources are available, an agreement will be promoted upon intervention criteria, patient typology, connection and coordination, focusing on continued and integrated attention, as well as to their equity, coverage and accessibility.

III.2.e. Clinical ethics and decision making

(87) Decision making will be based upon clinical ethics principles, promoting the expression, having in mind and respecting the values of the patient, his or her family and of the team members, the contribution of other teams and the common values reflected in this Guide. Furthermore, a close collaboration with the .... ethics committees will be established.

(88) Transcendental and spiritual dimension forms part of the integral attention provided to patients with advanced diseases. The teams will attend to those needs with an absolute respect of religious freedom and complying with the wishes expressed by the patient.

III.3. Assessment and improvement

(89) Evaluation processes include:

- Record and documentation systems
- Information and monitoring systems
- Quality improvement

III.3.a. Record and documentation systems

(90) General documentation will be interdisciplinary and will allow the recording of specific assistance activities. It must include, at least, the Clinical History and the Assistance Report.

(91) The Clinical chart is an essential report that summarises the personal history of the patient, his or her family and social history, pathological background, main diseases, physical symptoms relation, emotional situation, adjustment between patient and family, social and spiritual needs, information and communication with the patient and his or her family, decision making criteria, etc.

(92) The Chart must also reflect the assessments, follow-ups and reassessments results, therapeutic objectives and caring program, treatments received, examinations performed, as well as any other information the team should consider relevant to the complete attention to the needs of the patient. Furthermore, it should also contain the relevant documentation on informed consents to the interventions recommended in Palliative Care.

(93) Within the patients history, the Assistance Report must identify the rationale for the intervention of the Palliative Care team, data on the main disease evolution, main symptoms, emotional adjustment, familiar situation, evaluation by the team, therapeutic program proposed, foreseeable crises, indication or recommendation on the use of appropriate resources and information, communication and health education aspects of the patient.

(94) Regarding clinical information and documentation, generally established guidelines will be taken into account.

III.3.b. Information and monitoring system

(95) The team will clinically monitor symptoms control of the patient and the evolution of the results according to the therapeutic plans and their periodical reassessment.

(96) A recording system will be available for the following-up of clinical symptoms control. Such a system will allow the maintenance of evolutional graphs and facilitate the decision making work of the team.

(97) In patient evaluation, the Palliative Care team will have and use tools that allow determining degrees, intensities and response levels, thus objectifying the changes experienced by the patient in time (visual analogical scales, numerical scales, validated records, etc.).

(98) Further to the clinical monitoring system, an information system will be developed for assessing activities and results of the assistance team. This self-evaluation may include the following indicators:

- Assistance (new patients, typologies, first and successive visits, admissions)
- Functional: stay, survival rate, death rate, mean age
- Resource use (upgrading to hospital ERs, specific resources, outer consults, social services, place of death)
- Therapeutic effectivity monitoring
- Patient's life quality
- Patient's and family's satisfaction with the attention received
- Related teams satisfaction
- Emotional and communication aspects
- Costs

(99) This information and monitoring system, both clinically and organisationally, will be dimensioned according to the different areas where the team performs their activities.

III.3.c. Quality improvement

(100) Regardless of the external evaluation systems where the unit may participate, it is recommended that professionals develop periodic monitoring and self-assessment systems.

(101) The assessment of therapeutic results will be done by means of methodological tools of evaluation. Training in this quality evaluation methodology will be included in the educational training that will be offered.

(102) A system allowing to know the opinion and suggestions of patients, families and team professionals will be available..

(103) Team activities will be assessed by a continuous quality-improving program.

(104) In this Quality-improving Program, the team will define their annual objectives in relation with assistance activities, inner and outer training, as well as research and evaluation.

(105) Quality results and assessments will be registered in written and actions directed toward a quality improvement will be identified, highlighting the goals that have been reached as well as the areas where these improvements have been met.

(106) It is recommended that palliative care teams and services create and implement strategic programs that allow the evolution of their organisations and their continuous adaptation to inner and environmental changes. Thus, in a rational and planned way, the goal of service quality improvement will be reached.

Conclusions

It is our belief that the implementation of these recommendations will allow us to improve the attention we give to our patients and their families, as well as our professionalism and training level, increasing our ability of working as a team.

The Spanish Society of Palliative Care is committed to the divulgation of this Quality Criteria Guide and to properly develop it with the design of quality indicators, according to the guidelines included in it, hoping that it may be useful for improving the quality of Palliative Care teams.

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