

Palliative care. Alternatives for the treatment of frail CKD patients

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■ BACKGROUND

According to recent data from the USRDS, one in four patients starting dialysis is aged over 75, and as a group, they have a higher prevalence of comorbidities which dramatically reduce their life expectancy and impair their informed decision-making¹. Despite all the technical improvements the haemodialysis technique has experienced, overall patient mortality is still very high, in some units up to 25% per year.

The average age in our patient pool is 65 years old, and the life span of those older than 65, once admitted to a haemodialysis (HD) programme, is below three years. In another series, mortality in the first year after the initiation of dialysis exceeded 35% in patients older than 70 years of age and 50% in patients older than 80 years². In incident patients above 65 years of age, five-year survival is only 18%³.

In the special group of nursing home residents, within the first year of the initiation of dialysis 58% of residents had died, 29% had a decrease in functional status, which was maintained only in 13%, and 30% abandoned dialysis due to major physical or cognitive deterioration⁴.

During their dialysis years, our patients present a high symptomatic burden, pain in 75%, lack of

energy and dry mouth in 58%, itching in 53%, nausea, shortness of breath, anorexia, or depressive mood; a far greater suffering than what we find in ambulatory cancer patients⁵. Most of our patients (69%) die as hospital inpatients, where they were repeatedly admitted for management of recurrent cardiovascular or infectious complications, with no access to palliative care.

Unfortunately, most patients and their families are not involved in the decision process as to the kind of care they want to receive at the end of life. It is quite common to hear a patient regretting having initiated dialysis, and there is a wealth of literature demonstrating that patients and/or their families desire to receive accurate prognostic information and to be involved in the planning of their care. Elderly patients on haemodialysis report that their entire day is often taken up travelling to and from the dialysis unit and undergoing the treatment itself.

It is also a well-known fact that neither the attending physicians nor close family are able to accurately predict patients' will about the kind and intensity of care they want in the last months of their lives, both failing that prediction in about 50% of the cases. Although, in a recent series, 81% of observed dialysis patients had completed a health care proxy and a living will. Of all these with advance directives, only in about half did it help a great deal in patients' management⁵.

Dialysis prolongs survival for elderly patients who have ESRD with significant comorbidities by

approximately two years, but patients who choose conservative management, forgoing dialysis, can survive a substantial length of time, achieving similar numbers of hospital-free days⁶.

Nephrologists report withholding dialysis from 7 to 25% patients with ESRD because of age, comorbidity burden, impaired mental capacity and poor quality of life⁷, and in the US, 15 to 25% of all deaths on dialysis result from the decision to discontinue dialysis therapy, making it the second leading cause of death after cardiovascular disease⁸. However, not all elderly patients fare that badly, with some rewarding experiences reported from European units⁹.

Although comorbidity has a major effect on physicians' recommendation for conservative management, it is not considered as important for patient decision-making regarding initiation of dialysis, as the burden of comorbid illness or the prevalence of diabetes was identical between groups of patients opting for or against the initiation of dialysis. The burden of hospital admission was significantly higher in dialysed patients than in those in conservative management.

Above 75 years of age, the survival advantage of the dialysis option vs. conservative management is lost in those patients with high comorbidity scores, especially in the presence of ischaemic heart disease¹¹. The number of hospital-stay days and the rate of infection is much higher in those dialysed, making the number of outpatient days in both arms identical. In patients with a high number of comorbidities, life span can even be reduced if they elect to be treated by dialysis instead of palliative care. On the other hand, uraemic death is characterised by progressive somnolence and anorexia, but without major suffering or discomfort.

Concerned with these gaps in our continuum of care for the most fragile and vulnerable patients and impelled by a moral and ethical call, we decided to create a special programme to offer to selected patients as an alternative. This was either a conservative/palliative care to incident patients, or, in those already on a regular outpatient dialysis treatment in our Unit, withdrawing from dialysis whenever the physical and emotional burden imposed on them

and their families seems to be higher than the expected benefit. Our plan includes:

- a) Defining the selection criteria to identify patients that should be approached with a proposal for alternative care;
- b) Finding out if selected patients and/or their families wished to receive prognostic information and wanted to participate in decisions about their plan of care;
- c) Asking for all relevant sources of suffering and discomfort and intervening with symptomatic treatment;
- d) Inviting autonomous patients to issue a living will to allow us to know and respect their autonomy in case they were not competent when important care decisions arose;
- e) Identifying the best patient representative to act as an healthcare proxy if and when needed.

Individualised care is a joint effort from our multidisciplinary team (two nephrologists, one nurse, a dietician and a social worker), establishing a partnership with patient and family. Nephrologists are responsible for presenting relevant information as unbiased and easily as possible, to support and implement the treatment decisions reached by all stakeholders, without ever closing the door to an opinion change by the patient or his family in favour of prolonging life. We based patient selection on six criteria individually validated in the literature¹², that we lumped together for this purpose:

- 1) Age above 80 years;
- 2) Living in a nursing home or a similar institution;
- 3) Plasma albumin < 3gr/dl;
- 4) Negative answer to the "surprised question": *Would you be surprised if this patient died in the next six months?;*
- 5) High dependency for daily activities of self-care;
- 6) Severe dementia.

Each patient was also classified using the Stoke Comorbidity Score (validated to CKD 5d patients), the Karnofsky Performance Scale, the visual analogue pain scale, for those in pain, and the Brief Case-Find for depression screening.

■ ALTERNATIVE THERAPIES

Depending on the presentation to our unit, we may propose:

- A) Conservative Therapy: For patients still not on dialysis, or treated for less than one month, with at least three of the above criteria.
- B) Therapy withdrawn: For patients already on dialysis in our unit, with at least four of the above criteria.

In both cases, patients will be seen regularly in the clinic and will have palliative care at home.

■ PALLIATIVE CARE

The team designs a tailored programme for each patient, encompassing several domains.

As soon as a patient is admitted to the programme, his/her family physician is informed of his/her decisions and of the plan of care. Our social worker gets in touch with her colleague who assists this patient in our NHS, and tries to coordinate all the social and support tools available in the community to help us in this endeavor.

Medication will be selected only for symptomatic relief. Medication that does not serve that goal, such as statins, antiplatelet drugs, antibiotics and so on will be discontinued. For conservative management patients, calcium and phosphate balance was focused on symptomatic treatment to control pruritus, rather than achieving K/DOQI targets.

As soon as we test patient adaptation to conservative treatment, meaning that we assessed the rate of GFR loss and the capability to stay within fluid balance, if there is no need for intermittent ultrafiltration, if the patient has a catheter it is removed.

Our dietician creates an individualised diet for each patient, with highlights restrictions in salt, fluid volume, and potassium and phosphate. Protein intake is adjusted to avoid both malnutrition and toxic ureamic symptoms, and high caloric intake is prescribed. A nasogastric tube will not be used for

the sake of maintaining food intake if patients are anorectic, or refusing to feed themselves.

Priority symptoms, to be addressed according to our step-by-step protocol are pain, dyspnoea, anaemia, myoclonus, pruritus, anxiety and depression, delirium, nausea and vomiting, dry mouth and constipation. Families are instructed how to deal with each symptom, what medication to administer, when to provide oxygen and what to expect in the last hours of life, from the physical and mental standpoint.

Emergency care is coordinated through the palliative care team. The patient can be seen at home, brought to the unit, or in more severe cases will be taken to the emergency-room (ER) of his/her local hospital. In that case, the hospital receives a direct call from our staff, explaining the situation and patient takes with him/her his file, that includes a letter to the ER physician explaining in detail what is involved in his decision for palliative care, not to be dialysed (this does not exclude urgent UF), living will if one exists, patient's caretakers and proxies contact details, our phone numbers, current medication, prescribed diet and so on. Still to be worked out with health authorities are a specific inclusion modality of these patients in the common platform that registries all patients on dialysis, for reimbursement purposes of their providers, the delivery of all medication at home, the payment for the care of this patients without dialysis (obviously a lower rate than those on a regular dialysis programme), but with occasional UF, and patient transportation to and from the unit, or to the hospital ER.

Despite the urgency of a new approach to this selected group of patients, well known to all working in the field of chronic dialysis, we must be extremely careful, as age and frailty are easily used as targets for resource rationing, disguising a hidden agenda that cynically perverts the movements for patients' autonomy and "death with dignity"¹¹.

Unfortunately, attempts to define with accuracy a subpopulation of elderly patients who would not do well on dialysis have been largely unsuccessful. Age, functional status, mobility and comorbidity burden are predictive of survival, but do not explain all prognostic variability to allow the development of a criterion score that can be used to select patients

for dialysis¹³. Individualised assessment seems to be the best approach so far¹⁴.

Prior to the initiation of dialysis, elderly patients or their family must be informed about its modest benefits in their age group and the possibility of conservative therapy that does not involve dialysis. Conservative therapy must be discussed not as a last resort, when there is nothing left to do, but as a clear option that might be more effective in promoting patient goals¹⁵.

Our unit treats close to 300 patients, 47 older than 80 years, five bed-ridden, 11 in nursing homes, and we estimated that about four incident patients per year and five prevalent patients would be potential candidates for discussion of our programme. We hope to be able to report soon on the results of our pilot experiment.

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