

Renal supportive care and palliative care: revision and proposal in kidney replacement therapy

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Nefrología 2012;32(1):20-7

doi:10.3265/Nefrologia.pre2011.Nov.11065

ABSTRACT

Patients with chronic kidney disease may receive sustained renal supportive care and renal palliative care (RPC) starting with the diagnosis of the disease, throughout the various stages of renal replacement therapy (RRT), the cessation of the RRT, and in the decision of whether to provide conservative treatment or non-initiation of RRT. This article reviews the literature on the development of renal palliative care and proposed RPC models. We describe the progression of disease in organ failure, which is very different from other areas of palliative care (PC). We describe important components of resident nephrology training in PC. We discuss the management of pain and symptom control, as well as communication skills and other psychological and ethical aspects in the renal patient. We conclude that in chronic renal patients, a palliative care approach can provide a positive impact on the quality of life of patients and their families, as well as optimizing the complex treatment of the renal patient.

Keywords: Renal Palliative Care. Opioids and Renal Failure. Renal Palliative Care and Organization.

INTRODUCTION

The 21st century should be second nature to health professional has two obligations when performing his/her

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Cuidados de soporte renal y cuidados paliativos renales: revisión y propuesta en terapia renal sustitutiva

RESUMEN

El paciente con enfermedad renal crónica es susceptible de recibir tratamiento de soporte y cuidados paliativos renales (CPR) desde el diagnóstico de la enfermedad, durante las distintas etapas de tratamiento sustitutivo renal (TSR), en el cese de dicho TSR y también si se decide tratamiento conservador o no inicio de TSR. Este artículo revisa la literatura referente al desarrollo de cuidados CPR y los modelos propuestos. Exponemos la trayectoria de la enfermedad en el fallo de órgano, que marca diferencias respecto a otros campos de los cuidados paliativos (CP). Se describen componentes de formación importantes para el residente de nefrología en CP. Abordamos el manejo del dolor y el control de síntomas, así como habilidades de comunicación y otros aspectos psicológicos y éticos en el paciente renal. Concluimos que en la atención al paciente renal crónico, un enfoque desde la medicina paliativa puede suponer un provechoso impacto en la calidad de vida del paciente y su familia, además de optimizar el complejo tratamiento nefrológico del paciente.

Palabras clave: Cuidados paliativos renales. Opioides en insuficiencia renal. Organización en cuidados paliativos renales.

job: to cure disease, and to alleviate suffering.¹ In the case of chronic incurable diseases, the objective of treatment is to improve or preserve body function so as to avoid a premature death. This objective is carried out through palliative care (PC), defined by the World Health Organisation (WHO) in 2002² as total, active, and continued care of the patient and the patient's family by a multi-professional team when the medical expectation is no longer

one of curing the disease. The primary objective of this medicine field is not to prolong survival, but to achieve the highest possible quality of life for patients and their families. As such, PC practitioners must cover their patients' physical, psychological, social, and spiritual needs.² If necessary, this support must also be extended to the grieving process. Palliative medicine (PM) is not synonymous with terminal illness, although it does include it. There is a large knowledge base for the application of PM, but this experience is not benefiting the majority of people that have a need for it. Despite the efforts made in the last two decades, the majority of patients that require PC do not receive it.³ Recently, dramatic changes have occurred in the demographics of patients with advanced chronic kidney disease (ACKD).⁴ In 2009, the incidence of RRT in Spain was 126 patients per million population (pmp).⁵ Currently, approximately 1.5 million patients are receiving haemodialysis globally, and this value is growing at a 7% yearly rate in those populations that have the privilege of access to this type of treatment.⁶

Chronic kidney disease (CKD) follows a progressive deterioration through various stages, in which RRT is the final stage that only a small portion of CKD patients arrive at⁷; with this in mind, we performed a review focusing on the development of renal palliative care (RPC) and renal supportive care (RSC), areas of new and growing interest for nephrology in Spain.

For a better analysis of the subject, we will focus on the following aspects:

- 1) Concepts of RSC and RPC
- 2) Bioethics: fundamental basis for RRT
- 3) Progression and stages of the disease
- 4) Organisational models
- 5) Guidelines for training in PC for nephrology residents
- 6) Pain and symptom control
- 7) Psychological aspects and counselling

A NEW CONCEPT: RENAL SUPPORTIVE CARE

The term RSC is emerging as a central topic in nephrology. It deals with a concept that is similar to PC, end of life care, and conservative patient management,⁸ but with several differences. Although very similar, they are not synonymous, and as such it requires a definition. To tell a patient that he/she has advanced renal failure and needs dialysis involves very bad news that shatters

the concept of life expectancy previously held by the patient, placing them in a scenario of uncertainty where the perception of control is lost and quality of life is threatened. However, this psychological situation is rarely recognised or discussed. Experts in PM should work together with nephrologists in order to provide the best possible care and quality of life for patients and their families.⁹

The future course of this type of treatment will involve integrating the principles and practices of PC in the different areas of nephrology including haemodialysis, peritoneal dialysis, renal transplants when necessary, dealing with patients with CKD where the indicated approach is a conservative treatment, and, of course, patients that require end of life care. The objective is to ensure that all renal patients with a limited life expectancy receive high quality care with the help of the most appropriate professionals.

The concept of RSC has been analysed by Noble et al, using the Rogers method, which is based on the idea that concepts are dynamic, with constant modification and change. With this in mind, the following attributes of the concept of RSC were laid down⁸:

- 1) **RSC must be available from the moment of diagnosis to patient death, with emphasis on a clear prognosis and the impact of the advanced renal disease.** One difference with respect to oncology is that, in the case of oncology, some patients may recover but CKD patients have a very high probability of death due to the complications associated with their disease.
- 2) **Interdisciplinary approach to treatment.** This facilitates avoiding the medicalisation of the psychological and existential needs associated with RRT patients.

In addition, the concept of a nephrologist with extensive training in RPC has emerged, with great importance at centres where palliative care units (PCU) do not cover all the patients with non-oncological pathologies.
- 3) **Attention given to the patient's caretaker and family.** The support of patient caretakers is essential in RSC. The pressures felt by financial budgets are one important factor, making the patient the central focus.¹⁰ In family renal disease, unaffected caretakers tend to have an added emotional burden that may go unnoticed at first.¹¹
- 4) **Therapeutic communication skills, which ensure proper and opportune shared decision making.** The objectives of RSC are not reachable without proper training in communication skills.¹²

BIOETHICS: A FUNDAMENTAL BASIS FOR RENAL REPLACEMENT THERAPY

Within the sphere of RPC interventions, we must pay special attention to certain clinical situations with a high emotional impact that can generate difficulties in shared decision making, such as the withdrawal of a patient from dialysis or the decision not to start it, among others.⁶ At this point in the development of the field of nephrology, we know that not all that is technically possible is ethically admissible. Modern bioethics is based on the development of four fundamental principles that should be second nature to doctors attending to patients on RRT (Table 1). A detailed study of these principles falls outside the aims of this review.

PROGRESSION AND STAGES OF DISEASE

Most of patients with ACKD die due to non-renal causes, and although the renal disease may contribute to exitus, it is not directly responsible.¹² Four different progressions have been described for disease (Figure 1).^{13,14}

- 1) Sudden death may occur at any point during the progression of the disease, with no previous diagnosis (Figure 1A).
- 2) Following diagnosis of the terminal disease, function is preserved initially, followed by a rapid deterioration in advanced stages (Figure 1B); which is the typical pattern in oncology.

- 3) This pattern involves recurrences of acute episodes, requiring hospitalisation occasionally, with no recovery of previous functional states (Figure 1C), which poses a risk of death. This is the typical pattern in organ failure.
- 4) There is a gradual decrease in function prior to death, which is characteristic of dementia and advanced age (Figure 1D). These patterns may overlap in a patient on RRT.

Implications of the disease progressions

For ACKD patients and their families, as well as for the health professionals that treat them, it is of vital importance to understand these disease progressions towards death.¹² This is consistently becoming more important for nephrologists, who currently manage patients on RRT at more advanced ages and with more associated comorbidities. The disease progressions allow health care providers to: realise that “to do all that one can do may be the wrong choice,” carry out a practical plan for a good death, support both the patients and their caregivers, and avoid a “prognostic paralysis”.¹⁵ These implications lead us to the following conclusions: 1) **that one single model does not work for all cases:** the typical oncological PC model may not be adjustable to gradual and progressive patient decline with unpredictable exacerbations. Patients with non-malignant diseases may have more prolonged needs than, although similar in nature to, those of cancer patients; 2) **transferable lessons:** PC in oncology

Table 1. The four principles of modern bioethics

1. Level I or minimal:

1. Principle of non-maleficence: the obligation to do no harm to the patient, to not do damage (*primum non nocere*). Tends to be interpreted as the *lex artis* and the obligation to carry out only indicated actions and never contraindicated actions.
2. Principle of justice: equitable distribution of the costs and benefits of treatment, with no discrimination of patients based on any cause that might have to do with their social condition, sex, race, etc. The principle of justice has to do with equal opportunity and equitable allocation of available resources.

Level II, or maximum:

3. Principle of autonomy: all people are, inherently and unless otherwise demonstrated, capable of making their own decisions regarding whether or not to receive treatments that will affect their health.
4. Principle of beneficence: we are obliged to aid our patients, providing them with the greatest possible benefit.

(Source: TL Beauchamp y JF Childress, 1979).

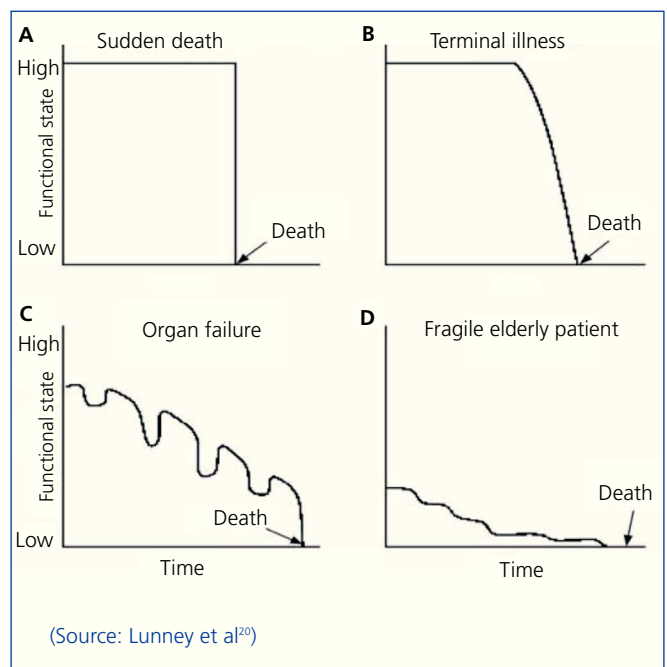


Figure 1. Typical progressions of disease, identified in different patients.

provides experiences that we can benefit from; 3) **challenges for research:** patients receiving PC are an especially vulnerable group, for which there is not usually a “second opportunity” that allows for improving the care given to them. As such, the idea of assigning patients to sub-optimal conditions of health care is unacceptable.¹⁵ Research is difficult to carry out in this field of medicine, but even so should be given more emphasis.

ORGANISATIONAL MODELS

Spanish authors have proposed a PC programme for terminal uraemia in patients with stage 5 CKD that do not respond to dialysis, with glomerular filtration rates (GFR) <15ml/min and who refuse RRT.¹⁶ In the model we propose in this review, we extend this concept, considering clinical and psychological criteria to be paramount above laboratory parameters for including a patient on RSC and RPC programmes; for example, a patient with a functioning renal graft and a GFR of 60ml/min but with musculoskeletal pain may benefit from the aid of an expert, multi-disciplinary team that manages this pain and immunosuppression therapy without compromising the patient’s GFR. A PC programme for terminal uraemia patients is only part of the proposed approach (Figure 2). Tejedor et al also propose the creation of a PCU for ACKD patients. We believe it to be more economically sound, safer, and more effective to train nephrology teams in RSC and RPC. Anyway, the essential step is to incorporate expert

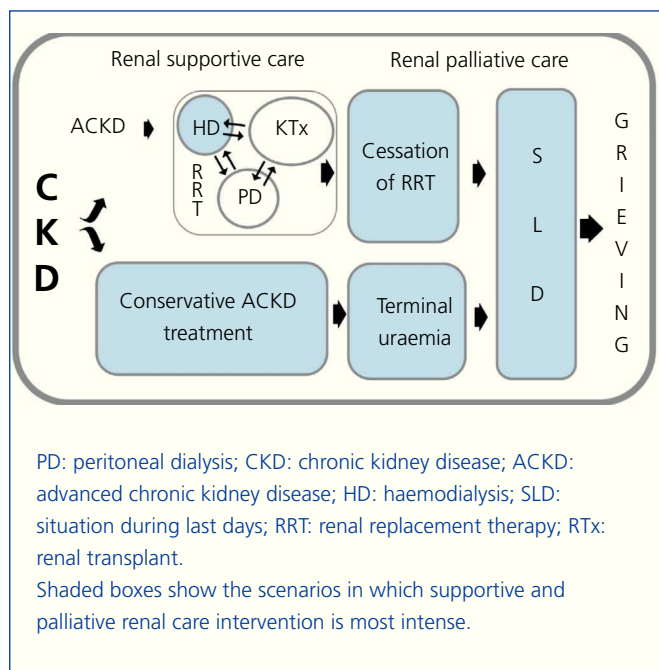


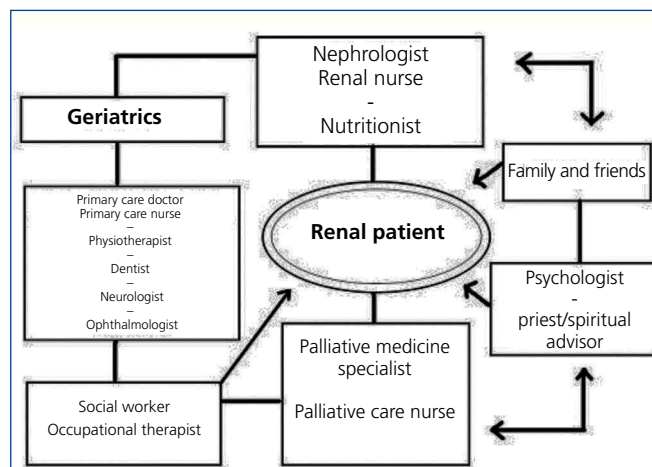
Figure 2. Proposed model for the application of renal supportive care and renal palliative care.

doctors in PM and psychologists, who can offer RSC and RPC from the hospital PCU, in the context of the nephrology department. They can provide aid to the patients and their families, as well as direct support for the nephrologist.⁹ As such, it is essential to adapt the PM model to the nephrology context and to incorporate RSC.⁴ This proposed model is in accordance with a recent publication in nephrology regarding the sustainability and equity of RRT in Spain,¹⁷ and is a humble addition to this shared task. PC could be developed and carried out by interdisciplinary teams that would also include the patient’s family and friends (Figure 3),⁴ who appreciate and recognise the importance of this type of care before and after the death of the patient.¹⁸

In some countries such as in Canada and the United States, the approval of recent guidelines and national publications have established the role of PC in the field of nephrology.¹⁹ Similar experiences have been described in England, Poland, Australia, Portugal, and Hong Kong.

GUIDELINES FOR TRAINING NEPHROLOGY RESIDENTS IN PALLIATIVE CARE

In Spain there are no recommendations from the national committee on nephrology for residents to carry out a specific rotation period for PC. A Canadian study concluded that residents that had contact with PM specialists had better training in situations dealing with the final stages of disease and are considered more competent for providing necessary end of life care,²⁰ and proposed a programme for PM training directed towards nephrology residents that covers the following aspects²¹:



(Source: Lichodziejewska et al³)

Figure 3. Diagram of the interactions amongst the multi-disciplinary team in renal palliative care.

- 1) Impact on the patient upon reaching the final stage of renal disease: life expectancy, survival, mortality, and comorbidity
- 2) PM-based focus in haemodialysis units
- 3) Living wills and cardiopulmonary resuscitation
- 4) Communication skills: counselling
- 5) Pain management in renal patients
- 6) Controlling symptoms in renal patients
- 7) Transferral to specialised PC units and grieving support
- 8) Clinical, ethical, and legal issues when starting and withdrawing dialysis treatment

PAIN AND SYMPTOM CONTROL

Pain

Chronic pain is suffered by 50%-63% of dialysis patients, and 42%-55% of them classify their pain as severe.²² The evidence provided by dialysis guidelines suggest that little recognition is given to this pain and other symptoms in dialysis patients, with consequent under-treatment.²³ The use of opioid analgesics is not very widespread, due to the threat of toxicity and a lack of experience in their use. This leads to inadequate treatment of pain in CKD patients. In a recent review on the use of opioids and benzodiazepines in dialysis patients, the effectiveness of treatment was variable and low; in 17%-38% of patients, the years spent on dialysis were correlated with the presence of pain, and 72%-84% of patients with severe pain did not receive any analgesia.²⁴ Recent research into the use of cannabinoids has motivated the evaluation of their potential use in controlling symptoms in renal patients on RRT. Although they had promising results, at the moment this option is limited due to the absence of long-term results.²⁵

Evaluation of pain

The quantification and later follow-up of pain using scales should be an added parameter for monitoring the management of renal patients. Several different validated pain measurement scales have been applied to groups of haemodialysis patients: the Visual Analogue Scale (VAS), the Pain Management Index (PMI), the McGill Pain Questionnaire (MGPQ), and the Brief Pain Inventory (BPI). The most common aetiology of pain observed during dialysis is ischaemic pain, and the most common extra-dialysis pain is chronic musculoskeletal pain. The prevalence

and intensity of pain during dialysis is higher than outside of dialysis, according to the VAS scale.²⁶ The revised Edmonton Staging System (rESS),²⁷ designed for the evaluation of oncological pain, could be a clinically useful tool for the study and treatment of pain in renal patients. This system has the advantage of predicting analgesic response, considering that a “difficult” pain does not necessarily mean that it cannot be controlled. In order to make a simple of effective evaluation, it is enough to know whether the pain is neuropathic, incidental episodes, or if it associated with emotional suffering and/or altered cognitive state, or drug abuse.²⁷

Arteriovenous fistulas are punctured an average of 300 times per year in haemodialysis patients, and are qualified as medium-intensity pain using the VAS scale.²⁸ The postoperative treatment of pain in patients with ACKD poses a problem due to the fear of accumulating metabolites that would depress the respiratory system. This also has been described by anaesthesiologists, and several drugs are being researched for their efficacy and safety in postoperative ACKD patients.²⁹

Opioids in chronic kidney disease

We have dedicated this section solely to opioid compounds listed for analgesia by the WHO, given the difficulty in their use and their notable usefulness in renal patients. The complex pharmacokinetics of opioid analgesics in patients with kidney disease, as well as a lack of familiarity with the medical use of these drugs, presents a barrier to the effective alleviation of pain.³⁰ The development of renal failure as a consequence of opioid use has not been described.³¹ A prospective study performed with 12 patients on haemodialysis concluded that hydromorphone could provide a safe and effective option in certain patients on haemodialysis.³² Similar conclusions were reached in a study comparing the use of hydromorphone in patients with normal urea and creatinine vs patients with renal failure.³³ The pharmacokinetic and pharmacodynamic profiles of hydromorphone, methadone, and fentanyl are apparently safe in patients with renal failure, making them recommendable in these cases. The dose should be adjusted when $GFR < 10 \text{ ml/min}$.³¹ It has also been recommended to reduce the dose and/or increase the dosing interval in renal failure patients on dialysis. Frequent patient monitoring is also indicated, and may even include home telephone follow-up. It is also recommended not to use morphine or codeine due to the difficulty of managing the adverse effects and complications produced in these patients.³¹ Morphine metabolites could accumulate between dialysis sessions. Methadone metabolites are inactive and are not dialysed, and so do not require adjusted doses in dialysis patients.³¹ These studies are limited to populations with poor statistical significance, and so we must use the recommended drugs

under close monitoring and perform a complete clinical/laboratory evaluation of our patients.

Symptom control

The general load of symptoms in CKD patients is high and similar to those produced at the end of life in cancer patients.³⁴

In patients with stage 5 CKD that are treated without the use of dialysis, the prevalence and severity of symptoms during the last month prior to death have been studied using the Memorial Symptom Assessment Scale-Short Form (MSAS-SF)³⁵; of the 74 patients that participated in the study, with a mean age of 81 years, 86% had severe asthenia, 84% had pruritus, 82% had somnolence, 80% had dyspnoea, 76% had difficulties concentrating, 73% suffered from pain, 71% had reduced appetite, 71% had oedema of the arms or legs, 69% had dry mouth, 65% had constipation, and 59% had nausea. The SMILE (Symptom Management Involving End-Stage Renal Disease) randomised clinical trial demonstrated that patients suffered from pain, sexual dysfunction, and depression when on haemodialysis, these being under-diagnosed symptoms even though they are very prevalent.³⁶

PSYCHOLOGICAL ASPECTS AND COUNSELLING

The interest in incorporating psychological aspects into the care of these patients and their families has been part of PC since its beginning. However, the integration of psychologists into nephrology teams is not widespread. As such, the importance of these variables in PC of renal patients is shown at an earlier stage at the end of their lives. The field of RPC poses an ideal space in which psychologists could exercise their specialty.³⁷

Depression is a psychological issue with a very high prevalence (10%-66%) in ACKD patients, and can be approached through psychological and/or combined intervention.³⁸ In certain scenarios, such as in peritoneal dialysis units, depression is under-diagnosed and difficult to treat.³⁸ Few controlled studies and even fewer randomised studies have considered this issue. Renal patients at the end of their lives are a special high-risk group, given their high vulnerability and dependence.³⁹

In a similar manner, anxiety disorders can be quite common among renal patients at the end of their lives if preventative treatment is not given. The prevalence rate of anxiety disorders in haemodialysis patients is approximately 45.7%, with negative effects on patient quality of life.⁴⁰

Table 2. Stressors in advanced chronic kidney disease treatable through psychological interventions

1. Secondary effects of ACKD and its treatments
2. Diet management and hydration restrictions
3. Anxiety and depression
4. Insomnia
5. Social alienation
6. Functional limits and dependency
7. Main caregiver burnout
8. Spiritual crisis
9. Complicated grieving process: prevention and treatment
10. Exhaustion of the health care team. Prevention of burnout

ACKD: advanced chronic kidney disease

According to Cukor et al, ACKD entails a large number of stressors that the patient and his/her close friends and relatives must face (Table 2). Preventative measures in RPC must be the gold standard for avoiding *psychopathologization* at the end of patients' lives.

Renal patients have a history of disease associated with multiple losses that intensifies upon reaching advanced phases. It is normal to encounter scenarios such as those in hospital haemodialysis units, where "biographical death," associated with reduced quality of life, can occur before "biological death." In order to deal with these differences, psychological intervention in chronic advanced diseases requires protocols for maximising resources rather than models orientated towards psychological pathologies.⁴¹

Psychological therapies in RPC include support for the family and after the patient has died.²³ In 10%-20% of cases, those grieving can have significant difficulties and even associated physical comorbidities in the process of adapting to the loss.⁴²

One therapeutic tool that has demonstrated its effectiveness in PC is counselling, since this is an ideal method for therapeutic communication in circumstances of intense emotional reactions.⁴³

There are several definitions of counselling available. According to Dietrich,⁴⁴ at its core, it is a form of a helpful, interventional, and preventative relationship in which an advisor, through communication, attempts in a relatively short span of time to provoke an active process of cognitive-emotional learning in a disorientated or overloaded person, during the course of which this person can improve his/her disposition towards self-help, his/her capacity for self-direction, and operational competence.

KEY CONCEPTS

1. The introduction of PC and its values within the field of nephrology generates a significant impact on the quality of life of renal patients and their families.
2. Clinical, psychological, and laboratory criteria are orientated towards including patients in RSC and RPC programmes, although this is not exclusively for terminal stage patients.
3. RSC and RPC involve a multidisciplinary team and can be improved by the inclusion of lessons learned in other fields of PC.
4. Training in PC for nephrology residents should be promoted within the teaching and research areas.
5. The study and management of pain in renal patients is a priority that should be promoted both within clinical practice and research.
6. Nephrology teams should be trained to develop communication skills such as counselling.

To our knowledge, there is no term in Spanish that translates the full conceptual richness of the English word. Counselling is not an assessment, nor is it assisted or clinical advice, but it is the opposite of giving advice. Perhaps the most closely related term would be “helping relationship.”

Counselling is not just an interventional tool based on problem solving and emotional management, but also a way of conceiving interpersonal relationships through an ethical concept based on recognising the capacity in others to make their own decisions. Counselling is the art and science of making open, focused questions in order to explore threats and detect resources. It is based on listening rather than talking, empathy rather than judgement, and a fundamental respect of the patient’s values rather than imposing our own. All of this is of the utmost importance during the end of a renal patient’s life.

CONCLUSIONS

It has been clearly demonstrated that the application of the principles of PC in the field of nephrology generates major benefits for the patient, the patient’s family, and the nephrologist. We are faced with a significant challenge in carrying out studies that offer better safety in the use of pain-controlling drugs and those used to treat other symptoms in these patients. The nephrologist also should learn to masterfully use the different options available for managing pain and suffering in advanced phases of renal disease, as well as communication skills for supporting the patients and their families. The development of PC in nephrology departments is a large and important development that we must strive for, involving the dedication of several different disciplines.

Conflicts of interest

Authors declare no potential conflicts of interest .

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