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Review

Nomenclature in Palliative and Kidney Supportive Care: Not Just at the End-of-Life

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ABSTRACT

The multidimensional view of disease is fundamental in the care of complex diseases such as chronic kidney disease (CKD). It is appropriate to define and unify concepts that allow the different professionals involved in care to provide a multidisciplinary approach tailored to the needs of each individual.

Given the increasing incidence of CKD worldwide and the fact that the disease may progress at different rates, there is a need to establish personalized, comprehensive approaches for each patient and their families at an earlier stage. This approach goes beyond the simple control of uremic symptoms or congestion and consists of addressing not only symptomatic but also functional, social and coping problems at an early stage, facilitating decision making both in the CKD and in acute situations, potentially irreversible or interventions that do not improve life expectancy.

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[1] † Juan Pablo Leiva-Santos (deceased), whose contributions were integral to this work, passed away prior to its publication. We honor his memory and dedication to the field.

To ensure excellence in care, it is important to assess indicators of palliative care and kidney support, such as the presence of advance and shared care planning, the inclusion of psychosocial, ethical, spiritual and bereavement care. This enables the provision of comprehensive, humanized, and high-quality care for patients and their families. Palliative and kidney care is not just about patients in the last days of life. Defining, unifying, and evaluating the concepts will allow them to be applied in a timely manner at each specific moment of the CKD trajectory.

Nomenclatura en cuidados paliativos y de soporte renal: no solo al final de la vida

RESUMEN

Palabras clave:
Nomenclatura
Nefrología
Enfermedad renal crónica
Cuidados paliativos
Cuidados de soporte

La visión multidimensional de la enfermedad es fundamental en la atención de patologías complejas como la enfermedad renal crónica (ERC). Es oportuno definir y unificar conceptos que permitan que los diferentes profesionales encargados de la atención ofrezcan una atención multidisciplinar, alineados a las necesidades de cada persona.

Debido al creciente aumento de la incidencia de ERC en el mundo y teniendo en cuenta que pueden existir diferentes trayectorias en el curso de la enfermedad, es necesario establecer abordajes integrales personalizados para cada paciente y sus familias de manera más temprana. Este planteamiento va más allá del simple control de los síntomas urémicos o de la congestión y consiste en abordar tempranamente los problemas no sólo sintomáticos sino también funcionales, sociales y de afrontamiento de la enfermedad, facilitando la toma de decisiones tanto en el escenario de la ERC como en situaciones agudas, potencialmente irreversibles o en intervenciones que no mejoren el pronóstico vital.

Para asegurar la excelencia en la atención es relevante evaluar indicadores para la atención paliativa y de soporte renal, como la presencia de la planificación anticipada y compartida de la atención, la inclusión de atención psicosocial, ética, espiritual y la atención al duelo. Esto permite ofrecer una atención integral, humanizada y de calidad para el paciente y sus familiares.

Los cuidados paliativos y de soporte renal no se orientan únicamente a los pacientes en los últimos días de vida. Definir, unificar y evaluar los conceptos permitirá aplicarlos de manera oportuna en cada momento especifico de la trayectoria de la ERC.

Key concepts

- Comprehensive care model for patients with palliative care needs and their families according to the clinical context:
    - none◦ *Palliative care* (PC) in advanced chronic kidney disease (ACKD), regardless of prognosis.
    - none◦ *Kidney supportive care* (SC), in all stages of kidney disease.
    - none◦ *Comprehensive conservative care,* in CKD G5 without kidney replacement therapy, equivalent to conservative kidney management.
- After the patientś need for palliative care has been identified, person-centred care is provided through a collaborative care planning process that develops structured and dynamic intervention strategies according to the patientś wishes.
- It is appropriate to use currently accepted terms, such as *therapeutic adequacy*, *end-of-life situation* and *last days of life situation,* to those previously used, such as limitation of therapeutic effort, terminal illness and agony.
- Palliative sedation aims to reduce the level of consciousness in a patient with a refractory symptom with the aim of relieving suffering. It should not be initiated if the patient or his or her representative (if expressly requested) does not wish and/or does not consent.
- There is currently no consensus on quality indicators for palliative care in patients with ACKD. However, some authors propose the evaluation of structural, process and outcome indicators.

Introduction

Standardisation of nomenclature is mainly based on appropriate and systematic naming of a concept, its correct description, and its relationship with other accepted terms.[1]

In short, standardisation of nomenclature is more than just a concern about the c̈orrectn̈aming of concepts, as the definition of a term or concept has a significant impact on care, teaching and research. The correct use of nomenclature influences the ability to communicate with other professionals, patients, relatives and students, allowing a better appreciation of different aspects such as disease burden to be conveyed. The perceptions of patients and their families about the disease allows the standarisation of concepts and definitions used to build databases and analyse them, even in the new era of *Big Dat* and *Machine Learning*. Conceptual clarification has been identified as a resource to reduce barriers to access to kidney palliative care and facilitate the integration of palliative care into nephrology.[2]

The consensus document of the Kidney Disease: Improving Global Outcomes (KDIGO) initiative was recently presentd in Nephrology[3] with the aim of homogenising the nomenclature for kidney function and disease. This consensus document allowed some authors of this manuscript to lead a multinational initiative towards the standardisation of nomenclature in Spanish.[4] Among other aspects, definitions accepted in Spanish-speaking countries were proposed both in acute situations[5] and in chronic kidney disease (CKD).[6,7] Palliative care (PC) is no stranger to this reality.[8] Terms such as *terminal CKD* or *limitation of therapeutic effort* continue to be used among nephrologists. At the same time, the false notion of the usefulness of PC only in last days situations or for the prescription of palliative sedation highlights the need to establish a common language, centred on the needs of the patient and not only based on the medical speciality.[9] Seeking care focused on the person, which allows care to be provided with dignity, compassion and respect; coordinated, personalised care with an active role for the patient.[10]

It is estimated that there are approximately 850 million kidney patients in the world, making it the 12th leading cause of death globally.[11] Unfortunately, it is estimated that by 2040, it will be the 5th leading cause of detah globally, especially considering that most of these patients will be 65 years of age or older. Despite progress in kidney replacement therapies (KRT), mortality in this group of patients is extraordinarily high compared to the general population of similar age.[12] Probably this highr mortality, at least in part, could be due to the high prevalence of frailty in the elderly population. It is estimated that frailty is 14% prevalernt in older adults with CKD without KRT and up to 40-70% in those on KRT, increasing the risk of mortality by up to 2.5 times in this population.[13]

It is for this reason that in recent years the importance of generating management guides has emerged,[14] that include the assessment of fragility with its different components (physical/functional, mental and nutritional) and adequate shared decision planning that allows for a suitable personalisation of care for these advance patients. This comprehensive assessment should include PC experts and in some cases also geriatric specialist in the follow-up of some patients with Advanced Chronic Kidney Disease (ACKD).[15–18]

The aim of this article is to correctly define terms related to the comprehensive approach to patients with palliative care needs and establish the minimum quality indicators necessary to improve the quality of life of patients with CKD and their families.

Defining terms in kidney palliative care

Structural concepts

PC should be offered to patients with advanced diseases from all areas of medicine at an early stage, and not only reserved for comprehensive care for patients and families in end-of-life situations. This is due to the change in the model experienced in recent years, which involves not only applying PC to the patient on the basis of prognosis but also to palliative care needs at any time during the advanced disease. It is necessary to avoid the still common interpretation that a patient receiving palliative care is believed to have a very short life prognosis or that their level of intervention/treatment has been appropriate.

Hui et al.[8] summarised the definitions published in articles, textbooks, dictionaries, etc., on concepts such as PC and supportive care (SC), among others.[8] Different definitions of PC were identified, the most cited being the one defined by the World Health Organization (WHO)[8,18] (Table 1). This review showed that the stage of the disease was a key factor in the differentiation of terms such as PC and SC,[8] classifying in the SC all patients who require comprehensive care during all phases of the disease, while the PC would only focus on care in patients with advanced disease.[8,19] However, at a practical level, it is understood the flexibility of these definitions to expand their scope.

In the area of nephrology, kidney supportive care (KSC) has been established, aimed at ensuring that all patients receive high quality care thanks to a timely multidisciplinary approach.[9,15,16,20] However, provision should be based on need and not just estimated survival.[15,16] These support teams usually include nephrologists, PC experts, nurses, social workers, nutritionists, and psychologists, among others, allowing the principles and practices of PC to be integrated into all areas of nephrology (clinical nephrology, haemodialysis, peritoneal dialysis, kidney transplant, patients undergoing conservative treatment or end-of-life situations). Contrary to what is often thought, it does not necessarily mean suspending dialysis and only offering symptom control. On the contrary, it is about transferring global attention to the different stages of kidney disease,[21] whether while they receive specific kidney management or *comprehensive conservative care*[15,16] (Fig. 1).

It is necessary to clarify that n̈on-dialysis treatment; as a definition in itself, does not integrate the concept of palliative care. An effort should be made to integrate PC into non-dialysis management.[22]

There are several tools to identify a patient need for palliative care, such as the PIG/GSF (Gold Standards Frame-

Table 1 – Concepts most used in palliative and renal support care.

Concept	Definition
Structural concepts	
Palliative care	A model of care that improves the quality of life of patients (adults and children) and their families facing the problems associated with a life-threatening illness. They prevent and alleviate suffering through early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.[18]
Supportive care	Comprehensive care to meet the physical, informational, emotional, psychological, social, spiritual and practical needs of patients during the pre-diagnostic, diagnostic, treatment and follow-up phases.[19] Care for prognostically stable CKD, but with dynamic needs ranging from non-complex to highly complex.[9]
Comprehensive conservative care	Holistic, patient-centred care for patients with G5 CKD who are not candidates for RRT, including - Interventions to delay progression of kidney disease and minimise the risk of adverse events or complications. - Shared decision making - Active symptom management - Detailed communication, including advance care planning - Psychological support - Social and family support - Cultural and spiritual areas of care.[15]
Conservative kidney management	It is an alternative to kidney replacement therapy that focuses on adequate control of the symptoms associated with kidney disease, is proposed for patients who do not want or are contraindicated for haemodialysis, peritoneal dialysis or kidney transplantation, and integrates the values and principles of palliative care.[16]
Basic concepts	
Frailty	An age-related physical condition characterised by a decline in several physiological systems and a reduced ability of the body to withstand stressful situations, leading to an increased risk of adverse health events. Modified from Fried et al.[61]
Adjustment of therapeutic effort	It implies the non-implementation or withdrawal of those diagnostic and/or therapeutic interventions that do not benefit the patient and may instead prolong their suffering and impair their quality of life.[32]
Advance care planning	The process of planning for future medical (or non-medical) care in the event that the patient is unable to make decisions for themselves.[33]
Advance directives	A document addressed to health professionals and drawn up by a person of full age, containing instructions to be followed in the event of the patient being unable to express his or her wishes in person, as well as the name of the person designated by the patient as guarantor of his or her wishes in the event of the patient being unable to express his or her will, and formalised before a notary or in the presence of three witnesses.[38]
Shared care planning	A communicative-deliberative, relational and structured process that facilitates reflection and understanding of the illness and care experience of those involved, with the person facing the illness at the centre, in order to identify and express their values, preferences and expectations of care. It aims to promote shared decision making.[33]
Palliative dialysis or ultrafiltration	Dialysis whose main objective is to improve the patient's symptoms without taking into account other aspects related to adequacy[41–44]
End-of-life concepts	
Last days of life situation	The period before death, when death is gradual, and when there is severe physical deterioration, extreme weakness, a high incidence of cognitive and consciousness disorders, difficulty in feeding and in relating to the environment, and a life expectancy of days or hours.[48]
Refractory symptom	Symptom that cannot be adequately controlled within a reasonable period of time without compromising the patient's consciousness, despite intensive efforts to find a tolerable treatment. Modified from Cherny and Portenoy,[49] Surges et al.,[50] Azulay Tapiero[51] and Porta Sales[52]
Palliative sedation	The deliberate administration of drugs, in the required doses and combinations, to reduce the consciousness of a patient with advanced disease to the extent necessary to provide adequate relief of one or more refractory symptoms. It requires the explicit or implicit consent of the patient (or their legal representative). Modified from “*Care of dying adults in the last days of life*”[47], “Clinical Practice Guide on palliative care for adults in the last days of life”[48] and Cherny and Portenoy[49]
Desire to hasten death	It is a response to suffering in the context of a life-threatening condition from which the patient sees no way out other than to hasten death. This wish may be expressed spontaneously or after being asked, but should be distinguished from acceptance of impending death or the wish to die naturally, but preferably in the short term. It may arise in response to one or more factors, including physical symptoms (present or anticipated), psychological distress (e.g. depression, hopelessness, anxiety), existential suffering (e.g. loss of meaning in life), or social aspects (e.g. feeling a burden to one's family)[53]
Euthanasia	An intentional act or omission that ends the life of a person, brought about by the person's express will and with the aim of avoiding suffering.[54]

CKD: chronic kidney disease; KRT: kidney replacement therapy.

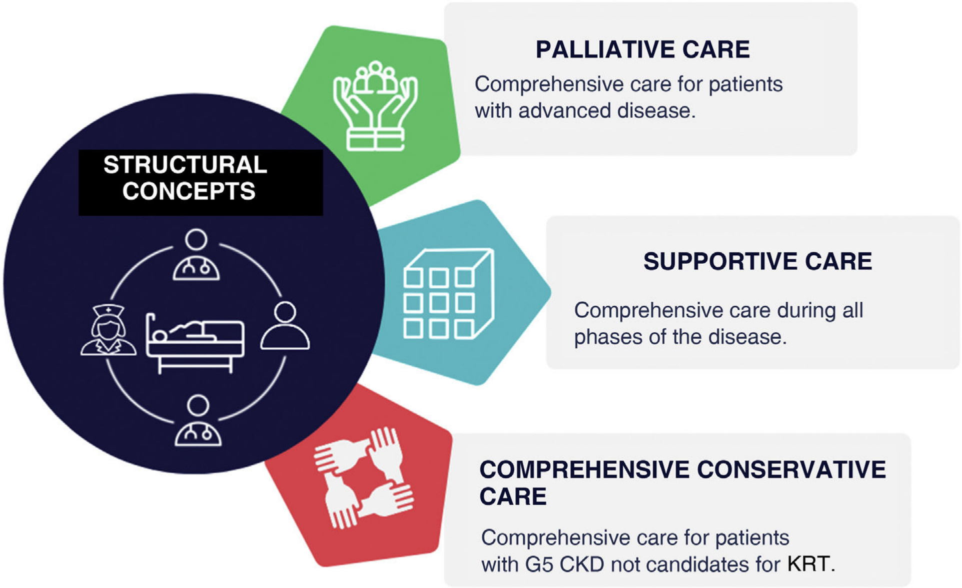


Fig. 1 – Structure of palliative care in patients with advanced chronic kidney disease.
CKD G5: grade 5 chronic kidney disease (refers to cases with a glomerular filtration rate that drops below 15 ml/min/1.73 m^2); KRT: kidney replacement therapy: comprehensive conservative care, synonymous with conservative kidney management (CKM).

work Prognostic Indicator Guidance) screening test,[23] the surprise question,[24] the SPICT^{TM} *(Supportive and Palliative Care Indicators)*[25] and the NECPAL CCOMS-ICO© (Identification of People with Advanced Terminal Illness and Need for Palliative Care in Health and Social Services)[26] originally developed in Catalonia and later extended nationally and internationally. The identification process includes whether there is a negative response to the surprise question (Would you be surprised if the patient died in 12 months?), the grading of the disease, and the patient's and/or family's need for care,[26,27] allowing the identification of palliative care needs with 92% (87.2%-94.2%) sensitivity and 33% (29.6%-36.3%) specificity.[27] Once this need is identified, disease-specific treatment measures are not excluded and can be implemented by any team in any health service. This allows stepwise implementation of a palliative approach, avoiding dichotomous positions. Other specific palliative care implementation programs are based on "triggering situations," such as the choice between conservative versus active treatment in the case of ACKD.[28] These programs based on specific triggering criteria, have been shown in oncology to be more effective in optimising the timing of PC integration in the disease trajectory.[29]

Once patients with palliative needs have been identified, it is necessary to detrmine what these needs are, and there are also specific tools for the assessing symptoms, such as the modified renal ESAS *(Edmonton Symptom Assessment System)*[30] and the POS version *(Palliative Care Outcome Renal Scale-Symptoms)*, the latter translated and validated in Spanish.[31]

Basic concepts

In the context of patients with ACKD and palliative care needs, it is essential to assess the trajectory of the disease in order to offer a replacement or conservative treatment, and to implement a timely adjustment of the therapeutic effort (ATE) in those patients in whom diagnostic tests or therapeutic interventions do not provide a benefit. It is crucial to note that ATE must be distinguished from concepts such as palliative sedation and euthanasia[32]; it is also the term that replaces the one previously used: *limitation of therapeutic effort*. In the field of nephrology, this adaptation implies certain peculiarities with respect to other life support therapies (such as mechanical ventilation), where the death of the patient occurs shortly after its cessation. In the case of dialysis or conservatively managed ACKD, however, the time is much longer and the patient's preferences must be recognised. In this way, ATE can have different applicable levels depending on the clinical situation and the preferences of the patient and their families, thus helping to avoid diagnostic and therapeutic interventions that could be considered futile. Certain institutions or departments have developed therapeutic adjustment

Table 2 – Example of levels of therapeutic intervention in patients with advanced disease.

Level 1	Patient requiring all diagnostic and therapeutic measures, including cardiopulmonary resuscitation and orotracheal intubation for mechanical ventilation. Must be treated in the intensive care unit.
Level 2	Patient requiring all diagnostic and therapeutic measures (including non-invasive mechanical ventilation, vasoactive drugs, haemodialysis, blood product transfusions, parenteral nutrition) except cardiopulmonary resuscitation and orotracheal intubation for mechanical ventilation. Do not treat in the intensive care unit.
Level 3	3A: Conditional measures: in the case of an intercurrent process, a temporary level 2 measure is introduced and withdrawal is agreed in the event of poor performance. 3B: No new measures. 3C: Gradual withdrawal of all measures except antibiotic treatment.
Level 4	Symptomatic and comfort care. Usually patients in the last days of life.

Modified from: https://ico.gencat.cat/web/.content/minisite/ico/professionals/documents/arxius/icopraxis_atencio_3.pdf [viewed on November 27, 2022].

guides that specify levels in order to standardise concepts and adjust interventions to the established level, which may vary according to the clinical situation and the patient's preferences (Table 2).

The ATE structure is based on processes such as advance care planning (ACP),[33] until recently called shared care planning (SCP).[34] The aim of this intervention is not only to record the patient's wishes, but also to understand and share preferences, values and expectations about future treatments and even the end of life, as well as to identify a representative for the patient at times when the person is unable to make decisions.[35] The family is essential in conducting the ACP, as it is an opportune time to answer questions, facilitate communication about the illness, and learn about the patient's and family's concerns.[36] An added benefit of the ACP is the creation of a bond of trust between the patient, family and healthcare team, which leads to better adherence to treatment.

Although ACP, understood as a process, could be carried out in a ẗraditionalẅay, expressing preferences on issues such as the use of invasive mechanical ventilation, cardiopulmonary resuscitation, transfusions, etc., the dynamic nature of the disease calls for individualised planning linked to clinical pathways, which in the context of ACKD could be divided into three phases: The first is the information phase, in wich the diagnosis and prognosis of the disease are explained to the patient and his family, which is particulary important in order to provide a solid basis for the continuity of the process; the second is the phase in which the loss of function is usually a turning point and a *therapeutic adaptation* is considered and *decisions are made*, such as conservative renal treatment versus KRT or admissions versus home management, among others; and the third is the phase in which decision are made in the context of the *end-of-life*. As clinical pathways affect the patient's health status and quality of life, it is useful to identify and review preferences for future care in light of a new clinical status.[37]

Sometimes ACP is confused with the Advance Directive (AD) or the Document of Prior Instructions.[38] The AD may be part of the ACP; however, conducting the ACP process facilitates greater concordance between the patient's wishes and the professionalsḱnowledge, helps to reduce the complexity of the decision-making process, and creates structured intervention strategies that are more effective than an isolated document.[39] The AD would be the legal document, whereas ACP is a clinical process that seeks to involve the patient and their family in the decision-making process.[40]

This planning, as a communication process, is not closed and can be carried out early and as often as the patient needs, as their views and needs or the situation may change.[37,39,40] The ACP and AD are flexible and their application will depend mainly on the patient's clinical situation and their ability to maintain active decision-making. An example in nephrology is that some patients on kidney replacement therapy have an AD in which measures to artificially prolong life through life support techniques are refused.

Specifically in nephrology, there are different concepts related to the approach to the patient in situations of advanced disease. One of these is the consensus between the clinician and the patient/family to maintain a conservative approach to the management of kidney disease (conservative renal treatment or comprehensive conservative care).[16] Another example is that of patients on a regular haemodialysis or peritoneal dialysis programme, who have a high burden of comorbidity, frailty or dementia. In these cases, if the clinical or functional situation has deteriorated, a consensus should be reached with the patient and/or family about a gradual change in the therapeutic goal. Changes can range from a gradual reduction in the time and number of sessions, to less intensive treatment (palliative dialysis).[41–43] In some cases, the possibility of stopping dialysis altogether should be considered. Palliative dialysis is in line with the goals of palliative care, which aims to ensure adequate symptom control and is not solely based on clinical indicators.[44]

It has been considered that the dialysis withdrawal can be a healthy process for the patient, the family and the professional team. With this in mind, a dialysis withdrawal protocol called Intro-ACP-WDC has been published.[21,45]

End-of-life-concepts

In clinical situations where the patient's prognosis is limited, there is a wide variety of terms: for example, *terminally ill*, *terminal-stage disease* (widely used in nephrology) and *agony*- which should be discarded because of their pejorative connotations. More widely accepted terms such as *end-of-life situation*, *last days of life situation,* and *actively dying* are preferred. Because of the ambiguity of some terms and the potential for misinterpretation, definitions have been explored to provide clarity and even a possible temporal consideration of prognosis. Hui et al.[46] suggest using the term *end-of-life situation* in the presence of a progressive disease with months or less of survival and using *actively dying* in the presence of processes where survival is limited to a few days. In our context, the term used is *last days of life situation*, synonymous with *actively dying*, proposed by the *National Institute for Health and Care Excellence* (NICE) on the care of adults in the last days of life and by the Guía de Práctica Clínica del Sistema Nacional de Salud [National Health System Clinical Practice Guide].[47,48]

The management of a patient in the last days of life requires an awareness of the multiple needs that arise and a focus on the biopsychosocial dimension of the process, symptom control, and spiritual and family support to ensure a death in accordance with the person's values and preferences. From the perspective of symptomatic management, some patients may present with refractory symptoms despite timely treatment (e.g., use of opioids for dyspnoea) (Table 1).[49,50] When suffering related to the refractory symptom persists, palliative sedation may be considered in the context of an advanced disease and with the patientś consent.[50–52] Therefore, within the framework of the above-mentioned ACP, it is necessary to know whether a patient in an end-of-life situation wishes to receive palliative sedation, where justified, always taking into account different personal aspects of the patient, such as religion, beliefs or wishes, as in some cases these aspects may influence the decision.

When a patient experiences a situation of suffering, whether due to poor symptom control, disease progression or demoralisation, he or she may express *wishes to hasten death*.[53] In most cases, these wishes are reactive and do not always represent a request for euthanasia, so it is necessary to identify this suffering, recognise its likely origin, and try to offer an intervention to alleviate it.[49,51,52]

In Spain, the organic law regulating euthanasia was recently passed (Organic Law 3/2021 of 24 March, in force since 25 June, 2021),[54] which is requested by the patient on the basis of certain criteria and evaluated by various specialists and committees to be approved or rejected.

Quality of palliative care in ACKD

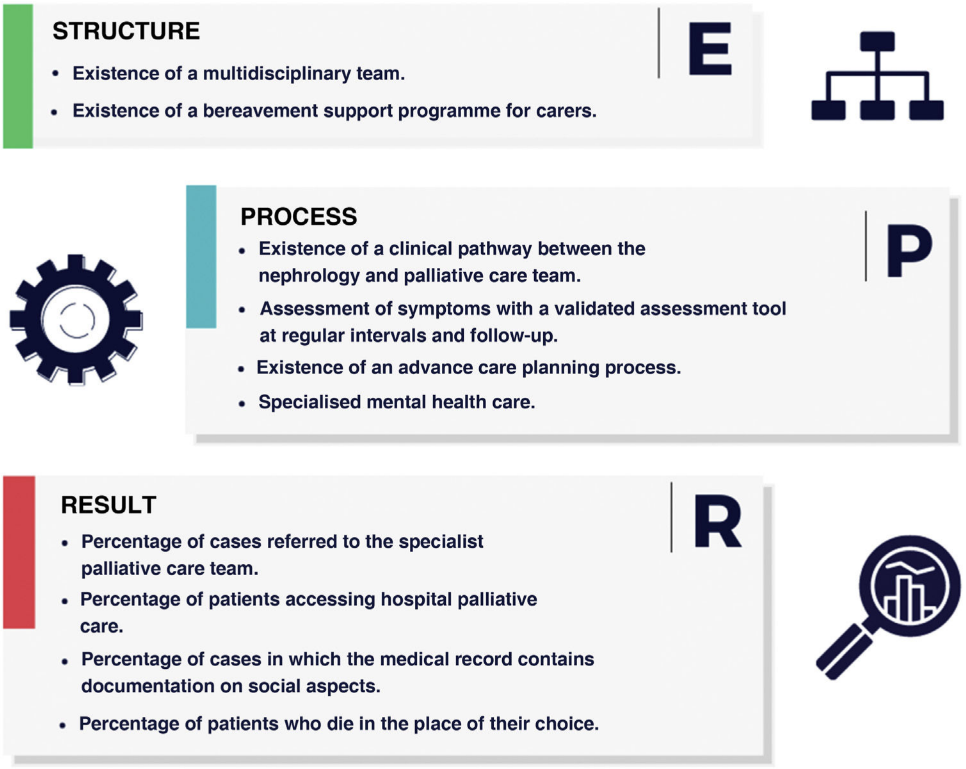
The quality of care for ACKD can be evaluated using indicators based on dimensions identified for the stage of the disease. Currently, there is no consensus on quality indicators for the management of PC in ACKD. However, numerous studies have presented metrics and standards that can guide the structure and process requirements of care and its expected outcomes. In 2015, the KDIGO Controversy Conference on Supportive Care in CKD[16] developed a roadmap to improve the quality of care in CKD that includes seven domains:

1 Delaying disease progression and minimising the risk of complications.
2 Shared decision making.
3 Active symptom management.
4 Advance care planning.
5 Psychological support.
6 Social and family support.
7 Addressing cultural and spiritual aspects of care.

A Canadian consensus conducted in 2018[55] used the domains to assess the quality of care in ACKD and identified 10 indicators, some of which are: pain assessment; access to specialised PC services; discussion of the treatment plan between the patient/family and the healthcare team; initiation of kidney replacement therapy despite the choice of conservative renal therapy; consideration of the patient's beliefs and values in choosing the therapeutic plan; continuous assessment of symptoms and the inclusion of clinical measures to reduce their burden on the patient. The indicator with the highest score in the consensus was the percentage of patients who die in the place of their choice, an aspect that guarantees patientsṕreferences and wishes.[56]

The development of quality indicators in ACKD has focused on hospital outcomes in various reports[55–57]; however, resources and processes to ensure comprehensive care in advanced disease are limited. The 2018 *Global Kidney Health Atlas*, which specifically addressed the availability, accessibility, and quality of conservative renal management, reported that in 154 countries surveyed, access to the structures needed to provide PC was low, particularly in low-income countries. Only 46% of respondents reported the existence of multidisciplinary programmes, 32% had implemented shared decision-making, and 36% had the resources to provide psychological, cultural, or spiritual support in the care of patients with kidney disease.[58] A comprehensive assessment of the quality of care must address elements of structure, process and outcomes to provide a comprehensive evaluation of the resources, actions and outcomes found in the holistic care of the person with ACKD and their family.

According to the quality assessment model proposed by Donabedian, information on the quality of care in ACKD should consider three categories: structure, processes and outcomes that incorporate palliative care.[59] Fig. 2 presents a list of ten quality indicators discussed in the literature to assess the comprehensive approach to advanced kidney disease, focusing on the presence of palliative care health resources, including mechanisms for patient referral and family bereavement.[55,58,60] Symptom control, advance care



STRUCTURE

- Existence of a multidisciplinary team.
- Existence of a bereavement support programme for carers.

PROCESS

- Existence of a clinical pathway between the nephrology and palliative care team.
- Assessment of symptoms with a validated assessment tool at regular intervals and follow-up.
- Existence of an advance care planning process.
- Specialised mental health care.

RESULT

- Percentage of cases referred to the specialist palliative care team.
- Percentage of patients accessing hospital palliative care.
- Percentage of cases in which the medical record contains documentation on social aspects.
- Percentage of patients who die in the place of their choice.

Fig. 2 – **Structural, process and outcome quality indicators in palliative care for patients with kidney disease.**

planning, and the inclusion of mental health in the care process are the main elements to be assessed in the integration of palliative care in ACKD.[55] Similarly, the evaluation of care outcomes focuses on measuring the effective use of palliative care in kidney disease and the inclusion of the psychosocial component in patient management and the assessment of family needs to promote well-being and quality of life as the overall goal of care and attention.[61]

Conclusion

Nephrologists' detailed knowledge of the nomenclature related to palliative and end-of-life care contributes to improving the care of patients and their families, avoiding misunderstandings in their care, providing the basis for quality teaching and promoting research in an area of convergence between different specialities for the benefit of knowledge. The use of quality indicators aligned with the new nomenclature will encourage the development of comprehensive care models that promote the quality of life of patients and their families throughout the course of the disease. The recognition of the global nature of palliative or supportive care highlights the need for self-care processes for the professional team providing this service and a multidisciplinary care, given the complexity of this work.

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Conflicts of interest

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REFERENCES

1. Gaudet-Blavignac C, Foufi V, Bjelogrlic M, Lovis C. Use of the systematized nomenclature of medicine clinical terms (SNOMED CT) for processing free text in health care: systematic scoping review. J Med Internet Res. 2021;23(1):e24594, http://dx.doi.org/10.2196/24594.
2. Jablonski A. Ethical issues in dialysis aaron spital, series editor: palliative care: misconceptions that limit access for patients with chronic renal disease. Semin Dial. 2008;21(3):206–9, http://dx.doi.org/10.1111/j.1525-139X.2007.00394.x.

3. Levey AS, Eckardt KU, Dorman NM, Christiansen SL, Hoorn EJ, Ingelfinger JR, et al. Nomenclature for kidney function and disease: report of a Kidney Disease: Improving Global Outcomes (KDIGO) Consensus Conference. Kidney Int. 2020;97(6):1117–29, http://dx.doi.org/10.1016/j.kint.2020.02.010.
4. Bover J, Bosch R, Luis Górriz J, Ureña P, Ortiz A, daSilva I, et al. Kidneys also speak Spanish: Initiatives towards standardisation of our nephrology nomenclature. Nefrologia. 2022;42(3):223–32, http://dx.doi.org/10.1016/J.NEFROE.2022.09.003.
5. Bover J, Romero-González G, Chávez-Iñiguez JS, Rizo-Topete L, Graterol F, Vila Santandreu A, et al. AKI (Acute Kidney Injury): AQUÍ la nomenclatura también es importante. Nefrología. 2022, http://dx.doi.org/10.1016/j.nefro.2022.07.003.
6. Bover J, Haarhaus ML, Furlano M, Ureña P, Vervloet M, daSilva I, et al. English–Latin nomenclature conundrum: should we use kidneylogy, kidneylogist? Kidney Int. 2020;98(5):1352–3, http://dx.doi.org/10.1016/j.kint.2020.08.015.
7. Ferreiro-Fuentes A, González-Bedat MC, Lombardi R, Lugon J, Mastroianni G, Mira F, et al. Consenso iberoamericano para uniformar la nomenclatura de la función y las enfermedades renales. Rev Nefro Latinoam. 2020;17(2), http://dx.doi.org/10.24875/NEFRO.M20000009.
8. Hui D, De La Cruz M, Mori M, Parsons HA, Kwon JH, Torres-Vigil I, et al. Concepts and definitions for "supportive care," "best supportive care," "palliative care," and "hospice care" in the published literature, dictionaries, and textbooks. Support Care Cancer. 2013;21(3):659–85, http://dx.doi.org/10.1007/s00520-012-1564-y.
9. Sánchez Hernández R, Zamora González-Mariño R, Rodríguez-Osorio Jiménez L. Cuidados paliativos en la enfermedad renal crónica. Nefrología. 2018;10(1):8–15 https://www.revistanefrologia.com/es-cuidados-paliativos-enfermedad-renal-cronica-articulo-X1888970018627957
10. Morton RL, Sellars M. From patient-centered to person-centered care for kidney diseases. Clin J Am Soc Nephrol. 2019;14(4):623–5, http://dx.doi.org/10.2215/CJN.10380818.
11. Bikbov B, Purcell CA, Levey AS, Smith M, Abdoli A, Abebe M, et al. Global, regional, and national burden of chronic kidney disease, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. Lancet. 2020;395(10225):709–33, http://dx.doi.org/10.1016/S0140-6736(20)30045-3.
12. CKD: the burden of disease invisible to research funders. Nefrología. 2022;42(1):65–84, http://dx.doi.org/10.1016/J.NEFRO.2021.09.004.
13. Mora-Gutiérrez JM, Slon Roblero MF, Castaño Bilbao I, Izquierdo Bautista D, Arteaga Coloma J, Martínez Velilla N. Enfermedad renal crónica en el paciente anciano. Rev Esp Geriatr Gerontol. 2017;52(3):152–8, http://dx.doi.org/10.1016/J.REGG.2016.03.006.
14. Farrington K, Covic A, Nistor I, Aucella F, Clyne N, de Vos L, et al. Clinical Practice Guideline on management of older patients with chronic kidney disease stage 3b or higher (eGFR<45 mL/min/1.73 m^2): a summary document from the European Renal Best Practice Group. Nephrol Dial Transplant. 2017;32(1):9–16, http://dx.doi.org/10.1093/NDT/GFW411.
15. Davison SN, Levin A, Moss AH, Jha V, Brown EA, Brennan F, et al. Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care. Kidney Int. 2015;88(3):447–59, http://dx.doi.org/10.1038/KI.2015.110.
16. Gelfand SL, Scherer JS, Koncicki HM. Kidney supportive care: core curriculum 2020. Am J Kidney Dis. 2020;75(5):793–806, http://dx.doi.org/10.1053/j.ajkd.2019.10.016.
17. García-Maset R, Bover J, Segura de la Morena J, Goicoechea Diezhandino M, Cebollada del Hoyo J, Escalada San Martín J, et al. Documento de información y consenso para la detección y manejo de la enfermedad renal crónica. Nefrología. 2022;42(3):233–64, http://dx.doi.org/10.1016/J.NEFRO.2021.07.010.
18. Cuidados paliativos. Accessed November 27, 2022. https://www.who.int/es/news-room/fact-sheets/detail/palliative-care.
19. Fitch MI. Supportive care framework. Can Oncol Nurs J/Revue Canadienne de Soins Infirmiers en Oncologie. 2008;18(1):6–14, http://dx.doi.org/10.5737/1181912x181614.
20. Leiva-Santos JP, Sánchez-Hernández R, García-Llana H, Fernández-Reyes MJ, Heras-Benito M, Molina-Ordas A, et al. Cuidados de soporte renal y cuidados paliativos renales: Revisión y propuesta en terapia renal sustitutiva. Nefrologia. 2012;32(1):20–7, http://dx.doi.org/10.3265/NEFROLOGIA.PRE2011.NOV.11065.
21. Sánchez Hernández R. Cuidados paliativos en la enfermedad renal crónica avanzada. In: Babarro AA, García Llana H, Leiva Santos JP, Sánchez Hernández R, editors. Cuidados Paliativos En Enfermedad Renal Crónica Avanzada. Pulso ediciones; 2018. p. 65–81.
22. Jassal SV, Kelman EE, Watson D. Non-dialysis care: an important component of care for elderly individuals with advanced stages of chronic kidney disease. Nephron Clin Pract. 2011;119 Suppl. 1:c5–9, http://dx.doi.org/10.1159/000328017.
23. O'Callaghan A, Laking G, Frey R, Robinson J, Gott M. Can we predict which hospitalised patients are in their last year of life? A prospective cross-sectional study of the Gold Standards Framework Prognostic Indicator Guidance as a screening tool in the acute hospital setting. Palliat Med. 2014;28(8):1046–52, http://dx.doi.org/10.1177/0269216314536089.
24. Downar J, Goldman R, Pinto R, Englesakis M, Adhikari NKJ. The "surprise question" for predicting death in seriously ill patients: a systematic review and meta-analysis. Can Med Assoc J. 2017;189(13):E484, http://dx.doi.org/10.1503/cmaj.160775.
25. Bergenholtz H, Weibull A, Raunkiær M. Supportive and palliative care indicators tool (SPICTTM) in a Danish healthcare context: translation, cross-cultural adaptation, and content validation. BMC Palliat Care. 2022;21(1):1–11, http://dx.doi.org/10.1186/S12904-022-00931-6/TABLES/2.
26. Gómez-Batiste X, Martínez-Muñoz M, Blay C, Amblàs J, Vila L, Costa X, et al. Identifying patients with chronic conditions in need of palliative care in the general population: development of the NECPAL tool and preliminary prevalence rates in Catalonia. BMJ Support Palliat Care. 2013;3(3):300–8, http://dx.doi.org/10.1136/BMJSPCARE-2012-000211.
27. Gómez-Batiste X, Martínez-Muñoz M, Blay C, Amblàs J, Vila L, Costa X. Identificación de personas con enfermedades crónicas avanzadas y necesidad de atención paliativa en servicios sanitarios y sociales: elaboración del instrumento

NECPAL CCOMS-ICO©. Med Clin (Barc). 2013;140(6):241–5, http://dx.doi.org/10.1016/j.medcli.2012.06.027.
28. Babarro AA, Rexach Cano L, Gisbert Aguilar A. Criterios de selección de pacientes con enfermedades no oncológicas en programas y/o servicios de cuidados paliativos. Med Paliat. 2010;17(3):161–71.
29. Kayastha N, LeBlanc TW. When to integrate palliative care in the trajectory of cancer care. Curr Treat Options Oncol. 2020;21(5):1–13, http://dx.doi.org/10.1007/S11864-020-00743-X.
30. Davison SN, Jhangri GS, Johnson JA. Cross-sectional validity of a modified Edmonton symptom assessment system in dialysis patients: a simple assessment of symptom burden. Kidney Int. 2006;69(9):1621–5, http://dx.doi.org/10.1038/SJ.KI.5000184.
31. Gutiérrez-Sánchez D, Leiva-Santos JP, Sánchez-Hernández R, Hernández-Marrero D, Cuesta-Vargas AI. Spanish modified version of the palliative care outcome scale–symptoms renal: cross-cultural adaptation and validation. BMC Nephrol. 2016;17(1):180, http://dx.doi.org/10.1186/s12882-016-0402-8.
32. Pérez Pérez FM. Adecuación del esfuerzo terapéutico, una estrategia al final de la vida. SEMERGEN - Medicina de Familia. 2016;42(8):566–74, http://dx.doi.org/10.1016/j.semerg.2015.11.006.
33. Emanuel LL, Von Gunten CF, Ferris FD. Advance care planning. Arch Fam Med. 2000;9(10):1181–7, http://dx.doi.org/10.1001/ARCHFAMI.9.10.1181.
34. Lasmarias C, Velasco Sanz T, Carrero Planes VE, Granero-Moya N. Planificación Compartida de la Atención AE de. Planificación compartida de la atención: la COVID-19, ¿una oportunidad? Medicina Paliativa. 2020;27(3):267–8, http://dx.doi.org/10.20986/medpal.2020.1164/2020.
35. Lasmarías C, Aradilla-Herrero A, Santaeugènia S, Blay C, Delgado S, Ela S, et al. Development and implementation of an advance care planning program in Catalonia. Spain. Palliat Support Care. 2019;17(4):415–24, http://dx.doi.org/10.1017/S1478951518000561.
36. Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, et al. Defining advance care planning for adults: a consensus definition from a multidisciplinary Delphi panel. J Pain Symptom Manage. 2017;53(5):821–32.e1, http://dx.doi.org/10.1016/j.jpainsymman.2016.12.331.
37. Holley JL. Advance care planning in CKD/ESRD: an evolving process. Clin J Am Soc Nephrol. 2012;7(6):1033–8, http://dx.doi.org/10.2215/CJN.00580112.
38. Champer Blasco A, Caritg Monfort F, Marquet Palomer R. Conocimientos y actitudes de los profesionales de los equipos de atención primaria sobre el documento de voluntades anticipadas. Aten Primaria. 2010;42(9):463–9, http://dx.doi.org/10.1016/J.APRIM.2010.02.011.
39. Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. Palliat Med. 2014;28(8):1000–25, http://dx.doi.org/10.1177/0269216314526272.
40. Rolnick JA, Asch DA, Halpern SD. Delegalizing advance directives — Facilitating advance care planning. N Eng J Med. 2017;376(22):2105–7, http://dx.doi.org/10.1056/NEJMp1700502.
41. Axelsson L, Benzein E, Lindberg J, Persson C. End-of-life and palliative care of patients on maintenance hemodialysis treatment: a focus group study. BMC Palliat Care. 2019;18(1):89, http://dx.doi.org/10.1186/s12904-019-0481-y.
42. Gorrin MR, Teruel-Briones JL, Vion VB, Rexach L, Quereda C. Diálisis peritoneal paliativa: implantación de un programa de atención domiciliaria a enfermos tratados con diálisis peritoneal (DP) en situación terminal. Nefrología. 2015;35(2):146–9, http://dx.doi.org/10.1016/J.NEFRO.2015.05.015.
43. Romano T, Romano TG, Palomba H. Palliative dialysis: a change of perspective. J Clin Med Res. 2014;6(4):234–8, http://dx.doi.org/10.14740/jocmr.v6i4.1773.
44. Tentori F, Hunt A, Nissenson AR. Palliative dialysis: addressing the need for alternative dialysis delivery modes. Semin Dial. 2019;32(5):391–5, http://dx.doi.org/10.1111/SDI.12820.
45. 10th World Research Congress of the European Association for Palliative Care (EAPC). Palliat Med. 2018;32(1):3–330, http://dx.doi.org/10.1177/0269216318769196.
46. Hui D, Nooruddin Z, Didwaniya N, Dev R, de la Cruz M, Kim SH, et al. Concepts and definitions for "actively dying," "end of life," "terminally ill," "terminal care," and "transition of care": a systematic review. J Pain Symptom Manage. 2014;47(1):77–89, http://dx.doi.org/10.1016/J.JPAINSYMMAN.2013.02.021.
47. Overview | Care of dying adults in the last days of life | Guidance | NICE. Accessed February 19, 2023. https://www.nice.org.uk/guidance/ng31.
48. Guía de Práctica Clínica sobre atención paliativa al adulto en situación de últimos días - Agencia Gallega de Conocimiento en Salud. Accessed February 19, 2023. https://acis.sergas.es/cartafol/GPC-AtencionPaliativaUltimosDias?idioma=es.
49. Cherny NI, Portenoy RK. Sedation in the management of refractory symptoms: guidelines for evaluation and treatment. J Palliat Care. 1994;10(2):31–8.
50. Surges SM, Garralda E, Jaspers B, Brunsch H, Rijpstra M, Hasselaar J, et al. Review of European guidelines on palliative sedation: a foundation for the updating of the european association for palliative care framework. J Palliat Med. 2022;25(11):1721–31, http://dx.doi.org/10.1089/jpm.2021.0646.
51. Azulay Tapero A. La sedación terminal: aspectos éticos. An Med Interna. 2003;20(12):49–53.
52. Porta Sales J. Sedación paliativa y eutanasia. Aten Primaria. 2007;39(1):45–8, http://dx.doi.org/10.1157/13098265.
53. Balaguer A, Monforte-Royo C, Porta-Sales J, Alonso-Babarro A, Altisent R, Aradilla-Herrero A, et al. An international consensus definition of the wish to hasten death and its related factors. PLoS One. 2016;11(1):e0146184, http://dx.doi.org/10.1371/JOURNAL.PONE.0146184.
54. BOE-A-2021-4628 Ley Orgánica 3/2021, de 24 de marzo, de regulación de la eutanasia. Accessed February 19, 2023. https://www.boe.es/diario_boe/txt.php?id=BOE-A-2021-4628.
55. Harrison TG, Tam-Tham H, Hemmelgarn BR, James MT, Sinnarajah A, Thomas CM. Identification and prioritization of quality indicators for conservative kidney management. Am J Kidney Dis. 2019;73(2):174–83, http://dx.doi.org/10.1053/j.ajkd.2018.08.014.
56. Nitola-Mendoza L, Centeno C. Lugar de fallecimiento de pacientes con procesos paliativos: invertir la tendencia de fallecer en el hospital? An Sist Sanit Navar. 2021;44(1):125–6, http://dx.doi.org/10.23938/ASSN.0942.
57. Van den Bulck SA, Vankrunkelsven P, Goderis G, van Pottelbergh G, Swerts J, Panis K, et al. Developing quality indicators for Chronic Kidney Disease in primary care, extractable from the Electronic Medical Record. A Rand-modified Delphi method. BMC Nephrol. 2020;21(1):161, http://dx.doi.org/10.1186/s12882-020-01788-8.
58. Hamroun A, Speyer E, Ayav C, Combe C, Fouque D, Jacquelinet C, et al. Barriers to conservative care from patients' and

nephrologists' perspectives: the CKD-REIN study. Nephrol Dial Transplant. 2022;37(12):2438–48, http://dx.doi.org/10.1093/ndt/gfac009.

59. Lunney M, Bello AK, Levin A, Tam-Tham H, Thomas C, Osman MA, et al. Availability, accessibility, and quality of conservative kidney management worldwide. Clin J Am Soc Nephrol. 2021;16(1) https://journals.lww.com/cjasn/Fulltext/2021/01000/Availability,_Accessibility,_and_Quality_of.12.aspx
60. Lupu D, Moss AH. The role of kidney supportive care and active medical management without dialysis in supporting well-being in kidney care. Semin Nephrol. 2021;41(6):580–91, http://dx.doi.org/10.1016/j.semnephrol.2021.10.010.
61. Fried LP, Ferrucci L, Darer J, Williamson JD, Anderson G. Untangling the concepts of disability, frailty, and comorbidity: implications for improved targeting and care. J Gerontol A Biol Sci Med Sci. 2004;59(3):M255–63, http://dx.doi.org/10.1093/gerona/59.3.M255.