The Evolution of Conservative Care in Portugal: From Ethical Foundations to Systematic Implementation

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INTRODUCTION

For decades, the initiation of kidney replacement therapy (KRT) was viewed as an almost mandatory clinical progression for patients reaching stage 5 CKD in Portugal. An aging demographic combined with an increasing burden of complex comorbidities has necessitated a rigorous re-evaluation of this "one-size-fits-all" approach. Evidence-based medicine now recognizes that for specific cohorts—particularly the elderly with high frailty scores and severe cardiovascular or cognitive impairment—dialysis may fail to offer a survival advantage over conservative care (CC). KRT can impose a disproportionate treatment burden that significantly diminishes health-related quality of life (HRQoL) without extending life expectancy.[1] CC is not the absence or withdrawal of treatment; it represents an active, highly structured, interdisciplinary intervention. It is anchored on three core pillars: proactive symptom management, shared decision-making that aligns clinical choices with patient values and advanced care planning (ACP) to guarantee that end-of-life choices are documented and legally respected.[2] Over the past decade, the Portuguese nephrology community has increasingly transitioned toward this holistic model.

HISTORICAL MILESTONES OF PALLIATIVE NEPHROLOGY IN PORTUGAL

The formal institutionalization of CC within the Portuguese National Health Service can be traced back to *Norma 017/2011* published by the Directorate-General for Health (DGS).[3] This landmark guideline introduced the concept of *"tratamento médico conservador"* (TMC) into the domestic regulatory landscape. It established a clear clinical framework for identifying patients for whom dialysis would be futile or disproportionate, legitimizing non-dialytic management and dictating that these patients must receive multi-professional care of equal quality to those on KRT. The translation of this theoretical framework into clinical practice was spearheaded in 2013 by the Unidade Local de Saúde de Matosinhos, which established the first dedicated clinic co-managed by both Nephrology and Palliative Care specialists. In 2015, Centro Hospitalar de Setúbal launched a structured program featuring a nephrologist with advanced PC training supported by a dedicated multidisciplinary team (nursing and social work).[4] Some Nephrology fellows manifested interest in this new area and started doing training to implement this option in their own departments. This initiative demonstrated the feasibility of the model across different hospital scales. Recognizing the country-wide heterogeneity and the lack of standardized protocols, the Portuguese Society of Nephrology (SPN) established the CC Working Group *(Grupo de Trabalho de Tratamento Médico Conservador* - GT-TMC) in 2021. The group's mandate focused on promoting specialized training, standardizing clinical protocols, and establishing a dedicated national registry module within the national registry (***Gabinete de Registo*** (DRC), Portuguese Society of Nephrology).[5]

QUANTITATIVE TRENDS AND REGISTRY DATA (2021–2025)

Data compiled over the five years since the registry's inception marks a critical turning point for the visibility of CC in Portugal. The longitudinal analysis demonstrates a sharp, linear upward trend in both patient volumes and institutional resources (Table 1).

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Table 1. National CCM Trends in Portugal (2021–2025)

Indicators	2021	2022	2023	2024	2025
Incident patients/year (% of total incident pts in CC)	102 (3.9%)	190 (7.0%)	231 (8.4%)	366 (12.6%)	397 (13.6%)
Patients pmp	9.86	18.30	22.06	34.40	37.30
Dialysis exit to CC (HD / PD)	NA / NA	32 / 2	52 / 0	52 / 4	NA / NA
Dialysis exit to Palliative Care (HD / PD)	153 / 2	132 / 7	189 / 3	209 / 4	311 / 2
Total patients with PC needs	257	363	475	635	710 + NA
Incident patients/year in PD (% of total incident)	24.65 (9.8%)	24.85 (9.5%)	26.85 (10.2%)	24.70 (9.2%)	25.50 (NA)
Number of services / Response rate	29 / 14 (48%)	29 / 14 (48%)	30 / 19 (60%)	32 / 19 (60%)	NA / NA
Units: Dedicated	10	7	9	13	NA
Units: Staff with PC education	5	6	9	13	NA
Units: Link with intra-hospital PC	5	6	9	13	NA
Units: Link with community PC	4	3	5	6	NA

Legend: CC: conservative care; HD: hemodialysis; PD: peritoneal dialysis; PC: palliative care; pmp: per million population; NA: not available. Based on data from: Registo da DRC da SPN4

Between 2021 and 2025, the number of incident patients undergoing CC per year quadrupled from 102 to 397, ultimately representing 13.6% of all incident ESKD patients and exceeding the annual incidence of peritoneal dialysis (25.5 patients; 9.2% in 2024). Prevalence rose concomitantly from 9.86 to 37.3 pmp. These indicators suggest not only greater clinical recognition of CC as a legitimate and cost-effective alternative to dialysis in geriatric populations or those with a high burden of comorbidities, but also a progressive alignment of Portugal with what happens in other countries where older and more vulnerable patients are frequently referred to palliative care (PC) instead of invasive procedures with decreased HRQoL. Parallel to the expansion of patients who choose not to pursue dialysis as first option, there is a growing pressure of patients with identified PC needs even in KRT. The number of patients on Hemodialysis that exit to CC or PC is also increasing but without an apparent articulation between these two options of care or stablished criteria to refer to each of them. The data also exposes a concerning gap between clinical need and structural response capacity. Although the number of units with professionals trained in PC and with active links to intra-hospital teams increased (from 5 in 2021 to 13 in 2024), the connection to the community remains critically underdeveloped, reflecting the scarce resources in the community that are beyond the nephrological capacity to intervene. This asymmetry suggests that palliative support for renal patients in Portugal is still heavily centralized within the acute hospital environment, failing to guarantee a home-based, community care network that ensures dignity at the end of life outside the hospital setting and the consequent frequent need for those patients to die in acute care settings like the Nephrology departments.

Finally, the interpretation of the data from the Registry requires methodological caution due to underreporting bias (missing data). The absence of official records regarding the number of responding services, dedicated units, and active transfers limits a robust interpretation of the latest period's outcomes or the real number of patients in need. This gap highlights the imperative requirement to strengthen national registry systems in palliative nephrology. The lack of continuous and mandatory monitoring hinders the strategic planning of human resources and infrastructures, which is essential to address an epidemiological curve of palliative needs that is expected to remain on a continuously upward trajectory.

INTERNATIONAL COMPARISON: THE UK MODEL AND IN EUROPE

In 2012, almost at the same time as in Portugal CC was established, nearly all UK renal units (94%) provided CC. They faced the same problems as we are facing now: data on patient numbers were inconsistent due to lack of standardized definitions (conservative care; supportive care, palliative care) and clinical practices (multidisciplinary team or not); some units had written guidelines, dedicated clinics, staff, training and also limited funding, with only a minority having dedicated budgets. Anyway, more than a decade apart, almost all UK units already discussed CC when patients were referred to pre-dialysis clinics or at specific GFR thresholds (~20 mL/min/1.73 m²) and all of them already collaborated with primary care and palliative services, providing advice to general practitioners and working with hospices and community teams.[6]

In Europe, CC implementation is heterogeneous,[7,8] varying from 0.0% (Slovakia and Slovenia) to 20.0% (Finland), but mainly underused. Several barriers have been identified,[9] although the experienced ways to overcome them are scarce.

CRITICAL BARRIERS, SYSTEMIC LIMITATIONS AND FUTURE PERSPECTIVES

Despite quantitative growth, the qualitative delivery of CC across Portugal remains deeply fragmented (Table 2). A stark disparity persists between centers possessing robust, dedicated units and centers offering only *ad hoc* care devoid of formal palliative protocols. Surveys in the literature indicate that while nephrologists feel technically proficient in advanced dialytic mechanics, they frequently report a lack of formalized training in advanced communication skills (e.g., breaking bad news), prognostic estimation, and complex pharmacological symptom management.[10] Education should be a priority. So, *Colégio de Nefrologia* included a structured Palliative Nephrology module directly into the national Nephrology medical residency (even if a formal curriculum standardization is still missing)[11] and integrated CC in *Manual de Boas Práticas em Diálise.*

Table 2. Barriers and strategies to implement Conservative Care in Portugal

Barriers to Implementation of CC in Portugal		Strategies
Provider barriers	Lack training in prognosis discussions and uncertainty about prognosis Lack training in end-of-life conversations and discomfort with discussing death Lack training in decision-making support, functional impairments or goals and values Neglect broader patient needs such as emotional, existential support Limited palliative care understanding and negative perceptions hinder integration.	Develop a uniform curriculum on CC Develop a model centered on early goals of care conversations and multidisciplinary support across the disease course, mainly in pre-dialysis setting
System barriers	Current models do not support unpredictable illness trajectories or align with patient goals, leading to underutilization and misaligned care. Reimbursement and regulatory structures incentivize standard quality metrics focused on dialysis adequacy and vascular access, which may conflict with patient-centered goals. End-of-life care metrics are not well aligned with palliative priorities.	Test innovative payment models such as ESRD Seamless Care Organizations* and the Care Choices Model** to incentivize palliative and conservative care options.
Care delivery barriers	Infrastructure limitations, such as lack of widespread staff-assisted home dialysis options restrict flexible less burdensome care models. Policies like priorities hospice rules, which restrict coverage of dialysis in terminal illness, discourage palliative approaches.	Change on structural policies and increase in PC resources

* Drewry KM, *et al.* Organizational Characteristics Associated with High Performance in Medicare's ESRD Seamless Care Organizations: FR-OR22. J Am Soc Nephrol. 2020; 31:22

** Kranker K, *et al.* "Medicare care choices model improved end-of-life care, lowered medicare expenditures, and increased hospice use: study examines medicare care choices model impact on end-of-life care, expenditures, and hospice use." Health Affairs. 2023;42: 1488-97.

General Palliative Services are still sparse and a significant barrier. Our data reveals a critical mismatch between clinical demand and community infrastructure. While hospital-centric milestones have improved—with units possessing intra-hospital PC links growing from 5 to 13 between 2021 and 2024—units integrated with community-based PC teams stalled at merely six nationwide. Consequently, palliative support remains overly centralized in acute-care facilities. Furthermore, there is a severe operational disconnect between outpatient dialysis clinics (which are predominantly private or outsourced) and public hospital CC units. When a patient decides to withdraw from dialysis, the transition pathway is rarely streamlined, frequently culminating in traumatic, "crisis-mode" emergency department admissions rather than a planned, home-based dignified death.

Another major systemic barrier is the asymmetry in legal and financial coverage. In Portugal, chronic dialysis is fully subsidized, encompassing all associated clinical costs and non-urgent medical transportation. Paradoxically, CC — which imposes a substantially lower financial burden on the healthcare system — lacks a dedicated public funding stream. This creates profound transport inequity, as CC patients must frequently fund their own travel for clinical consultations. Additionally, essential outpatient palliative medications face higher reimbursement hurdles compared to their inpatient or in-dialysis counterparts.

Finally, CC suffers from pronounced underreporting bias *(missing data)* in official registries, driven by limitations within the current GID (*Gabinete de Informação e Dados*) software architecture. The lack of a mandatory, streamlined reporting system prevents accurate strategic resource planning to ensure that the "conservative care" label accurately reflects the comprehensive model and creates the suspicion that the number of those patients in need is even greater than what our registry shows.

CONCLUSION

Portugal has successfully transitioned from an era of informal, isolated conservative practices to a phase of verified institutional growth. The evolution of CC in Portugal is a testament to the resilience of our nephrology community, but the journey from a recognized guideline to a universal right for every Portuguese citizen with kidney failure is still underway.

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