

Home care programme for patients with advanced chronic kidney disease. A two-year experience

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Nefrología 2014;34(5):611-6

doi:10.3265/Nefrologia.pre2014.Jun.12595

ABSTRACT

Introduction: Healthcare for patients with advanced chronic kidney disease (ACKD) on conservative treatment very often poses healthcare problems that are difficult to solve. Many patients are elderly and have mobility problems, and it is very difficult for them to travel to hospital. At the end of 2011, we began a programme based on the care and monitoring of these patients by Primary Care teams. **Material and method:** ACKD patients who opted for conservative treatment were offered the chance to be cared for mainly at home by the Primary Care doctor, under the coordination of the Palliative Care Unit and the Nephrology Department. **Results:** During 2012 and 2013, 50 patients received treatment in this programme. Mean age: 81 years, Charlson age-comorbidity index: 10 and mean glomerular filtration rate: 11.8ml/min/1.73.m². The mean patient follow-up time (until death or until 31/12/2013) was 184 days. During this period, 44% of patients did not have to visit the hospital's Emergency Department and 58% did not require hospitalisation. 29 of the 50 patients died after a mean time of 163 days on the programme; 14 (48%) died at home. **Conclusions:** Our experience indicates that with the support of the Palliative Care Unit and the Nephrology Department, ACKD patients who are not dialysis candidates may be monitored at home by Primary Care.

Keywords: Chronic kidney disease. Conservative treatment. Palliative care. Home care.

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Programa de atención domiciliaria a pacientes con enfermedad renal crónica avanzada. Experiencia de dos años

RESUMEN

Introducción: La atención sanitaria de los pacientes con enfermedad renal crónica avanzada (ERCA) bajo tratamiento conservador plantea con gran frecuencia problemas asistenciales de difícil solución. Muchos de ellos son enfermos añosos, con dificultad de movilidad, en los que los desplazamientos al centro hospitalario suponen una gran dificultad. A finales del año 2011 iniciamos un programa basado en la asistencia y el control de estos enfermos por los equipos de Atención Primaria. **Material y métodos:** A los pacientes con ERCA que han elegido tratamiento conservador, se les ofrece la posibilidad de recibir una asistencia fundamentalmente domiciliaria por el médico de Atención Primaria, bajo la coordinación de la Unidad de Cuidados Paliativos y del Servicio de Nefrología. **Resultados:** Durante los años 2012 y 2013, 50 enfermos recibieron tratamiento en este programa. Edad media: 81 años, índice edad-comorbilidad de Charlson: 10, y filtrado glomerular medio 11,8 ml/min/1,73 m². El tiempo de seguimiento medio por enfermo (hasta el fallecimiento o hasta el 31/12/2013) fue de 184 días. Durante este período, el 44 % de los enfermos no tuvo que acudir al Servicio de Urgencias del hospital, y el 58 % no precisó ingreso hospitalario. Fallecieron 29 de los 50 enfermos, tras un tiempo medio de permanencia en el programa de 163 días; en 14 de ellos (48 %), el sitio de fallecimiento fue su domicilio. **Conclusiones:** Nuestra experiencia indica que con soporte de la Unidad de Cuidados Paliativos y del Servicio de Nefrología, el paciente con ERCA no candidato a diálisis puede ser controlado en su domicilio por Atención Primaria.

Palabras clave: Enfermedad renal crónica. Tratamiento conservador. Cuidados paliativos. Cuidados domiciliarios.

INTRODUCTION

Kidney disease in which treatment with dialysis has been excluded usually involves complex patients with high comorbidity, often with functional deterioration and

occasionally with cognitive deterioration. Healthcare of these individuals is characterised by their transfer from one clinic to another of various medical specialties, in general with poor resolution and by many visits to emergency departments and hospitalisations.

The objective of treatment in this stage of the disease must not be reduced to decreasing the rate of renal function deterioration and extending life, but rather it must be focussed on achieving the best quality of life possible for the patient and relieving the consequences of the disease for the family. These objectives often relate the conservative treatment of kidney disease to palliative care^{1,2}.

One aspect that must be borne in mind when providing quality care is the location in which the care will be administered. Repeated travel to healthcare centres is one of the aspects that most negatively affects the patients and their family. Home care may be the most suitable form of care and should be one of our objectives³.

The Nephrology Department of Hospital Gregorio Marañón in collaboration with a home palliative care support team (ESAPD) implemented a home care programme in 1997 for end-stage renal disease patients not eligible for dialysis. The home visits were carried out by ESAPD members with a mean 8-day interval and by the nephrologist with a scheduled visit every 1-2 months⁴.

Given the work overload that the ESAPD currently have and the difficulty for nephrologists to carry out home visits, we considered that follow-up of these patients could be performed by Primary Care Teams (EAP) until more advanced stages of the disease, with the support and advice of the Palliative Care Unit and the Nephrology Department, with the ESAPD assuming this follow-up whenever the patient circumstances or their EAP require it. In December 2011, we implemented a programme for advanced chronic kidney disease (ACKD) patient care for individuals on conservative treatment in which the main work fell mainly to Primary Care, whenever the patient and their family indicated a preference for home care. In this study, we present our experience in the first two years in which this project has been running.

MATERIAL AND METHOD

The Hospital Ramón y Cajal serves a population of 558,000 inhabitants. There are 20 health centres in its catchment area and 2 speciality outpatient centres. It has an ESAPD and a Hospital Palliative Care Unit, each of which contains three doctors and three nurses.

In 2011, the Nephrology Department and the Palliative Care Unit organised a home care project for ACKD patients on conservative treatment.

The programme included the following stages:

1. Patient detection:

We considered all patients with stage 4 or 5 chronic kidney disease who for different reasons were not candidates for renal replacement therapy to be candidates for this programme. This decision, which required the agreement of the patient and their family, was recorded in the clinical records and in the clinical report issued by the Nephrology Department. At this time, they were offered the chance to be included in the home care programme. If the patient and their family agreed, we put them in contact with the Palliative Care Unit. If not, they continued to be cared for in the ACKD clinic of the Nephrology Department.

2. Patient inclusion in the home care programme:

The Palliative Care Unit carried out a comprehensive patient assessment to detect their problems and needs in the different dimensions (physical, emotional, social, cultural and spiritual), and identified the main care provider.

If the patient was suitable for the home care programme, a care plan was drawn up and the patient was included in the programme records. Subsequently, their Primary Care doctor was contacted by telephone to inform them of patient inclusion, the actions carried out and the care that they required from that time onwards. The Nephrology Department reports were sent by fax, the comprehensive assessment was carried out by the Palliative Care Unit, and a line of communication was established by telephone and e-mail with the doctors responsible for the programme in both services.

If it was considered necessary due to the complexity of the needs assessed, contact was also made with ESAPD, although this did not involve its immediate involvement and its intervention would be determined by a decision made by the EAP.

After reviewing all the aforementioned programmes with various specialists, we reduced them to those that were absolutely necessary.

3. Patients follow-up:

The patients were mainly cared for by Primary Care professionals, with the support and advice needed from the hospital's Nephrology Department and Palliative Care Unit. The main patient care location was their home, although it may also have been the health centre, at the discretion of the EAP, bearing in mind the patient's characteristics and their suitability to travel.

The Palliative Care Unit was in charge of coordinating the other teams and following up the patients by monthly

telephone contact with them or their care provider and professionals.

At least one blood test was carried out every three months with the following parameters: complete blood count, creatinine, urea, glucose, sodium, potassium, calcium, phosphorus and ferritin. The glomerular filtration rate was estimated using the formula MDRD-4 IDMS. Blood was taken for scheduled blood tests mainly at the patient's home. The patient's carers submitted the results to the ACKD clinic for assessment by the nephrologist, who made the treatment changes that he/she deemed to be appropriate and provided them with the prescriptions dispensed by the hospital (mainly erythropoietin).

The patient was treated at the Nephrology Department's ACKD clinic whenever the EAP, the Palliative Care Unit or patient considered it appropriate.

In order to facilitate flexible contact, the patient and their family were provided with the telephone numbers of the Palliative Care Unit and the ACKD clinic. As indicated previously, the Primary Care professionals were also given these telephone numbers and the e-mail addresses of the nephrologists responsible for this programme in order that they might make consultations as they deemed appropriate.

4. Hospitalisation:

If the patient needed to be hospitalised in the opinion of the EAP doctors or the Palliative Care Unit, we tried to facilitate direct access to the Nephrology Department, avoiding as far as possible having to resort to the Emergency Department. Hospitalised patients were monitored in coordination with the Palliative Care Unit.

5. Referral to an intermediate-term palliative care hospital:

At any time during follow-up, whenever it was considered that the patient care needs exceeded the capacity of the home, the intervention of an intermediate-term palliative care unit was requested.

Functional deterioration was assessed using the Barthel scale⁵, walking condition by the FAC (*Functional Ambulation Category*) scale⁶, and the degree of cognitive deterioration by the GDS (*Global Deterioration Scale*)⁷. If the Barthel scale score was less than 60, it was considered that the patient was dependent for basic activities of daily life (from 40 to 55 the degree of dependency was considered to be moderate, from 20 to 35 dependency was severe and with less than 20, dependency was total). The FAC walking scale has 6 levels (0: incapable of walking; 1: walks with difficulty holding onto another person; 2: walks with the support of another person; 3: can only walk under supervision; 4: walks independently

on a flat surface but cannot climb stairs; 5: walks dependently on a flat surface and can climb stairs). The GDS has 7 stages (stage 1: without cognitive alteration; stages 2 and 3 indicate mild cognitive deterioration; stage 4 indicates moderate cognitive deterioration; stage 5 corresponds to moderate-severe cognitive deterioration, requiring care in a short period of time; and stages 6 and 7 represent severe or very severe levels of cognitive deterioration).

The results were expressed as a mean \pm standard deviation or as the mean, median and interquartile range, according to whether or not the variable analysed had a normal distribution. The survival analysis was carried out using the Kaplan-Meier method.

RESULTS

Between 1 January 2012 and 31 December 2013, 50 ACKD patients on conservative treatment were included in the home care programme on their own decision. These patients included 32 males and 18 females with a mean age of 81 ± 8 years of age (range 61-92). The most common nephropathy was vascular (36%), followed by diabetic nephropathy (24%).

Conservative treatment was chosen for kidney disease due to the existence of another pathology that determined short-term prognosis which was not likely to improve with renal replacement therapy in 40 cases and significant cognitive deterioration. In all of these 44 cases, the decision to carry out conservative treatment was agreed with the patient and their family. The 6 remaining patients rejected renal replacement therapy despite it not being formally contraindicated.

At the time of inclusion in the programme, the glomerular filtration rate was 11.8 ± 6 ml/min/1.73m² (range 4.5-29.5). 24% of patients (12 cases) had stage 4 chronic kidney disease and 38 (76%) had stage 5 CKD. Haemoglobin concentration was 10.5 ± 1.6 g/dl and 34 patients (68%) were receiving treatment with erythropoietin-stimulating agents.

We included patient data in Table 1. The mean and the median of the Charlson age-comorbidity index was 10 (interquartile range 9, 11).

In the initial assessment, the Barthel index was 62 ± 34 . According to this index, 22 patients (44%) were dependent for the basic activities of daily life (10 with moderate dependency, 6 with severe dependency and 6 with total dependency).

The walking assessment showed that 22 patients were independent for walking (levels 4 and 5 of the FAC scale) and that the 28 remaining (56%) required help or supervision to walk (level 0 FAC: 3 patients, level 1: 7 patients, level 2: 7 patients and level 3: 11 patients).

Table 1. Baseline data at the time of inclusion in the programme

Charlson index	10 (9, 11)
Barthel index	
≥ 60	28 (56 %)
40-55	10
20-35	6
< 20	6
FAC scale	
Level 0-3	28 (56 %)
Level 4-5	22 (44 %)
Escala GDS	
Stage 1	26 (52 %)
Stage 2-3	14
Stage 4-5	6
Stage 6-7	4

(Global Deterioration Scale); Functional Ambulation Category)⁶

A severe or very severe cognitive deterioration was the main reason for advising against renal replacement therapy in 4 patients. In 26 (52%), we did not observe cognitive deterioration, in 14 we observed mild cognitive deterioration and in 6 there was moderate cognitive deterioration.

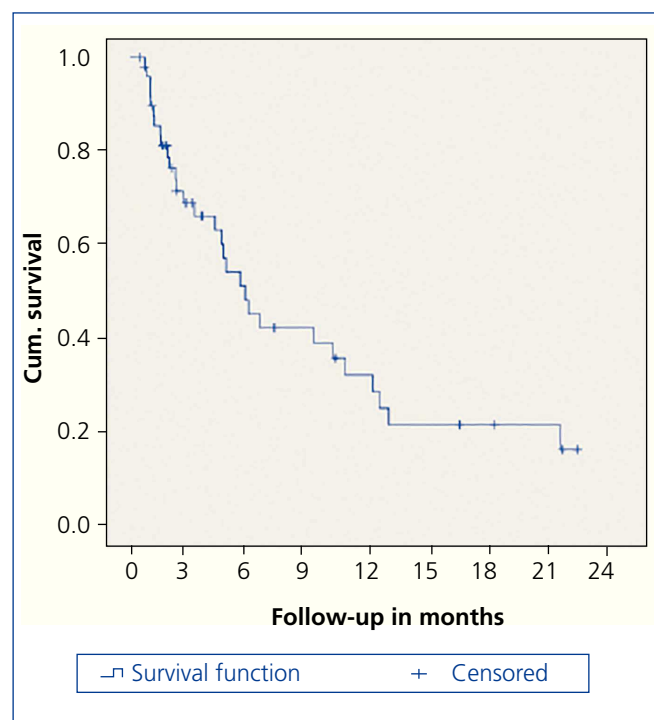
The total evolution time (from their inclusion in the programme until death or until 31 December 2013) was 9179 days (mean patient follow-up: 184 days, median: 97 days, interquartile range: 49, 289 days). During this follow-up period, we recorded a total of 66 visits to the Emergency Department by 28 patients (one visit every 139 days-patient). The most common cause of referral to the Emergency Department was heart failure (47%). It must be highlighted that 22 patients (44%) did not have to visit the Hospital's Emergency Department during the period of time analysed. The mean follow-up time of patients who did not have to visit the Emergency Department was 116 days, median 58 days (interquartile range 44, 118 days).

There were 36 hospitalisations of 21 patients (one admission every 255 days-patient); 83% were admitted to the Nephrology Department and the most common cause continued to be heart failure (47%). Of the patients, 58% did not require hospitalisation; the mean follow-up time for patients in the programme who did not require hospitalisation was 163 days and the median was 64 days (interquartile range 42, 184 days).

The EAP's main point of contact was the Palliative Care Unit, who they communicated with by regular telephone calls.

The Nephrology Department and Primary Care regularly communicated via the family of patients, who visited the ACKD clinic to submit blood test results and collect the medication adjustment information and the prescriptions of drugs for hospital use. Only in four cases was a patient review requested in the Nephrology Clinic by the patient or the Primary Care doctor. During evolution, the assistance of ESAPD was required for 12 patients and 5 had to be transferred to an intermediate-term palliative care unit when home care became impossible in the final periods of the disease or by the express wish of the patient not to die at home. One patient who had initially rejected renal replacement therapy reconsidered his decision and began treatment with haemodialysis. No other patient displayed their intention to leave the home care programme and return to receive specialised care.

Figure 1 displays the patient survival curve. Patient death after 3 months was 32%, after 6 months it was 55% and after 12 months it was 68%. A total of 29 patients had died after a mean follow-up time in the programme of 163 days, with a median of 130 days (interquartile range 47, 241). In 14 of these patients (48%), the place of death was their home, 5 (17%) died in an intermediate-term palliative care unit and 10 (35%) in the Hospital Ramón y Cajal (all in the Nephrology Department). The 21 other patients remained alive at 31 December 2013, with the mean time on the home care programme being 212 days, with a median of 85 days (interquartile range 50, 410 days).

**Figure 1.** Survival curve

DISCUSSION

Access to renal replacement therapy is not limited in Spain. The coexistence of renal failure with other pathological conditions that lead to short-term mortality or that result in a poor quality of life that cannot be improved with dialysis are the only situations in which the aforementioned treatment is advised against. Even in these cases, the patient's opinion and that of their family may determine the indication. In this context, patients who accept or choose a conservative treatment of renal failure in its most advanced stage usually have high comorbidity and in many occasions high functional deterioration. The objective of treatment in these cases is to provide the highest level of comfort possible, reducing the impact of the disease on the patient and their family, and home care may contribute to this goal.

The home care model proposed is similar to that used in the Hospital Gregorio Marañón⁴, but in our project, uraemic patient care is mainly the responsibility of Primary Care professionals.

Given the low prevalence of ACKD in the general population, the EAP are not as used to monitoring these patients as they may be with other diseases of the same severity but which are more common. Our data indicate that with the assistance of the Palliative Care Unit and the Nephrology Department, both the follow-up of these patients by the EAP and mainly home care are possible.

Patients who decided to be included in our home care programme were usually elderly (mean age 81 years old), with significant comorbidity (Charlson index with a median of 10), significant walking difficulties (56% required assistance or supervision to walk) and significant functional deterioration (44% were dependent for basic activities of daily life). Travel to healthcare centres is a burden for the patient and their family in this population. However, cognitive deterioration was not a significant problem in these patients, since 80% did not display these problems or they were mild.

The capacity of Primary Care to assist these patients will depend on the more common healthcare needs at this stage of the evolution of kidney disease. In 2003, Lunney et al., reported four functional deterioration models at the end of life: sudden death, functional stability, progressive deterioration and a fluctuating trajectory⁸. Murtagh et al. analysed the evolution of uraemic patients treated conservatively and observed that the most common models were that of functional stability and that of progressive deterioration, and only 21% of patients had a fluctuating trajectory with intermittent relapses⁹.

Our experience shows that these patients can be exclusively treated by EAP over significant periods of time. In the two years of the programme, we observed that 44% of patients did not have to visit the Emergency Department and that

58% did not require hospitalisation after a mean follow-up time of 116 and 163 days respectively. Regular telephone contact of the Palliative Care Unit with the patient and the Primary Care doctor and communication between the latter and the ACKD clinic have been very effective in allowing the disease to be monitored without the patient having to travel. In 12 patients, it was necessary for the Primary Care doctor to request assistance from the ESAPD and 5 required care in an intermediate-term palliative care hospital in the final stage of the disease.

Of the 50 patients included in the care programme, 29 died after a mean follow-up time of 163 days. After 12 months, 68% of patients had died. The duration of ACKD and the glomerular filtration rate at the time of inclusion in the programme were very variable. Due to these aspects and the number of patients, which was low, we did not believe it was appropriate to carry out a factor analysis with a prognosis value. One figure that we should highlight is that almost half of patients (48%) died at home, which is a similar value to that obtained in the programme of the Hospital Gregorio Marañón⁴.

Alonso Babarro et al. analysed the influence of a home palliative care programme on hospitalisation rates, visits to the emergency department and the place of death in cancer patients¹⁰. Our data in ACKD patients on conservative treatment can be favourably compared with those obtained in those with cancer: need for hospitalisation (42% vs. 66.4%), visits to the emergency department (56% vs. 68.1%) and death at home (48% vs. 20.8%). The healthcare needs of both pathologies may explain these differences.

Tejedor and Cuevas estimate that the number of candidates for a programme of these characteristics varies between 10 and 20 cases/million inhabitants-year¹. During 2012 and 2013, 50 patients were assisted, representing an incidence of 45 cases/million inhabitants-year. We must bear in mind that these were the first two years of the programme and that we may know the true incidence in subsequent years.

In all outpatient care and palliative care programmes of kidney disease patients, we insist on the need for palliative care training and previous training of the healthcare workers involved^{4,11,12}. Without denying the importance of refresher courses and seminars, continuous contact with Primary Care professionals by the Palliative Care Team and the Nephrology Department would seem more effective.

Other Spanish authors have developed kidney disease palliative care programmes. Leiva-Santos et al. propose the extension of the palliative care concept to a complete renal support care programme provided by a multidisciplinary team who would act in all chronic kidney disease stages¹¹. Our aim was to begin with a modest programme that could be carried out with the means available, whose results were

satisfactory in our opinion. The additional effort required for this programme was assumed by the teams involved (Primary Care, Palliative Care and the Nephrology Department), a key aspect for guaranteeing it persisted once the initial enthusiasm had diminished.

We can conclude that it is possible for Primary Care to carry out home care of uraemic patients who are not candidates for dialysis, provided that there is close collaboration with the Palliative Care Team and the Nephrology Department. The fluid communication between all agents involved in the process of caring for these patients and their families is essential.

Conflicts of interest

The authors declare that they have no conflicts of interest related to the contents of this article.

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