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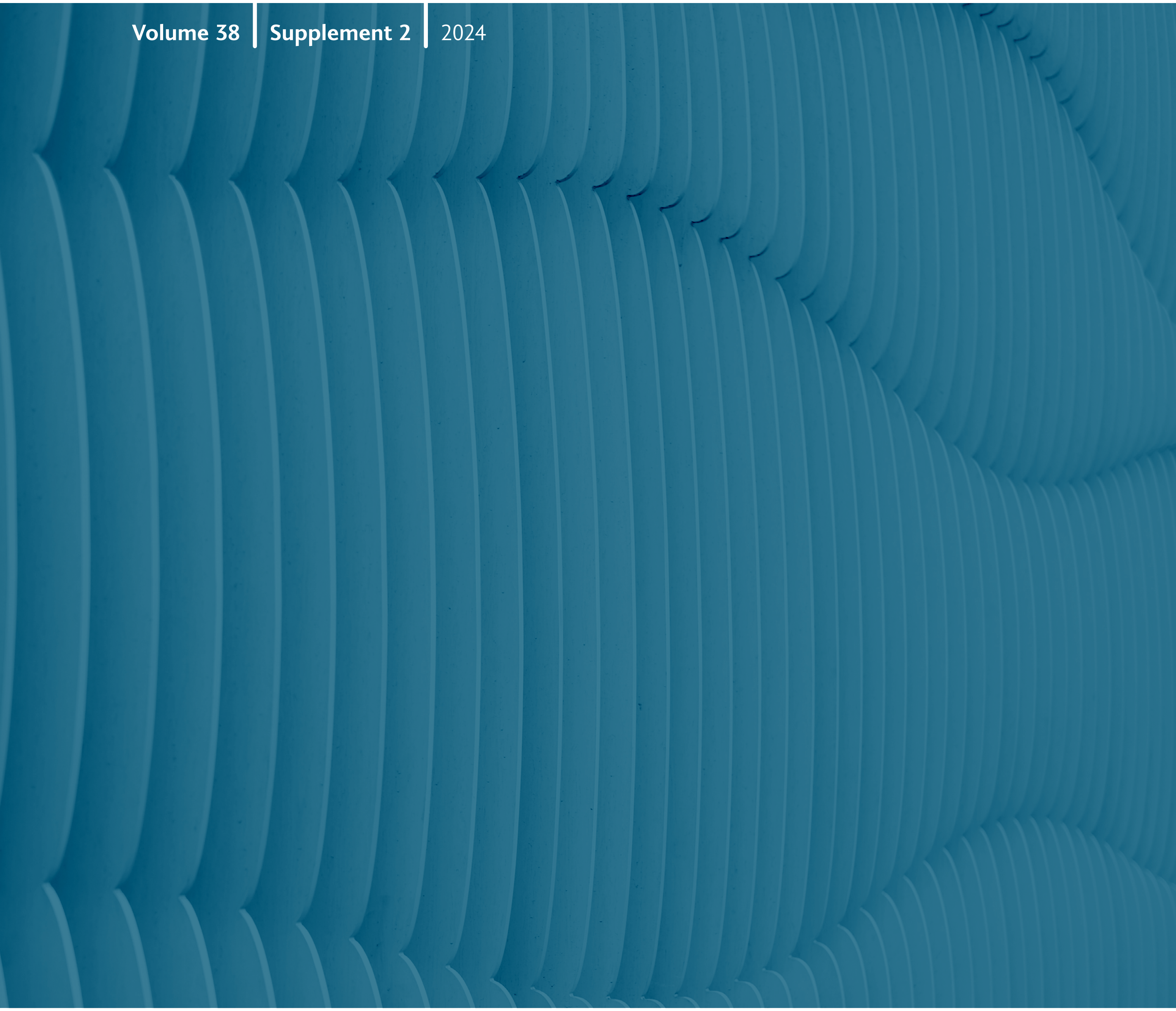

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Conservative Care Consensus Document Portuguese Society of Nephrology Conservative Care Working Group

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1. INTRODUCTION

Despite the widespread availability of kidney replacement therapies (KRT) it is increasingly clear that not all patients benefit from dialysis treatments. New evidence suggests that in patients with advanced age, high comorbidity burden and/or poor functional status, the survival benefit conferred by dialysis is modest, and the improvements in quality of life and patient reported symptoms are low.[1-6]
In this document we review essential steps to create an integrated program in Portugal that offers care across the complete spectrum of patients with end stage kidney disease (ESKD).

Portugal has the highest incidence of end stage kidney disease (ESKD) in Europe. Early mortality is high (reported at 6.7% within the first 90 days of starting dialysis) resulting in significant economic pressures on an already stressed healthcare system.[7,8] In Portugal, the burden of chronic kidney disease (CKD) is higher than that of most countries in Western Europe and Canada, with estimates lying between 200 and 299 disability adjusted life years per 100 000 inhabitants.[9] Within nephrology, there is a recognized need to create a cohesive strategy to address current limitations of ESKD care.[10] One strategy is to improve supportive care for those individuals with kidney failure who are at highest risk of poor outcomes.

In 2011, a guideline issued by *Direção Geral da Saúde* (DGS) approved and supported the introduction of a conservative approach for individuals with ESKD.[11] The DGS stated that *"all therapeutic measures without dialysis and transplantation should be applied when KRT is not indicated or not possible or when it does not provide a better quality of life than supportive care".* Despite this guideline, only a limited number of nephrology departments have modified their clinical routines to incorporate this treatment (referred to as conservative care, CC in this document) and address the specific needs of more vulnerable or older patients and their families. Barriers to implementation of CC include misconceptions about the goals of palliative medicine, limited access to palliative care (PC) services, inadequate resources and training of nephrology personnel, limited awareness of the practical tools available for implementation, and a lack of financial support.[12,13] The objective of this work group is to identify key barriers to providing conservative kidney care, and to support the increased use of high-quality integrated care programs across Portugal.[14,15]

2. DEFINITION AND STANDARDISATION OF CONCEPTS

Palliative care is an essential and increasingly recognized component of health care. Consistent with the World Health Organization values, all patients with ESKD, regardless of age, should have access to the health services they need to ensure adequate care for themselves and their families.[16] The World Health Assembly Declaration 67.19 stated that palliative care is *"fundamental to improving the quality of life" and that there is an "urgent need to include palliative care in all health care ".*[17] Palliative care is also part of the concept of universal health coverage, which states that *"all people and communities have access to the promotive, preventive, curative, rehabilitative and palliative health services they need, the quality of which is sufficient to be effective".*[17]

Palliative care should no longer be viewed as "giving up" or "accepting death". It is a form of care that supports patients and their families as they live with the experience of chronic, life-limiting illness. It can be instituted from the onset of symptoms to the final time of death, depending on need. Societal perceptions, however, link palliative and hospice care to death, and as a result there are a multitude of names used interchangeably in the literature. We propose that there is an urgent need to clarify and standardise terminology.

In the DGS directive, titled Norma 017/2011 (12), the term *"Tratamento Médico Conservador" was used.*

We recommend the following definitions:

- Palliative care (*"cuidados paliativos"*): an interdisciplinary model of person-centred care that seeks to optimise health-related quality of life and preserve human dignity through the prevention and relief of physical, spiritual and psychosocial suffering of patients and their families. Palliative interventions are not incompatible with ongoing life support, such as dialysis.
- Supportive care (*"cuidados de suporte"*): should be used as a synonym of renal palliative care. It can be offered alongside disease centred treatments such as dialysis treatments.
- Conservative care (*"tratamento conservador"*): holistic, patient-centred care used to treat ESKD patients who choose not to undergo any kind of KRT or who are too unfit to proceed to it; aiming to delay further deterioration of renal function, preventing and relieving symptoms and adverse events resulting from irreversible progression of renal disease. Also sometimes called comprehensive conservative care.

3. DISEASE TRAJECTORIES

Recognition of the most common disease trajectories may help clinicians to understand a patient's prognosis. This, in turn, allows the clinician to communicate and identify key goals of care and to adopt strategies to meet these needs (Fig. 1). ESKD commonly has one of two different disease trajectories, according to the choice of a dialysis or a non-dialysis pathway.[18]

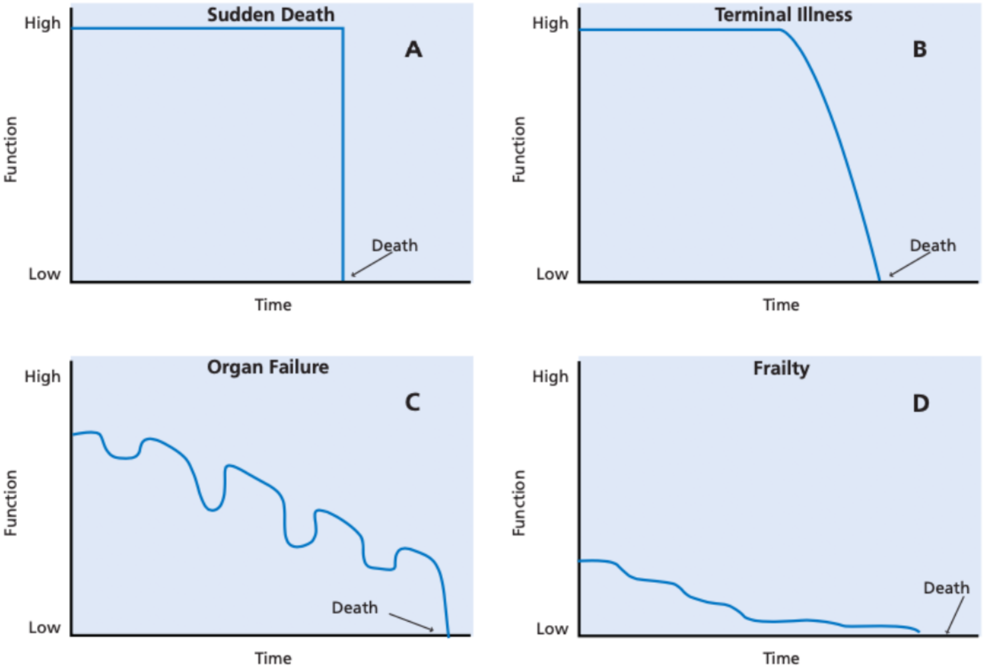

Figure 1. Trajectories of decline towards end of life.

Adapted from[18]

A – Sudden death, usually by cardiac disease; B – Reasonable good health, until a decline in the last few weeks or months, for example related to a terminal malignancy; C – Slow deterioration, marked by abrupt and only partially reversible acute events (e.g. organ insufficiency/ failure); D – Gradual and insidious decline, usually in older and frail patients (e.g. dementia).[18]

Patients who chose CC often have a health trajectory that is a blend of the terminal illness (Fig. 1B) and frailty trajectories (Fig. 1D). In contrast, the dialysis trajectory is characterised by a steep decline around the time of dialysis initiation, followed by that typical of organ failure (Fig. 1C). Events such as the diagnosis of a life-limiting disease or the occurrence of critical events (e.g. stroke or other diagnosis that limits a patient's autonomy) that change a patient's life trajectory should be immediately recognized and trigger a review. Such patients may choose to integrate a palliative strategy.

4. ESTIMATING PROGNOSIS AND INTRODUCING CONSERVATIVE CARE AS A TREATMENT OPTION

Although treatment of ESKD with dialysis is associated with a patient survival advantage, this may be substantially lower in those with major comorbidities (mainly coronary artery disease), non-disease specific conditions including poor functional status and in those of advanced age. The overall benefits of dialysis treatments may be lost particularly if measured as hospital free survival and health-related quality of life.[15,19] Individuals previously resident in a nursing home setting appear to be at most risk, with US data showing mortality rates of more than 50%, substantial additional functional decline with less than one fifth of patients having stabilisation of their health and functional status despite dialysis initiation.[20] In otherwise healthy octogenarians, similar results were seen with less than one third being alive, with maintained functional status at one year.[21] Morbidity is high, with estimates of the proportion of remaining lifetime spent in a hospital setting being as high as 30%-70% in older age groups starting dialysis emergently.[22]

Estimating CKD prognosis can be challenging. In a recent meta-analysis including 28 studies, age, body mass index, higher comorbidity index, frailty, functional impairment, cognitive impairment and falls were recognized as the main risk factors associated with increased mortality in elderly patients starting hemodialysis.[23] In another meta-analysis focusing on geriatric syndromes, investigators found non--clinical factors, such as family and community support, to be important though rarely reported.[24] Table 1 lists factors and tools that can be useful for prognostication.

Table 1. Factors that affect prognosis in ESKD patients

Factors that affect prognosis on CKD	Evaluation tool examples
Age	-
Frailty and functional impairment	Edmonton Frailty Scale
Quality of life	KDQOL-SF™ 1.3
Comorbidities	Charlson Comorbidity Index
Dementia and cognitive decline	Clock drawing test, MiniCOG, MoCA
Surprise question	"Would you be surprised if this patient died in 6 months/one year?"
Nutritional status	Albumin level

Prognostic tools

Prognostic tools such as the REIN score and the Cohen model have been developed based on some of the risk factors listed in the table above. The European Best Practice Guideline for the Management of Older Patients with Chronic Kidney Disease suggests the use of such tools to prioritise care and facilitate shared decision-making (Fig. 2).[25-27]

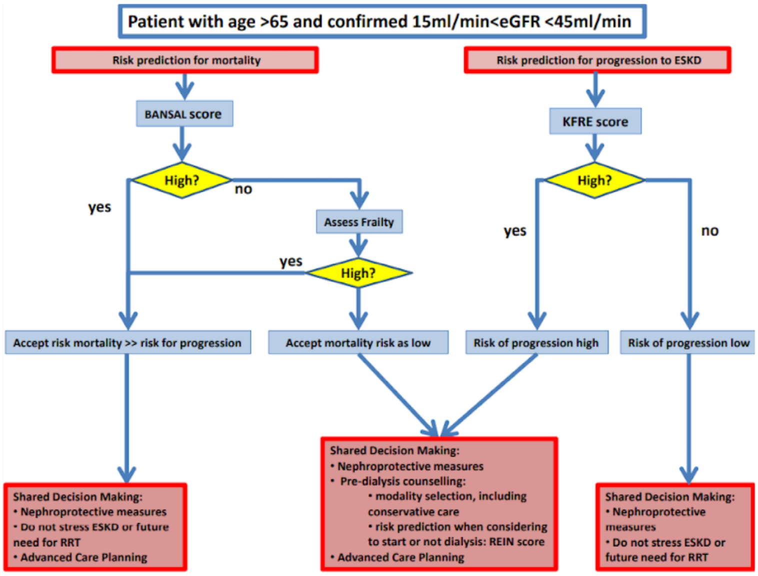

Figure 2. Proposed management pathway for older patients with advanced CKD. European Best Practice Guideline on Management of Older Patients with Chronic Kidney Disease.[27]

KFRE: Kidney Failure Risk equation

Prognostic tools are best used critically to quantify and communicate potential outcomes for patients. There can be ethical concerns about misuse and clinicians must take care to ensure they are not used[28]:

- to deny a treatment,
- beyond the boundaries of the derivation or validation cohort without recognition of the limitations,
- without consideration of uncertainty in prognostic estimates,
- to irreversibly classify or categorise a patient without appreciation of the possibility of a change in status, and finally,
- in isolation without considerations of clinical context.

5. WHO MIGHT BENEFIT FROM CONSERVATIVE CARE

Patients at highest risk of early mortality and poor quality of life are most likely to benefit from conservative care.[18,29,30] The European Renal Best Practice Group guideline[27] on the management of elderly CKD patients (older than 65 years) includes an algorithm based on mortality risk, CKD progression risk and frailty. Similar approaches are also recommended in other guidelines.[29] Non disease-specific factors such as cognitive impairment, depressive symptoms, exhaustion, falls, impaired mobility, and polypharmacy have been linked to higher mortality in CKD patients[31] and therefore it is important to expand assessments to identify barriers arising from geriatric syndromes and social determinants of health.

The following groups of individuals may benefit most from education about CC[29,32,33]:

- Patients in whom clinicians say NO to the surprise question ("Would you be surprised if your patient died in the next 12 months?"). This method is frequently used in the oncology setting with several studies confirming its value in ESKD.[34,35]
- Evaluation of prognosis using clinical scores:
  - o Cohen score[36]: used in those already on dialysis, this score is calculated using the surprise question plus four additional variables (age, serum albumin, presence of dementia and peripheral vascular disease). Patients in the fifth quintile have a high risk of early mortality;
  - o Couchoud score[37]: used in patients, aged 70 years or more, who have not started dialysis. This score includes nine variables (body mass index, diabetes, congestive heart failure, peripheral vascular disease, dysrhythmia, active malignancy, severe behavioural disorder, total dependency for transfers and unplanned dialysis) and gives a probability of mortality 3 months after dialysis is started.
- Evaluation of comorbidity burden using the modified Charlson Comorbidity Index (mCCI) (e.g., a mCCI ≥8).[38]
- Documentation of sentinel events such as those who have had more than 2 falls in last year, recurrent hospitalizations (2 or more in the last 3 months), multiple visits to emergency services, a decline in quality of life

rating, recent institutionalisation, marked functional impairment (e.g. Karnofsky performance status score < 40); severe malnutrition (with a serum albumin < 2.5 g/dL) can identify those at highest risk of having poor health after dialysis initiation.

It is important to emphasise that these strategies should not determine the choice of treatment, but rather guide the shared decision-making (SDM) process for the individual.

There are, however, circumstances when CC is the preferred professional choice of treatment. These circumstances are consistent across several guidelines and include[11,29,32,39]:

- Circumstances when the patient no longer possesses decision capacity, and it is clear CC was the previous informed choice of the patient or is currently what the appointed health attorney believes the patient would wish.
- Severe and irreversible dementia.
- Technical or clinical impossibility of dialysis treatment and kidney transplantation.
- Coexistence of non-renal disease that leads to a short life expectancy.
- Coexistence of non-renal disease or condition that predicts severe and irreversible suffering.

6. ADVANCED CARE PLANNING AND SHARED DECISION MAKING

The choice of KRT should be a process that the patient, the nephrologist, and the caregivers go through together using a shared decision-making process. During this process the nephrologist gives information about available treatments, those that are appropriate, and about the competing risks and benefits of appropriate interventions (e.g., life expectancy, risk of progression of other diseases, types/nature of symptoms/complications arising from the treatments) and educates the patient (and if appropriate, their caregivers). Patients and caregivers consider their own needs and life preferences and collaborate in making the treatment choice.[40]

Regardless of the nephrologist's individual opinion, patients have the right to decline any treatments they do not wish to receive, including dialysis. They do not, however, have the right to treatments that the clinician perceives as harmful or inappropriate. As such, CC should be included as an option for most patients after an honest discussion about prognosis, personal values and goals of care.[40]

Advanced care planning is the process of thinking, talking, informing, discussing and deciding which *future* treatments are appropriate or not, according to each person's values and way of living.[41] This process helps the patient to understand his/her condition, recognize his/her wishes, anticipate decisions as the condition progresses (or when decision capacity is lost) and achieve the goals of end of life (EoL) care, which is particularly relevant when dealing with organ support therapy.[40]

As recommended by the Renal Physician Association Guidelines[40] advanced care planning should be achieved through shared decision-making processes that include the health care provider, the patient and family to align treatment goals with the patient´s values and preferences. In patients with cognitive impairment and CKD patients, discussions around future planning should be started as early as possible, particularly as decline in cognition appears accelerated around the time when dialysis decision making typically occurs. Both the patient and their caregivers will require time to understand how changes in cognition can impact the ability to adapt to kidney-focused interventions.[40] In patients with a high burden of cognitive dysfunction, key components of these discussions include[40,42]:

- A conservative treatment pathway rarely involves change to the individual's daily routine and the personnel providing care.
- Dialysis can result in substantial changes to the daily routine. It is important to include a description of how patients may need to modify their day. Examples include details of how they would adapt their waking and meal schedules to allow travel time to and from dialysis, how their meals would change to adhere to fluid or solute intake, as well as details of whether the patient would receive care from a small number of staff in a familiar environment or if they would be in a large unit with a number of staff not previously known to them.
- A discussion of the risk that clinical deterioration often occurs despite dialysis.
- Information of circumstances when dialysis discontinuation could/should be considered.
- A review of trajectory and goals when a sentinel event occurs (acute illness or hospitalisation).

Advanced care planning should therefore be initiated after establishing a trusting patient-doctor relationship when facing the risk of progression to renal failure. Prognostic events, such as a hospitalisation or fall could be used as an opportunity to engage patients and caregivers.[40,42] Good communication is a key point in this process. Communication models adapted from "How to break bad news"[43] like SPIRES (Table 2)[44] are useful to guide difficult conversations and help to develop communication skills. Communication skills to non–PC clinicians can be trained in PC courses or in other valid resources such as http://www.nephro-talk.com/.[45] Specialists in communication techniques, particularly those from palliative care, can be involved in complex situations, or where there appears to be conflict between health care teams and family, or within family groups.[46]

Table 2. Framework to communicate SPIRES

Setup	Prepare relevant prognostic information; include relevant participants
Perceptions and Perspectives	Ask what the patient knows about treatments; what are his/her pleasurable activities; what causes distress with the options
Invitation	After hearing the patient, propose to give your recommendation
Recommendation	Give recommendation and what to expect from it
Emphasise	Discussion about the future, uncertainty, doubts
Summarise and strategize	Identify the positive objectives of the choice, outline the milestones; give a strategy if the goals are not met

Adapted from[44]

Advanced directives can be expressed in a living-will, by appointing a health attorney or both. The living-will was first introduced in Portugal in 2012 and accounts for more than 47 000 records. The form can be obtained online in the platform of the "*Registo Nacional do Testamento Vital*"- RENTEV (https://servicos.min-saude.pt/). It is recommended that the form be filled with the help of a doctor. It can then be handed over or mailed to a RENTEV counter (https://www.spms.min-saude.pt/balcoes-rentev/), located in specific health centres, free of charge. After that it becomes easily accessible through the national electronic health registry (*Registo de Saúde Eletrónico - RSE*). Use of this form is not mandatory.

7. DIALYSIS DISCONTINUATION

In the literature, both dialysis withdrawal and dialysis discontinuation are often used interchangeably. We propose the latter term may be preferred when communicating with families and patients. Language experts have suggested the term withdrawal may imply denial or taking away of a treatment. In contrast discontinuation implies an active strategy to not use a treatment in the future, and when linked to observed symptoms or decline may be easier to accept.

Dialysis discontinuation is most commonly triggered by a number of clinical circumstances (Table 3). Patients discontinuing dialysis benefit from care provided by a multidisciplinary team (Fig. 3).[47] The Kidney Disease Improving Global Outcomes (KDIGO) and Renal Physicians Association/ American Society of Nephrology (RPA/ASN)[40] guidelines suggest dialysis discontinuation when:

1. Dialysis is technically not possible (e.g., vascular and peritoneal access failure) or cannot be provided safely (e.g. severe refractory hypotension) or
2. When a conscious informed patient with decision-making capacity does not wish to continue dialysis. In the absence of decision-making capacity, if there are advanced care directives stating the conditions for dialysis discontinuation or if the appointed health attorney considers that it would be the patient's wish to do so.

The former is usually a medical decision based on observed technical or clinical factors that preclude effective treatments. The latter however are circumstances triggered by the professional concerns for beneficence, non-maleficence, autonomy and justice (Table 3). Under these circumstances, discontinuation of dialysis is ethically and clinically defensible.[40]

Table 3. Criteria for dialysis discontinuation (Criteria are not cumulative)

Life limiting illness with advanced progressive, non-reversible disease
Frail, elderly with a high level of comorbid disease
Exhaustion of vascular accesses and transplantation or peritoneal dialysis not possible
Physical inability to tolerate dialysis (e.g., severe hypotension)
Patient request
Mental health burden

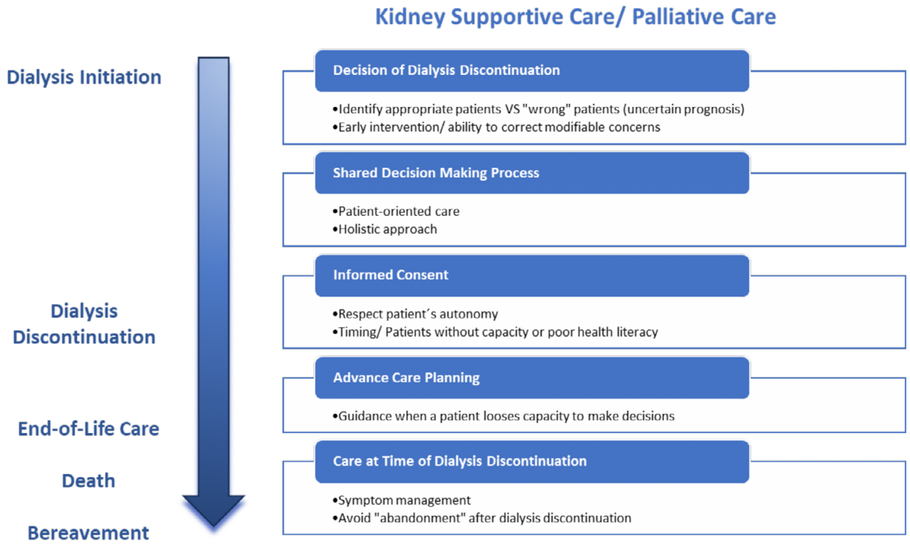

Figure 3. Plan of care in the dialysis discontinuation process

Adapted from[47]

Patient Driven Requests for Dialysis Discontinuation

The patient, family or team caring for the patient in the renal unit may be the ones to propose dialysis discontinuation. Often, a patient's lived experience on dialysis relates to their perception of post-dialysis fatigue and dietary restrictions. Integrating a comprehensive frailty assessment in the shared decision-making process may provide a more objective prognostic understanding.[47] Identifying frail patients, or those at increased risk of treatment related morbidity, may allow discussions about dialysis discontinuation to be held early in the dialysis trajectory. This normalises the act of discontinuation and allows patients and families time to process the information. Patients and families may be empowered to exert their autonomy on the decision about continuation or discontinuation of dialysis. Clinicians need to reassess the appropriateness of dialysis discontinuation through ongoing conversations in multiple clinical settings.

Discussions between the multidisciplinary team and the patient/family should be collaborative, and strive to identify mutual goals, particularly when there is disagreement between concerned parties.[48] Disagreement can arise when:

- The attending physician believes that dialysis is futile, but the patient and/or family disagree. Under these circumstances, discussions could focus on better understanding of the patient and family spiritual beliefs, lifestyle choices and financial factors, and should elicit if there is a fear of death.
- The attending physician is focused on potential survival benefits, while the patient and family are focusing on the lived experience of life with dialysis.[47] Under these circumstances the clinicians need to address their own personal biases and beliefs, and recognise the reasons behind their personal discomfort with dialysis discontinuation. They must actively listen to the patient's interpretation of how day-to-day living is for them.

Informed Consent

It is important to assess a patient's decision-making capacity, and if necessary (when the patient does not appear to have capacity) to seek prior information about their wishes, and integrate them with those expressed by his/her health attorney. "*Informed consent entails three major components: competency, voluntary decision and provision of sufficient information*".[47] Competency refers to if the patient (or health attorney) has the ability to understand and process the information needed to make the decision. It is individual to each decision. Under optimal circumstances the team should assess if medication overdose, dementia, depression or uraemia are potentially interfering in decision making.[49,50] If so, the decision may be guided by previous advance care directives and/or the health attorney.[14]

All feasible treatment options, including palliative dialysis, should be included in discussions, as palliative dialysis may limit symptoms without entailing rigid dialysis schedules.

The team must ensure that patient and family discussions are held and documented in the patient's records. Barriers such as poor health literacy and language may hamper this process. Visual and audio educational materials for selected patients may improve health literacy and aid in patient decision. Written guidance on how and when to discuss discontinuation and how to manage patients after discontinuation should be available in renal units.[14]

The multidisciplinary team should assess and continuously evaluate potentially reversible factors that can interfere with a patient's or family's decision. Every effort should be made to improve situations such as depression and psychosocial issues, complications during dialysis, untreated symptoms, acute life-threatening illness and practical issues such as transport. Family members benefit from ongoing supportive listening and communication even beyond the time of death.

The Process of Dialysis Discontinuation

It is important to continue to meet with the patient and family regularly after dialysis has been discontinued. This allows all individuals involved to reconsider or re-evaluate previous discussions and can be important for family members. During this period the focus lies on:

- Establish a process where symptoms are sought and treated.
- Review medications with the goal to suspend unnecessary medications and prescribe anticipatory medicines needed for symptom management.
- Teach family and caregivers about what they should expect, particularly as the patient approaches final hours.
- Establish preferred place of death: home, hospice, nursing home or hospital.
- Plan for care in the last days of life.
- Refer to specialist PC (community/ hospital) if appropriate.
- Offer spiritual, social and psychological support to the patient and family.
- Provide written information to family members, if possible, e.g., in the form of a leaflet.
- Notify community services and general practitioner.
- Ensure appropriate information is included for those assuming care if the patient is being discharged to another facility.

Healthcare Priorities and Societal Ethics

National policies continue to have a significant impact on discontinuation decisions. A European survey showed that the dialysis discontinuation was twice as likely when palliative care reimbursement was available.[4,51] Similarly in an international comparison, countries more likely to offer conservative care tended to have higher rates of dialysis discontinuation suggesting societal values are an important aspect in care expectations.[52] Healthcare funding policies should be adapted to allow equal access to medical care and reimbursement for patients who are undergoing dialysis, conservative treatment or for whom dialysis has been discontinued.[14,15,53]

8. SYMPTOM ASSESSMENT AND MANAGEMENT

The average time to death following dialysis discontinuation varies between 7-10 days but can extend up to 3 weeks. Longer survival is seen in those with frailty and low nutritional status, while those with active infection, or other comorbidity may experience shorter survival times. In patients with significant residual kidney function, survival is also prolonged, though the risk of fluid overload is lower.[30,54]

After dialysis discontinuation, symptom management becomes the main priority. During the discontinuation period, the clinician should screen for and treat symptoms including pain, pruritus, confusion or somnolence, dyspnoea, nausea and associated emotional distress.[55] Bereavement support should extend to family members and friends, even after the patient's death, to minimise complex grief reactions.[56,57] For patients who choose CC the slow decline in kidney function means they may live for several weeks to months and sometimes even years.[54,58] In these individuals' preservation of residual kidney function is highly important, and the focus of care is around nutrition and wellbeing rather than preventative care. Timely referral to integrated CC programs allows clinicians to identify key symptoms that would distress the individual, particularly as this will vary with the individual's goals of care.[33]

Patients with CKD suffer a high burden of physical and psychological symptoms, which negatively impact their quality of life.[59] As symptoms can be underrecognized, underestimated and undertreated it is important to establish a process to actively identify and manage symptoms. Several validated tools exist to assess symptom burden in CKD patients. Three common tools include the Edmonton Symptom Assessment System-revised, the Renal Palliative Care Outcome Scale–Renal and the Dialysis Symptom Index. The KDIGO Supportive Care in CKD workgroup recommended regular global symptom screening using validated tools be incorporated into routine clinical practice.[14] The workgroup also emphasised the importance of a stepwise approach, with first-line interventions focusing on nonpharmacological interventions and then advancing to more complex therapies, including pharmacologic therapy. Consideration should be given to low-dose pharmacological therapy that may have efficacy across several symptoms (Tables 4 and 5).

Pain

Pain is one of the most common symptoms experienced by patients with CKD, with an estimated prevalence reaching 60% in those on dialysis. It has known associations with sleep disturbances, depression and poor quality of life.[60,61] Pain assessment is important. Clinicians must identify the cause, type, intensity and underlying causative factors, in order to choose the optimal treatment. Clinicians should set feasible treatment expectations ensuring the patient understands that pain will not disappear, but lessened to the point where pain is tolerable and causes minimal interference with daily activities.[62] Pain can be classified as nociceptive or neuropathic. The distinction is important as different pharmacologic approaches to pain management are needed. Nociceptive pain results from tissue damage in the skin, muscle, and other tissues, causing stimulation of sensory receptors, and tends to respond well to analgesics such as opioids. On the other hand, neuropathic pain results from damage to the nervous system resulting in either dysfunction or pathologic change, and tends to respond poorly to analgesics, typically requiring adjuvant therapy such as anticonvulsants or dopamine modulators (gabapentin, carbamazepine, duloxetine) and/or tricyclic antidepressants.

Nonpharmacologic therapies are effective and have the benefit that they lack negative effects. These include cognitive behaviour therapy, exercise, massage, music therapy, acupuncture and cold/heat applications. Topical agents, including lidocaine or NSAID patches, can also be used if pain is localised. Use of the World Health Organization analgesic ladder may help chronic pain management.[63] It involves the slow introduction and upward titration of analgesics, starting with nonopioids, progressing to weak and then strong opioids as required for pain relief.[64] In CKD however nonsteroidal anti-inflammatory (NSAIDS) medications must be used with caution due to increased risks of bleeding, cardiovascular events and the potential effect on glomerular filtration rate. NSAIDS are best reserved for acute inflammatory causes of pain, limiting their use to the lowest effective dose and shortest duration.

Opioid use in CKD is complex as all formulations are associated with accumulation. Typically, hydromorphone, methadone, fentanyl and buprenorphine are most commonly used and different formulations should be used according to individual expertise and availability. Morphine has a powerful analgesic effect, but metabolites can accumulate in patients with renal impairment, causing intense analgesia, sedation and neurotoxicity. Hydromorphone and methadone metabolite accumulation is lower in CKD however the latter is not widely available. Fentanyl is well-tolerated in CKD and not cleared by dialysis. It is about 80 times more powerful than morphine and should be used with extreme caution. It is available transdermally and can be useful for managing pain at the extreme of life when patients cannot take oral medications, however, cannot be used in opioid-naïve CKD patients as it may cause respiratory depression. Buprenorphine may be a beneficial strong opioid in CKD, and it is 30 times stronger than morphine. It is not eliminated by dialysis and is also available for transdermal administration.[65]

Tramadol is a compound structurally associated with codeine and morphine. It is highly renally cleared (90%) with only 7% being cleared by dialysis. As the prevalence of side effects ranges between 1% and 6%, dose reduction and avoidance of modified-release formulation is recommended in the dialysis population.[64,65]

Pruritus

Pruritus is reported in up to 84% of patients receiving dialysis. It is often clustered with other symptoms such as sleep disturbances, decreased quality of life and depression.[66] Treatment involves a multifocal approach including optimising dialysis adequacy,[67] controlling calcium and phosphorus levels and hydrating the skin with emollients. Non-pharmacologic therapies include UVB phototherapy and acupuncture. If symptoms persist, systemic treatments such as low dose gabapentinoids (gabapentin 100 mg or pregabalin 25 mg nightly) and difelikefalin may be effective. Difelikefalin, a kappa opioid receptor agonist administered intravenously three times weekly, has only been studied over short 12 week periods in the haemodialysis population and data in the CC population are yet to emerge.[68] Antihistamines are often ineffective, and although frequently prescribed, are not recommended.[69]

Restless Leg Syndrome

Patients with restless leg syndrome experience an uncontrollable urge to move the legs at night or at rest. It occurs in approximately 25% of patients receiving dialysis.[70] It is associated with cardiovascular mortality, anxiety, daytime sleepiness and poor quality of life.[71] A correlation with low haemoglobin, low transferrin and poor erythrocyte stimulating agent responsiveness has been reported. Pharmacologic treatment includes medications targeting either dopamine or serotonin pathways.[72] Dopamine receptor antagonists, such as ropinirole, have been shown to be effective. Gabapentinoids inhibit glutamate release and have also been proven effective.[73] Non-pharmacologic therapy, including intradialytic exercise have shown some benefit.[74] Removal of stimulants, good sleep hygiene and changes in dialysis regimen should be part of the global approach.

Depression

Reported in up to 20% of patients in dialysis, depression is associated with increased hospitalisation and mortality, including discontinuation of dialysis. Although no formal guidelines are available, there are recommendations by the European Renal Best Practice (ERBP), on the efficacy and safety of antidepressants to treat depression in CKD.[75] The best screening tool in this population is not defined.[76,77] Evidence exists for the use of serotonin reuptake inhibitors as well as tricyclic antidepressants.[75] Although a few randomised controlled trials with fluoxetine, escitalopram and sertraline did not demonstrate efficacy, numerous non RCT demonstrated benefits. Side effects were common but mild. The efficacy of nonpharmacologic treatments, including cognitive behavioural therapy and exercise, have also been demonstrated.[78-80]

Sleep Disorders

Sleep disorders are very common in CKD patients, but unfortunately less than 20% of patients report improvement after dialysis initiation.[81,82] Non-kidney disease factors should be addressed, such as sleep apnoea, nocturia, delirium and medications, and corrected if possible. Non-pharmacologic intervention, including counselling on basic sleep hygiene and behavioural therapy have been shown to be effective. Pharmacologic interventions including benzodiazepine receptor agonists such as zolpidem can be prescribed, however benefits of treatment must be balanced against risks of increased falls and confusion in the most vulnerable groups of patients.[83]

Shortness of Breath

This symptom can be related to hypervolemia and associated comorbidities, such as congestive heart failure, pulmonary disease and infection. Symptoms can, in part, be exacerbated by patient or caregiver anxiety and early education about non pharmacologic approaches including positioning, ensuring ventilation and kinesiotherapy can be helpful. Control of hypervolemia with fluid restriction and diuretics, such as furosemide and metolazone, is beneficial. In advanced phases, opioids can be used to alleviate shortness of breath, while midazolam can be used as palliative sedation in the patient with severe symptoms entering the final hours of life. Ultrafiltration or palliative dialysis may be considered if aligned with the patient's goals of care and if volume control is unresponsive to other measures.[84]

Nausea

Nausea may be present in up to 25% of CKD patients and has various aetiologies, such as uraemia, electrolyte disturbances, acidosis and constipation. Trials of metoclopramide, haloperidol, ondansetron, in conjunction with non-pharmacologic approaches such as cold and fractionated meals, may be tried.[85,86]

Fatigue

Fatigue is a highly prevalent, and complex symptom that is reported across all stages of CKD. Contributing factors include anaemia, anxiety, sleep disturbances, pain, infections, malnutrition, concomitant comorbidities, compounded by existential suffering. Treatments include modification of factors such as anaemia using erythropoiesis stimulators and intravenous iron, de-escalation of drugs that may contribute to fatigue, and use of antidepressants if appropriate. Treatment goals are modified to place a higher emphasis on improved wellbeing rather than specific haemoglobin targets. Iron deficiency should also be addressed and corrected. The role of new HIF inhibitors lacks evidence but seems more convenient in this selected population. Corticosteroids and psychostimulants such as methylphenidate or modafinil have been used in the non-CKD population but there are still concerns they have lower benefit- risk ratio in CKD.[87-89]

Table 4. Symptom prevalence and intensity in CKD patients.[90,91]

Symptom	Mean prevalence (%)	Intensity (1-5)
Fatigue / tiredness	69-74	3.12
Uremic pruritus / itch	54 – 64	3.24
Anorexia	29 – 41	2.52
Nausea / vomiting	20-26	3.50
Pain	41	3.60
Dyspnoea	19-34	2.90
Anxiety	31	3.04

Table 5. Drugs frequently used in supportive care in ESRD patients.[84]

Drug	Dose	Route	Indication	Side effect	Dialysable
Butyl scopolamine	40-80 mg 3 times a day	Oral, SC, IV	Dyspnoea (respiratory secretions) Anorexia (intestinal obstruction)	Anticholinergic effects	Yes
Dexamethasone	4-12 mg	Oral, SC, IV	Fatigue Anorexia (intestinal obstruction)	Steroid effects (oedema, steroids myopathy or insulin resistance, ...)	No in CAPD/HD Unlikely in HDF
Fentanyl	0.125 µg	Oral, SC, IV	Pain, dyspnoea	Sedation, nausea, constipation, dry mouth	No
Gabapentin	100-400 mg	oral	Pain, pruritus	Dizziness, somnolence	Yes
Haloperidol	1.25-5 mg 3 times a day	Oral, SC, IV	Nausea/vomiting	Sedation, Qt prolongation, extrapyramidal effects	No
Hydroxyzine	25 mg 3 times a day	Oral	Pruritus	Sedation	No
Lorazepam	0.5-1 mg	Oral	Anxiety, dyspnoea	Sedation	No
Megestrol	160-400 mg	Oral	Anorexia	Peripheral oedema	Unknown
Methylphenidate	5-10 mg	Oral	Fatigue	Activation SNS	Unknown
Metoclopramide	5-10 mg 3 times a day	Oral, SC, IV	Nausea/vomiting, anorexia	Extrapyramidal effects	Yes
Midazolam	1.25-2.5 mg	Oral, SC, IV	Anxiety, dyspnoea	Sedation	No
Mirtazapine	7.5-15 mg	Oral	Anxiety, anorexia, pruritus, Fatigue	Sedation, anticholinergic effects	Unknown Unlikely
Ondansetron	4-8 mg	Oral, IV	Nausea/vomiting, pruritus	Qt prolongation, constipation	Unknown

IV- intravenous, SC- subcutaneous

9. END OF LIFE CARE

While traditionally the term "end of life (EoL) care" is used to describe the care provided in the last year of life (Fig. 4), it can be extended across a wider spectrum of patients, regardless of treatment modality, who have advanced chronic kidney disease particularly as the last year of life may be difficult to recognize.[18,29] Prognostic tools may help (see chapter above) as well as clinical situations identified as "redflags":

- Weight loss and malnutrition.
- Institutionalisation.
- Recurrent hospitalizations.
- Age > 85 years.
- Dementia.

Quality EoL care is care that aligns with patients' goals, values and wishes.[92] If completed, a living-will may guide preferences for pre-specified invasive measures like endotracheal intubation or order not to resuscitate. Discussions with the patient, and caregivers, include eliciting their choice of the place of death, and wishes should be respected whenever possible. A timely referral to a CC team facilitates this process in the different settings: Timely referral to a PC team is key for those who prefer to spend their final days in a PC unit, while adaptation of hospital regulations allowing a private room and a flexible visiting schedule for family are key components of care of those choosing to die in hospital, both physical and emotional support is needed for caregivers, as well as the patient, for those choosing to die in their own home environment. Where possible, a plan for how death certification and removal of the body from the home occurs should be discussed with the family.[93]

There are two specific situations that require a detailed discussion.[18] First, patients on regular dialysis, as they get older also have other organs' failure, leading to deterioration of their clinical situation until the point that EoL care is necessary. In these cases, dialysis could become an additional burden for patients and their caregivers, a situation described in the literature as "deteriorating despite dialysis". There are two available approaches according to the patient's goals of care: dialysis discontinuation or palliative dialysis. Second, patients who choose CC are often elderly and frail and suffer from insufficiency of other organs that have a meaningful impact on prognosis; a timely referral to CC programs allows the implementation of strategies to prevent kidney disease progression and symptom control, the latter being crucial in the EoL phase. While early in the disease trajectory the main goal is a careful balance between maximising quality of life and preserving residual kidney function, when reaching EoL the main goal is patient comfort and symptom control.[18,33] In this phase, patients may experience not only physical suffering but also emotional, spiritual and social distress. Family and caregivers may also need support and care should continue through bereavement.[93]

The Last Days of Life

The main challenge for most clinicians without palliative care training is to recognize final days.[18] Specific clinical signs seen as death is imminent include[93]:

- Decreased ability to change position in the bed or to turn sides independently.
- Increasing drowsiness with decreased response to verbal or visual stimuli.
- Indifference to food and fluids.
- Inability to swallow oral medications.
- Alteration in breathing patterns including Kussmauls or Cheyne Stokes breathing.

In an initial evaluation, it is essential to identify and correct potentially reversible causes of patient deterioration such as dehydration, infection, opioid toxicity, delirium or metabolic derangements. It is important to differentiate these causes from the natural disease progression, in which case the conservative care team should proceed according to the previously defined advance care plan.

There is a high risk of drug related complications at the end of life. Non-essential and potentially inappropriate medications should be stopped. This includes discontinuation of drugs used for primary or secondary prevention of chronic diseases.[93] Examples of drugs that could be modified or discontinued include:

- Antihypertensive drugs, especially when oral intake decreases.
- Oral hypoglycemic drugs.[94]
- Antianginal and cardiac medications can be down titrated to maintain the patient symptom-free.
- Medications that act in the central nervous system such as benzodiazepines and anticonvulsants are usually maintained, but the reason for the initial prescription should be reviewed.

As end-of-life approaches patients may not be able to take oral medications. Under these circumstances sublingual, rectal or transdermal administration of medications should be considered, particularly in those patients with minimal support at home. Subcutaneous administration of medications is preferred over intravenous routes, for those receiving care in hospital, hospice settings and in those with community PC teams.[93]

Delirium, severe dyspnoea and copious airway secretions are terminal symptoms that can cause distress in the last days of life.[93] It is appropriate to use certain, less common therapeutic approaches, for management of these symptoms at the EoL. For example, morphine may be used to manage dyspnoea even though it is not recommended in earlier phases of CKD; midazolam may be used to control anxiety or delirium (see comments below regarding palliative sedation); butylscopolamine may alleviate respiratory secretions. In cases where extreme suffering is present palliative sedation may be necessary. Palliative sedation is defined as a deliberate and monitored intervention aiming at alleviation of intolerable suffering from refractory symptoms. The presence of intolerable suffering differentiates it from situations where sedation is a side effect of treatment. The goal is not to shorten a patient's life but to cause relief with the lowest dose possible, in a stepwise approach. Sedation may be intermittent or continuous, the latter being reserved to use in the terminal phase of life. Midazolam is considered the drug of choice but levomepromazine may be a second option. It should be decided according to the advance care plan established previously, under the umbrella of bioethics.[95]

Bereavement care is an important component of end-of-life care. It includes ongoing and open communication with the caregivers and family after the patient is deceased and is designed to facilitate healthy grieving. A multidisciplinary approach is often needed.

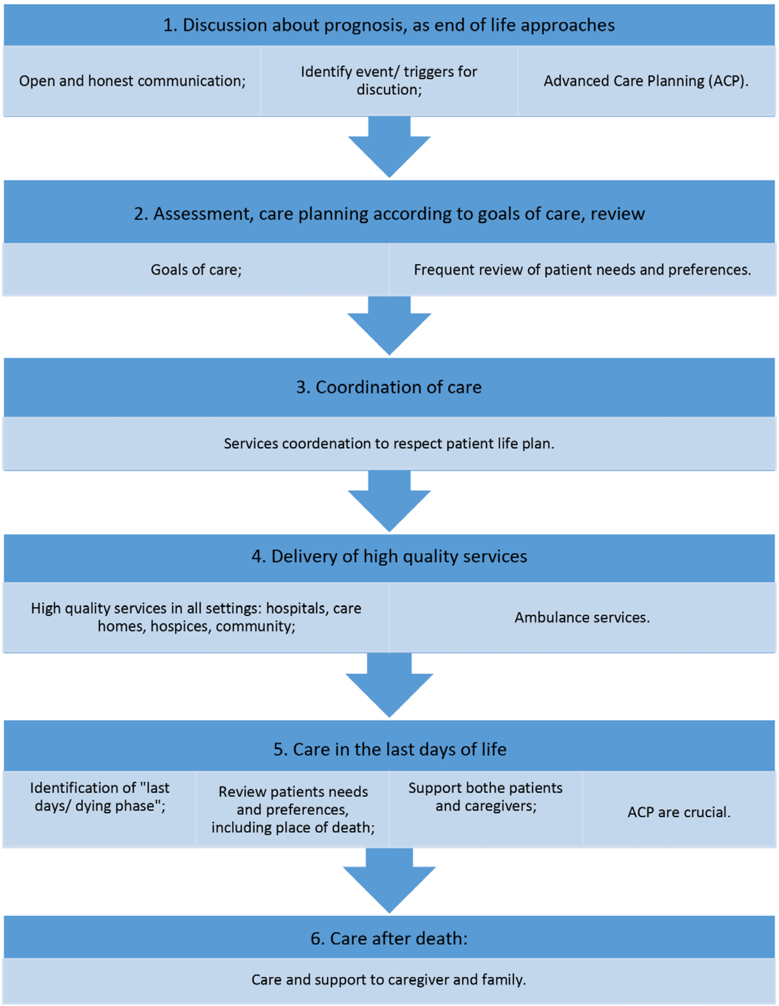

Figure 4. EoL pathway

Adapted from[18]

Spirituality

Spiritual care has become increasingly integral to patient-centred care, with an evolution of spiritual assessment tools in healthcare.[96,97] Spirituality involves seeking meaning, personal growth, and connecting beyond sensory experiences. It is a universal human trait deepened by life events.[98] Though separate from religion, spirituality can coexist inside a religious framework since religion provides a social setting for cultivating spirituality and exploring one's purpose in life.[99,100]

Recognizing its importance, the World Health Organization emphasises early identification of spiritual issues.[101,102] Recent guidelines aim to incorporate spirituality more seamlessly into end-of-life care, emphasising the importance of spiritual assessments.[103] Simple questions like "Are you at peace?" or "Do you have any spiritual questions you want to share with a member of the medical staff?" can be initial touchpoints, providing the groundwork for more comprehensive discussions regarding spirituality.[104]

Despite the acknowledged importance of addressing spiritual concerns during life-threatening, chronic illnesses, these issues often remain unaddressed in standard clinical settings. Many healthcare professionals hesitate to broach the subject.[105-107] Understanding how these spiritual concerns manifest in clinical practice is essential, and when necessary, referrals should be made to spiritual care specialists to ensure comprehensive patient care.

10. MULTIDISCIPLINARY TEAM FOR KIDNEY SUPPORTIVE CARE

"Team-Based" Care Requires a Multidisciplinary Approach

Team-based care is associated with higher understanding, improved patient-self-care and lower rehospitalization rates. Patients and families have a deeper sense of trust and are less likely to request a change in the plan of care when they feel well supported by the team.[108,109] A interdisciplinary model allows for *(i)* a healthy exchange of ideas and mutual learning among different health professionals, *(ii)* prioritisation of treatments based on patient needs despite a number of competing priorities, *(iii)* improved coordination of services to minimise redundancy, *(iv)* treatment flexibility as disease or symptoms progresses. Interdisciplinary care leads to holistic care across the continuum of disease and dying.

The Logistics of Team-Based Palliative Care in CKD

A multidisciplinary conservative kidney care team consists of various health care providers from different specialties, as well as patients and caregivers. The three main medical specialties include primary care, nephrology and PC, each one represented by physicians, advanced practitioners and nurses.[110] Collaboration is key, particularly as there is a nationwide shortage of PC clinicians,[111] which is coinciding with an increase in the number of older, multimorbid patients with CKD.[112] Ideally teams would include nurses, nutritionists, psychologists and social workers, to provide holistic care, while frequent collaborative meetings would create an opportunity to enhance the education of general practitioners and nephrologists empowering them to provide PC to their patients with kidney disease, such that, palliative medicine teams would only manage the more difficult or complex issues and, atypical symptom clusters.[113]

When Should Team-Based Kidney Supportive Care Take Place

There are no clear guidelines on the optimal timing and location of supportive care for patients with CKD, with the exception that an early and gradual intervention is preferred. The idea is that "*early difficult discussions simplify difficult decisions later.*" Discussions early in the course of disease allow patients and caregivers more time to accept upcoming changes in health, to understand the principles of advance care planning, and to contemplate their future needs.[114] Planning can help patients avoid the struggle of unpredictable health deterioration and mitigate the isolation and dependency that often ensues, by identifying resources and early support.[115] Late hospice referrals are associated with lower family satisfaction with hospice, unmet needs, low awareness of the expected time of death, low confidence in participation in care, and perceived lack of coordination of care.[116]

11. COMPLEX PATIENTS AND PALLIATIVE CARE REFERRAL

The concept of complexity in PC has emerged because of the wide range of needs and care requirements associated with palliative patients. Classifying patients according to the complexity of their needs is crucial to allocate the most appropriate resources. Furthermore, the concept of Complex Palliative Patient has not been easy to define as there is no consistent approach to interpret or classify it.[117,118]

Palliative Care - National Network and Available Resources

In Portugal, since 2012, the responsibility of the State in matters of Palliative Care has been defined by the Basic Law of Palliative Care – Law nº 52/2012 of 5 September.[119] With this legislation, the *"Rede Nacional de Cuidados Paliativos"* (RNCP) was established, under the tutelage of the Ministry of Health and it was defined that the Coordination of the RNCP is ensured by the *"Comissão Nacional de Cuidados Paliativos"* (CNCP), in articulation with the Regional Health Administrations, through the respective Regional Coordinators of the RNCP.

Palliative Services must fulfil the purpose of integrating PC in the structure and financing of our health system, representing low-cost and high-value interventions. Recognizing the different levels of complexity, it is essential to develop programs that give clinicians the tools and technical skills required. The conceptual map presented in the Strategic Plan for the Development of PC for the biennium 2021-2022 integrates three levels of training typologies: Level 1 (Basic); Level 2 (Intermediate) and Level 3 (Advanced), and designates the areas of fundamental knowledge for each domain of intervention.[120]

Under the Law n.º 52/2012,[119] published in *Diário da República* n.172/2012, Series I of 2012-09-05, the teams providing specialised PC at the local level are very well defined:

i. Palliative Care Units
   The PC unit is a specific service for the treatment of patients who need differentiated and multidisciplinary PC, namely in complex acute clinical situations, and provides inpatient care, which may be integrated into a hospital.
ii. In-Hospital Palliative Care Support Teams
   These teams provide advice and differentiated support in specialised PC to other professionals and hospital departments, as well as to patient and families, for the execution of the individual plan of care for hospitalised patients suffering from a serious or incurable illness, in an advanced and progressive phase or with a limited life prognosis, for which its action is requested.
iii. Community Palliative Care Support Teams
   Community support teams provide specialised PC to patients and support their families or caregivers, at home. The integration of patients in the RNCP is possible through the Gestcare CCI app, a platform in which all professionals working in PC can register their approach to an individual patient.[121] Another important domain within the provision of care to the patient and family is the need to support the caregiver as they are an important member of the team. In Portugal, the

first legislation that intended to regulate the rights and duties of the caregiver and the person cared for was approved in an annex to Law No. 100/2019, of 6 September. In January 2022, the publication of regulatory decree number 1/2022 established the terms and conditions for recognizing the status of informal caregiver as well as measures to support informal caregivers and people cared for.[122] Respite care, where a patient is admitted to an UCP-RNCCI unit as a reprieve for the caregiver, applies only to users referred from the domicile, by a specific CP team (ECSCP or EIHSCP).

All the above structures can be activated by the attending nephrologist when deemed appropriate. In some cases, referral by the family doctor may be necessary, but most community teams accept direct referral. One of the objectives of the Strategic Plan for the Development of PC 2021-2022 is precisely the creation of a universal signalling form.[120]

Complex Patients who might Benefit from Level 2 and Level 3 Palliative Care

Some patients may be treated by an intermediate Level 2 team led by a nephrologist. This team would have intermediate palliative care knowledge and can provide care to less complex cases. This path has widespread future opportunities particularly in areas with limited resources. Importantly this would allow better use of limited resources in a subset of patients who due to their complexity still require Level 3 (Advanced) team care. These patients should be referred to Level 3 PC teams. Examples include:

- Patients with cancer in palliative stage.
- Patients with other uncontrolled organ failure.
- Patients with uncontrolled symptoms despite implemented measures.

12. ETHICS AND LEGAL ISSUES

To initiate, withhold, discontinue or choose a no dialysis pathway is a process of decision making that can be emotionally burdensome to the nephrologist.[123] Furthermore, the implementation and expansion of renal conservative treatment programs or operationalization of withdrawing from dialysis is restrained by insufficient support of PC specialists, scarce beds in PC units[120,124] or nephrologist training in this area.

The four principles of bioethics that are the core of moral reasoning in health care (beneficence, nonmaleficence, justice and autonomy) should guide the resolution of conflicts and dilemmas in this process of decision making.[125,126] These principles may conflict and must be taken in their context.[127] A systematic approach (Tables 6 and 7) to ethic problem-solving includes:

- Clinical assessment (identifying medical problems, treatment options and goals).
- Patients' values (identifying preferences on treatments and goals of care).
- Impact of options in quality of life.
- The context (family, spiritual, cultural factors).

In the deliberation process proposed by Gracia it is important to identify: the main ethical problem, the existence of a conflict and possible courses of action. A family conference may be useful for clarifying doubts and provide the consistency of the decision, in the case of moderate conflicts. Serious conflicts may not be solvable (Table 6).[126,128]

Particular Points to Highlight

- To forgo or withhold dialysis is not euthanasia.
- Initiating or maintaining treatments that are consistent with futile care (such as dialysis in some circumstances) is akin to dysthanasia.

Euthanasia is a practice to intentionally end life in order to eliminate pain or suffering. Forgoing dialysis permits natural death. This aligns with care that does not interfere in the natural history of the disease.

Legal Considerations

Fear of a lawsuit has been identified as a reason to put patients into dialysis.[129] There are several common situations that should be considered. Patients have the right to self-determination, even if this results in death: patient's refusal to a treatment is irrevocable. On the other hand, the patient cannot ask for a treatment that is not aligned with medicine leges artis or that the physician believes would be futile. In this situation, the physician has no obligation to "treat" the patient in the way he/she determines.[130] Health care providers have the right to refuse treatments that are considered inappropriate or disproportional (conscientious objection) or whenever they contradict moral judgement.[131] In this situation, the patient must be referred to another doctor or it would otherwise be a form of abandonment, a practice that is ethically reprehensible. The decision to use or not use a treatment cannot be made by the family, which configures *consumerism.*

Dialysis discontinuation and dialysis withholding are considered within the same bioethical framework. In the "Ethical aspect of EoL care" the National Council of Ethics for the Life Sciences declares that "it is ethical to interrupt disproportionate and ineffective treatments, even more so when they cause discomfort and suffering to the patient, so this interruption, even if it shortens the life span is not considered euthanasia". Dialysis treatments are considered futile when they do not contribute to achieve physiological, clinical or palliative goals or do not benefit the patient's overall wellbeing. As these principles consider all treatments must be evaluated equally according to usefulness and/or futility, decision making principles for dialysis follow the same principles as used for mechanical ventilation, intravenous drip or nasogastric tube feeding. In each of these scenarios they are continued only if useful to treat a disease or alleviate suffering. When there is no foreseeable chance that they will meet these objectives, it is legitimate to withhold or discontinue the treatment.[132] As stated by Pellegrino,[132] care is a continuing moral obligation, while continuation of medical interventions may not be.

Table 4. Application of principles of ethics in patient care

Beneficence, nonmaleficence	*Clinical assessment* Nature of illness (acute, chronic, reversible, terminal) Goals of treatment Treatment options and probability of success for each option Adverse effects of treatment and balance between benefit and harm Effects of no medical/surgical treatment If treated, plans for limiting or stopping treatment
Respect for autonomy	*Patient rights and preferences* Information given to patients on benefits and risks of treatment. Patient understand the information and give consent? Patient mentally competent? If competent, what are his/her preferences? If a patient mentally incompetent, are the patient's prior preferences known? If preferences are unknown, who is the appropriate surrogate?
Beneficence, nonmaleficence, respect for autonomy	*Quality of life (QOL)* Expected QOL with and without treatment Physical, mental, social deficits that may arise after treatment Judging the QOL of a patient who cannot express himself/herself- who is the judge? Recognition of possible physician bias in judging QOL Rationale to forgo life-sustaining treatments
Distributive justice	*External forces and context* Conflicts of interests – does physician benefit financially or professionally by ordering tests, prescribing medications, seeking consultations? Research or educational considerations that affect clinical decisions and physician orders Conflicts of interests based on religious beliefs or legal issues Conflicts of interests between organisations (clinics, hospitals), existence of third party payers Public health and safety issues Problems in allocation of scarce resources

Adapted from[133]

Table 5. Deliberative process

Decision control consistency:
The legality test: is this a legal decision?
The publicity test: "would you be prepared to defend it publicly?"
The consistency in time test: "would you arrive at the same decision in a few more hours or a few more days' time?".

Adapted from[128]

13. PRIMARY PALLIATIVE CARE EDUCATION FOR THE NEPHROLOGY TEAM

One of the largest barriers to timely palliative care is the relatively small number of health care providers with adequate training in palliative care.[134,135] Therefore, strategies to increase access to education are needed.[136] The WHO PC roadmap proposes the introduction of three levels of PC education: *(i)* basic education for primary care physicians; *(ii)* intermediate education for secondary care professionals and *(iii)* tertiary education for specialists.[137] In 2013, the European Association for Palliative Care (EAPC) developed a document with core competencies for PC addressed to physicians and other health professionals in Europe.[138] In April 2021, the Resolution No. 131/2021 of the *Assembleia da República of Portugal* recommended that the government urgently strengthen the national network and training in PC.[139]

Primary PC care skills that all nephrology care providers should have include the following[113,140-142]:

- Understanding and communicating prognosis.
- Patient-centred decision-making.
- Symptom management in ESKD.
- Communication.
- Advance care planning.
- EoL in ESKD.
- Discontinuation of dialysis.

The integration of primary PC into general nephrology education is an evolving topic. In some institutions, formal PC curricula or electives taught by interprofessional teams (physicians, social workers and nurses) have been established in collaboration with the departments of PC, geriatrics, and nephrology.[143] Expanding the primary skills of all clinicians will be a key step toward overcoming the shortage in the PC workforce. We recommend that nephrology residents consider a three-month fellowship in a department with a conservative care program and/or a fellowship in a level 3 PC team.

14. IMPLEMENTATION, FINANCING AND COST-BENEFIT ASSESSMENT MODELS

A palliative approach to ESKD represents a transition from a conventional disease-oriented focus on dialysis as a rehabilitative treatment, to a perspective that prioritises comfort and alignment with patient preferences and goals of care in order to improve quality of life and reduce symptom burden.[13] Non Palliative care specialists should be able to address the majority of these aspects, except perhaps for the most complex palliative needs.[144] Nephrologists ought in fact to be deeply involved in PC, considering the following:

- We have a unique set-up of non-oncologic chronic disease patients, for whom we act as primary care physicians, suffering high morbidity and mortality and facing difficult access to PC.
- We have a unique experience with prescription specificities for patients with ESKD as well as with performing on demand ultrafiltration to treat fluid overload that can complicate conservative treatment.
- Our patients are connected for life to our care network, and they interact with the team 3 times per week.
- In our units we have already truly multidisciplinary teams of physicians, nurses, social workers, psychologists, pharmacists and dietitians, maximising resource utilisation.
- We have acquired a large experience, and we are licensed for acquisition and distribution of medication.
- Our parliament *Assembleia da República* approved a resolution[139] recommending formal training at an intermediate level in PC for nephrologists (among other specialties).

Implementation Models of Supportive and Conservative Care

The International Society of Nephrology Second Global Kidney Health Summit declared supportive care as an essential component of an integrated ESKD program. To be considered a comprehensive program, it should cover 3 phases in the continuum of kidney care[10]:

- CKD care prior to deciding about RRT. It includes patient education about all care options, as well as medical management without dialysis (conservative care).
- Supportive care concurrent with dialysis.
- EoL care.

CKD patients on stages 4 and 5 should be followed formally in a "low clearance clinic" where they can be educated about their disease, treatment options and how these treatments would impact their personal daily routines. Education about conservative kidney care (i.e., care that forgoes dialysis) should be included as noted in the DGS recommendation (Norma 017/2011). Patients should also be taught about the option to withdraw from dialysis if at any stage they feel it is too burdensome. In both scenarios (conservative care and discontinuation of dialysis) patients should be supported with basic and intermediate palliative care support.[11]

Ideally team competencies include the ability to[145]:

- Identify patients that are more likely to benefit from supportive care interventions.
- Assess and manage symptoms effectively.
- Find out if selected patients and/or their families wish to receive prognostic information and want to participate in decisions about their plan of care. In that case estimate and communicate prognosis, survival and probable illness trajectory.
- Elicit patient's preferences, goals and values to support shared decisions about their care planning.
- Possess knowledge of available local supportive care services and be aware of when and how to refer.
- Lead care coordination, including referral to specialised PC as well as to hospice care if available and appropriate.
- Invite autonomous patients to issue a living-will, allowing the team to know and respect their autonomy in case they are not competent when important care decisions arise.
- Identify the best patient representative that will act as a health care proxy if and when needed.

Conservative care programs should include outpatient care, day hospital care, and where possible access to inpatient nephrology beds. Dialysis units should integrate a process to provide care if a patient wishes to withdraw from dialysis treatment. A dedicated team who can support these patients through to death is optimal. To identify those who may wish to discuss dialysis discontinuation, patients maintained on dialysis should be evaluated once or twice a year (depending on frailty and cognitive impairment). Signs indicating patients may benefit from a discussion about palliation include those listed below (Table 8).

Table 6. Patient assessment in each type of PC consult

Incident Patients Assessment Consider for Referral if:	In patients apparently not benefiting from dialysis treatment A) Answer to Surprise Question at 6 mo » NO and B) Charlson Comorbidity Index > 8
Prevalent Patients Assessment Consider for Referral if:	Any sentinel event is present: A) More than 2 hospital admissions in 3 months; B) Weight loss more than 10% in 6 months, or Albumin < 2.5 g/dL; C) Recurrent vascular access problems; D) Enters an Institution or sudden functional loss; E) Surprise question at 6 month- NO;
Palliative Team Consult Assessment	A) Functional status; B) Cognitive function; C) Other scoring considered useful; D) Discuss Conservative treatment

Reviewing the literature, we can find essentially 4 models of kidney supportive care programs.[146] Given the current lack of evidence favouring any of these models over another, program leaders need to carry out a careful assessment of local conditions when planning a supportive kidney care program. Individual programs have demonstrated a positive impact on outcomes such as ACP and place of death, but there is not yet systematic evidence comparing the impact of model type on effectiveness or cost-utility.[147] Therefore, the composition and functions of this team, detailed in other chapters, should be adapted to the specificities of each unit and the PC resources in the region.

Requirements for Supportive Care Process Implementation

The implementation of a PC program to support ESKD patients in a dialysis network requires:

- Professionals (nephrologists, dialysis nurses, psychologists, social workers, dietitians) with experience and education in PC (at least basic to intermediate level) organised in teams in each nephrology unit or group of units, that will attend patients referred to them by other nephrologists and that will assume the responsibility of continuous education of all the staff, interacting with local specialised PC infrastructure for referral of more complex cases.
- An electronic health record platform to register all clinical encounters, clinical management and outcomes assessment, with specific fields to enter information concerning first and follow-up consults with nephrologists, and special consults by the PC team.

It is of utmost importance that the team is cognizant of the local PC infrastructure. It is well known that our National Palliative Care Network is clearly undersized for the community of chronic disease needs. The dialysis unit absolutely needs to know in detail all the available long--term and PC resources in its community and integrate that network with its unique contribution. As noted below patients choosing conservative care and/or dialysis discontinuation should remain registered within the DGS Registry platform (GID).

It is advisable to provide an information package that patients carry with them to all appointments or encounters with the health care system (primary care, emergency room, hospitalisation). This package could include up-to--date information with:

- A brief description of the goals of supportive treatment and the PC program.
- The elements and contacts of the team and next of kin.
- A formal letter for the general practitioner and the Emergency Room doctor.
- Medication list and dietetic prescription.
- How to act in specific emergencies (pain, dyspnoea, bleeding).
- Diary with relevant clinical and existential events and decisions.
- If existent, a copy of the living-will and durable power of attorney (name and contact of the legal representative).

Costs and Financing of a Supportive Care Program in a Network of Dialysis Units

Although the clinical benefit of a supportive care program is well documented, there must be some caution. Inpatient access to PC is associated with lower intensity of care and costs, particularly in those unlikely to benefit from dialysis.[144,148] It is therefore possible that age, dementia and frailty become targets of cost-containment policies and lower dialysis use results from resource rationing.[149] Clinicians are reminded they must avoid situations where they judge the patient's quality of life or impose their opinions at the EoL.

Future costs of a supportive care program should be analysed. Cost-benefit analyses should include costs associated with:

- Patient transportation to and from the dialysis unit or hospital visits if needed.
- Acquisition and distribution of medication to the patient's home.
- Home visits by clinicians and nurses providing in-home care.
- Virtual consultative support from a nephrologist or kidney-care nurse.
- Services from a specialised PC team (physicians, nurses and other allied health members).

Improving wellbeing and the quality of dying comes with its own expenses. However, if we adopt a palliative strategy, a significant amount of regular costs will be cut, including:

- Costs directly related to treatments, such as disposable supplies, treated water and waste disposal.
- Number of hours per week of professionals needed (mostly nephrologists and nurses).
- Reduction of the number of hospital referrals and admissions.
- Avoidance of the costs of medication not specifically dedicated to relief suffering or discomfort such as medications for mineral bone disease.

Key Quality Indicators for the Death Process and End of Life Care Audit

Key indicators to assess the quality of EoL care are not currently established or validated but quality assurance has a crucial role in all future programs. Suggested quality indicators include: the number of hospitalisation days in the last 3 months of life, ICU admission, no evidence of a do-not-resuscitate order, cardiopulmonary resuscitation in case of cardiac arrest, number of dialysis treatments in the last week of life, need for emergent ultrafiltration in patients on supportive care; absence of a living- will, or the indication of a legal representative.[150]

15. REGISTRIES AND DOCUMENTATION

According to the data from the *Gabinete de Registo de Doença Renal Crónica* from *Sociedade Portuguesa de Nefrologia,* on 31 December 2022 there were 21 357 patients in Portugal undergoing renal replacement therapy in its 4 modalities: haemodialysis, peritoneal dialysis, kidney transplantation and conservative kidney care, resulting in a prevalence of 1330 patients per million population. Based on this data, Portugal has one of the highest incidences of stage 5 CKD in the world, with the possible loss in quality of life and economic burden on the healthcare system.[8,151,152]

Additionally, in 2008 the Portuguese National Health Service (NHS) designed and implemented a new model for the integrated care of stage 5 CKD: Disease Management Platform *(Plataforma Gestão Integrada da Doença, GID)* (http://gid.minsaude.pt). To support the implementation of this model, an individual online registry, including administrative and clinical data, was set up in 2009. Every movement of patients admitted to dialysis, transferred to other renal replacement techniques or to PC, as well as outcomes such as death or recovery of renal function, should be registered on this platform.[153]

The collection of data from the national register has included information on conservative care patients only in the last two years. In 2022, this registry recorded 159 patients in conservative care programs in our country, the majority older than 80 years old (87%). It is imperative to characterise this population so that strategic plans can be designed to ensure the best possible quality of life for patients, in parallel with accurate reimbursement policies. This data should be integrated in the *Gabinete de Registo de Doença Renal Crónica* from *Sociedade Portuguesa de Nefrologia,* and on the Online Platform on the NHS (GID) and made available to all nephrologists.

16. BARRIERS TO THE IMPLEMENTATION OF A CONSERVATIVE TREATMENT PROGRAM

The following are major barriers to the adoption of conservative care or dialysis discontinuation programs and only likely to be overcome with programs offering ongoing training and education for health care professionals[145,154,155]:

- Physician lack of training and low clinical experience within the treating institution.
- The belief that discussion of conservative or palliative care would harm the patient-doctor relationship, and result in patients losing hope.
- The observation that it may be easier, faster and more profitable to provide dialysis treatments rather than to have difficult and time-consuming conversations about conservative approaches to care.
- The challenge of communicating uncertainty: clinicians struggle with the variability in clinical outcomes and the resulting *Medical Uncertainty.* Ongoing training in communicating uncertainty will be required.
- The cultural burden: religious beliefs, professional ethics concerns or fear of legal litigation may also present as obstacles.
- Lack of available PC infrastructure in most communities, including access to inpatient services for patients in different stages of their CC trajectory.
- Lack of strong evidence of a clear benefit in cost-utility of PC programs was cited as a barrier, both in convincing colleagues (centred on a technological culture of curative care) and in providing patients with information they need in their decision-making process.[156]
- Lack of a specific policy for reimbursement for CC including for example medication supply, emergent ultrafiltration, home-based visits and community support. Defining clear rules will enable all interested stakeholders to enter this field with their own expertise.
- Incentivized metrics for payment, established by National Health Service (the universal payer for the whole ESKD treatment), aim to establish targets for dialysis care through performance standards. Unfortunately, it can be challenging to assess quality of care when individualised patient-centred care is being provided.

17. RESEARCH OPPORTUNITIES IN GERIATRIC AND PALLIATIVE NEPHROLOGY

Comprehensive conservative care and the geriatric aspects of renal replacement therapies are relatively recent. Therefore, there are vast opportunities to produce new evidence and improve our knowledge and services. The authors of this document enthusiastically encourage and will gladly support research projects in this field.

The authors identified a few areas of research:

- Qualitative research on elderly Portuguese patient and family experiences through the choice of renal replacement therapy modality: transmission of information, Shared decision making, factors that influence choice, and experience through dialysis and non-dialysis pathways.
- Impact on survival, hospitalisation and institutionalisation for all 4 modalities of RRT (haemodialysis, peritoneal dialysis, kidney transplant and conservative care).
- Establishment of a national registry of patients who choose Conservative Care and those who withdraw from dialysis with the possibility of researchers to access that data upon request.
- Identification of risk factors for poor outcomes in advanced CKD and ESKD, especially unconventional risk factors like geriatric syndromes (e.g. frailty, falls, polypharmacy, pressure ulcers, delirium and cognitive decline, functional decline, etc.) and social determinants of health (e.g. income level, education, family and social network, social support structures, illiteracy, racial and gender disparities, geographic inequalities, etc.).

- Identification of patient-centred outcomes and generalisation of their use in all trials (e.g. quality of life).
- Creation of evidence on symptom control strategies.
- Assessment of the impact of geriatric syndromes on the management of ESKD patients (e.g. nutritional indications, dialysis initiation timing, vascular access interventions, access to transplantation, solute clearance goals, anaemia and secondary hyperparathyroidism treatment goals, etc.).
- Identification of modifiable geriatric risk factors and assessment of the impact of interventions (e.g. rehabilitation to prevent functional decline, nutrition therapy).
- The role (or lack thereof) of palliative dialysis/ultrafiltration in CC.
- Development of audit measures for CC programs.
- Cost analysis of CC programs. Cost-benefit analysis in terms of patient-centred outcomes and models to deliver CC.
- Development of a reimbursement plan to CC.

18. CONCLUSION

The ageing population is in dire need of innovative and person-centred healthcare solutions.[157] The aim of this working group collaborative statement is to identify strengths and opportunities, within Portugal, that would lead to high-quality integrated kidney care programs that incorporate a wide range of services for older individuals that include renal transplantation, dialysis as well as conservative approaches to kidney care treatment.

Based on values and ideologies published in 2011 in the DGS directive 017/2011,[11] and recent state of the art literature, we have included strategies to identify, and counsel vulnerable patients on options that include conservative care, and palliative dialysis, as well as a plan to increase awareness of the rights of patients to discontinue dialysis and transition to end-of-life care. We describe the legal and ethical principles that support introduction of dialysis discontinuation, and advocate for improved awareness and reimbursement policies. Included are summarised data supporting the role of dialysis care in prolonging survival, and the counter information showing the substantial negative effects on physical and cognitive function, the ongoing symptom progression and the modest change in quality of life.

Key principles described in this document include the need for political, social and healthcare change. High quality kidney care requires a diverse multiplicity of professionals who join forces in the approach of the physical, social, spiritual and existential needs of the patient and family; open and honest communication between providers, and patient and families; and the creation of coordinated specialist services. We emphasise the need for improved training and education across the nephrological community including training for physicians, nurses and allied health teams. This working group recommends funding to support further extension of kidney care beyond the traditional multidisciplinary model into an inter-institutional model, involving palliative, nephrology and community care across hospital, primary health care and the religious and social structures of the community in which the family unit is integrated.[160]

Individualised care is a collaborative effort of a multidisciplinary team, establishing a partnership with patient and family. Nephrologists are responsible for presenting relevant information as unbiased and easy as possible, to share the decision process with patients/ families, to support and implement the treatment decisions reached by all stakeholders, without closing the door to an opinion change by the patient or his family in favour of life prolonging. Ultimately the responsibility of caring for ESKD patients and treating their symptoms, either related to CKD itself or to comorbid disease, is in the nephrology teamś hands. Nephrology programs and dialysis providers need to develop and integrate a palliative support strategy for ESKD patients.[46]

This Document is our response to these gaps in the continuum of care for the most fragile and vulnerable patients. There is no time to wait.

Ethical Disclosures

Conflicts of Interest: one declared.

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