



Advanced directives in end-stage chronic renal failure patients on dialysis therapy

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SUMMARY

Background and objective: Knowledge of the life-sustaining treatment preferences of the dialysis patients would be extremely helpful to substitute decision-makers and nephrologists in deciding whether to continue or stop a treatment. The population of the Mediterranean countries show this opinion with less frequency. The objective of this study is: 1) the knowledge of the patient's view for the advance directives; it may increase the likelihood to get the correct decisions of the staff when complications break the normal course of chronic dialysis, and 2) the statement of the advance directives.

Material and method: We distributed 135 questionnaires to patients with chronic renal failure in dialysis treatment of the Sabadell's Hospital to explore demographic information about responders and not-responders and explore the rate of questionnaires was completed about the cardiopulmonary resuscitation, respirator, tube feeding and dialysis in case of coma, persistent vegetative state, severe dementia and terminal illness. We explore about the representative of patients and in case of not-responders about the cause to not answer.

Results: Sixty-four of 135 patients (47,8%) did not want cardiopulmonary resuscitation, respirator, tube feeding or dialysis in case of coma, persistent vegetative state, severe dementia or terminal illness. Compared with patients who wanted the treatments, those who did not were older (71,2 versus 62,2 years; $p = 0.002$). There was no difference in the other demographic questions, including sex ($p = 0.674$), cause of kidney failure ($p = 0.815$), comorbid conditions ($p = 0.824$), and social status (language of questionnaire $-0.155-$ and standard of education $-0.288-$). Advance care planning does not occur solely within the context of the physician-patient relationship; the respondents reported the representative in the family, sons and daughters, particular. The patients not-responders doesn't want to think in those situations and also they show doubt about the interpretation of their answers.

Conclusions: Near 50% patients in chronic dialysis want to stop certain treatments in case of resuscitation cardiopulmonary, coma, persistent vegetative state, severe dementia or terminal illness. The older patients want the limitation of treatments more frequently.

Key words: **Advance directives. Chronic dialysis patients.**

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DOCUMENTO DE VOLUNTADES ANTICIPADAS DE PACIENTES CON INSUFICIENCIA RENAL CRÓNICA TERMINAL EN TRATAMIENTO SUSTITUTIVO MEDIANTE DIÁLISIS

RESUMEN

Fundamento y objetivo: En la cultura latina no hay experiencia sobre estudios que definan la opinión de los pacientes con enfermedades crónicas acerca de cómo quisieran ser tratados en caso de complicaciones severas que inhabiliten su calidad de vida y su capacidad para decidir. El objetivo del estudio es: 1) tener el conocimiento de esas opiniones que podrían facilitar las decisiones de los médicos que tratan a estos enfermos, en el caso especial de surgir complicaciones que alteren esa capacidad de decidir de los pacientes, y 2) la invitación a la verdadera elaboración de un documento de voluntades anticipadas.

Material y método: Se facilita un cuestionario a 135 pacientes de la Unidad de Hemodiálisis del hospital de Sabadell, en el que se les pregunta si desearían limitaciones terapéuticas (resucitación cardiopulmonar en caso de paro cardiorrespiratorio, ventilación mecánica, alimentación artificial, seguir en proceso de diálisis) en caso de estar en coma profundo, estado vegetativo, demencia profunda irreversible o enfermedad crónica en fase terminal. Se establecen diferencias epidemiológicas entre los pacientes que manifiestan desear esas limitaciones en esas circunstancias y los que no lo hacen. Se pregunta sobre el representante en caso de incapacidad y acerca de los motivos por los que no contestan a los pacientes que no responden el cuestionario.

Resultados: Entre los dos grupos de pacientes, tan sólo la edad les diferencia significativamente ($p = 0,002$) pues el promedio de edad de los enfermos que quisieran limitaciones es de 71,2 años y el del que no manifiestan querer limitaciones es de 62,2 años. El sexo ($p = 0,674$), comorbilidad ($p = 0,824$), estudios ($p = 0,288$), factores culturales como el idioma ($p = 0,155$) y nefropatía primaria ($p = 0,815$) no ofrecen diferencias entre ambos grupos. Un 47,8% de los pacientes de nuestro medio tratados con diálisis crónica, se manifiestan abiertamente partidarios de limitar esfuerzos terapéuticos en alguna de las circunstancias mencionadas. La mayoría de pacientes que realizan voluntades anticipadas tienen como representante un familiar, especialmente hijos. Los que no responden al cuestionario no lo hacen principalmente por rechazar la posibilidad de pensar en ello y también por desconfianza.

Conclusiones: En nuestro medio, casi el 50% de los pacientes tratados mediante hemodiálisis periódica son partidarios de limitar ciertos tratamientos en circunstancias de pronóstico infausto, siendo los enfermos más ancianos los más partidarios a manifestar la voluntad sobre esas limitaciones.

Palabras clave: **Voluntades anticipadas. Pacientes en diálisis crónica.**

INTRODUCTION

Between 13% and 26% of the deaths occurring in end-stage chronic renal failure (ESCRF) patients are due to dialysis discontinuation.¹⁻³ Health care workers assisting these patients are frequently faced with the decision of not accomplishing therapeutic maneuvers that otherwise would be mandatory. Renal function is vital and its replacement by dialysis allows many patients living «artificially». In spite of techno-

logical advances, coadjuvant anemia therapy with erythropoietin, renal osteodystrophy with phosphorus chelating agents and vitamin D derivatives, etc., the CRF or uremic status progresses, as does patient's age and the likelihood of occurrence of complications or new diseases.

Besides, as time goes by, there an increasing incidence of renal replacement therapy in older patients with greater comorbidity. This fact also increases the likelihood of facing the decision of whether or not

applying a therapeutic technique that may be beneficial in some cases or trivial under a different clinical setting. For instance, resuscitation maneuvers for cardiac arrest (CA) in a very old patient with multiple diseases and CRF-associated complications may be useless if the patient's prognosis is very poor in the short term.

Our experience^{4,5} shows us that people are more and more aware of this issue and that they are concerned as patients and many of them are determined to participate in such decisions by speaking out their priorities in the case of a possible CA, progressive dementia, etc.

The project of creation of an advanced directives document (ADD) requires a plan dealing with ethical, psychological, and for many people even religious issues. Planning for therapeutic options is not a decision identical to establishing regulations mandatory under any circumstance. It may be advisable to plan for these possibilities depending on the disease prognosis, and there are entities recommending so, in particular in dialysis units.⁶

Therefore, we created a formulary as an ADD that was given to all chronic hemodialysis (HD) patients at our Unit in order to know their opinion on this issue and how they would want to be treated under certain clinical conditions. The aim of this formulary was to verify its usefulness for clinicians when taking decisions, and it represents a true invitation to elaborate an ADD. In our country and culture there are no previous experiences contrary to what is happening since several years ago in other countries, especially Anglo-Saxon ones.⁷⁻⁹

MATERIAL AND METHODS

A formulary is created for dialysis patients as a questionnaire facilitating their opinion on how they want to be treated in case of disability, and being the first step to elaborate an ADD -living will- at the hospital and elaborated by the Health Care Office of the Govern of Catalonia. This formulary is done as a Postgraduate work on Bioethics and Quality of Life of the Moral Philosophy and Politics Department of the University of Barcelona (Professor M. Boladeras). The work and the questionnaire have received the reconnaissance of the Medical Sciences Academy of Catalonia and the Balearic Islands by the Jaume Blanchart y Suñol Award for the improvement of patients' information. This patient's information has been centered in one single investigator with knowledge on communication with the patients. The main objectives are: 1) to know the opinion of ESCR patients being treated with regular HD on how they would want to be treated in case of having diseases with no hope for improvement, and inviting

them to speak out their opinion; 2) to invite the patients to elaborate a true living wills document. Secondary objectives were: 1) make the patients' opinion, reflected on an ADD, be written on their clinical charts and considering it in case of mental disability and provided that clinical circumstances would occur setting the possibility of discontinuing renal replacement therapy; that is to say, to verify the usefulness of the ADD; 2) to study the epidemiological differences between the group of patients expressing their will of limiting therapeutic actions and the group of patients not wishing such limitations and/or not expressing their opinion on such issues.

A descriptive study of the patients' answers to the questionnaire is carried out, making a comparison by gender, age, primary nephropathy, comorbid factors, educational level, family structure, and cultural factors such as the language (the questionnaire is given in Catalan and Spanish according to the patient's preference) between the group of patients stating their will for therapeutic limitations in case of the clinical circumstances being indicated, and the group of patients not wanting such limitations under any circumstance and those not expressing an opinion on this issue.

The questionnaire (summarized in eh appendix at the end of the paper) is given to all patients on regular HD, aged 18-95 years, in our chronic patients unit, being on dialysis for at least three months and not having received a very poor prognosis (a survival shorter than 3 months). Patients with current disability to understand the questions set (those not knowing how to read give the questionnaire to a representative of their designation to complete the questionnaire together with the patient). The questionnaire was given during July of 2005 and the answers were gathered between October and November of the same year, once it was thought within the socio-familial context and consulted with the investigator/person informing as many times as required.

Before administering the ADD questionnaire, the patients were asked if they had ever done an ADD before. We assessed whether they answered by written with some will or not, whether they manifest doing so in a different way (verbalization, etc.), or if they prefer not or do manifest no particular will. The patients were asked if they have designated a representative and if that person understands them well, very well, or most of the times well. We also recorded if they were living within a family, by themselves, or in a nursing home.

Besides gender and age (in years), each one of the other studied variables is summarized in Table I. The questions included in the questionnaire are shown at the appendix. The patients received explanations on the terms «coma», «vegetative state», «dementia»,

Table 1. Variables recorded by patient that have been compared between groups

1) Primary nephropathy	2) Comorbidity	3) Educational level
-Vascular	-Without other diseases	-Does not know how to read or write
-Diabetic	-One or two associated diseases	-Elementary studies
-Polycystic renal disease	-More than two associated diseases	-Secondary studies
-Chronic/interstitial		-Intermediate level
-Unknown		-High level
-Other		

and «end-stage disease» that are considered as irreversible clinical conditions. During the four months following the questionnaire administration, the patients were repeatedly asked about doubts that may have risen, and this was considered a reasonable amount of time to assure the quality of the information given and of the answers gathered.

The deaths occurring during the year 2006 were recorded and we verified the application done of the ADD.

Statistical analysis

A descriptive study of all patients by gender, age, nephropathy, comorbidity, educational level, and response to the document was undertaken. If there was an affirmative response to the document, the following variables were recorded: representative chosen, language (also if the answer to the document was negative), the different responses to the clinical situations of coma, vegetative state, dementia, and end-stage disease, and in case of need for mechanical ventilation, artificial feeding, cardiopulmonary resuscitation, and dialysis withdrawal.

The qualitative variables are summarized as frequency and percentage, and quantitative variables, such as age, as mean and range.

In order to observe and determine the existence of differences between groups, we categorized the patients as those answering to the advanced directives questionnaire and those not doing so. About the distribution by gender, nephropathy, comorbidity, educational level, and language, contingency tables were created and the Chi-squared test was carried out. For comparison by age, the Student's t test for independent samples was used. The p values < 0.05 were considered as being statistically significant.

RESULTS

During June of 2005, 135 questionnaires were administered to the same number of patients diagnosed

with ESRF and treated by regular HD for more than 3 months at the Chronic Patients Unit of the Health Corporation Parc Taulí of Sabadell. This center comprises a health care area of 400,000 inhabitants, belonging to the industrial area of Barcelona with high immigration rate.

The questionnaire was administered to 84 men and 51 women, mean age 66.9 (28-89) years. The primary nephropathy is of vascular origin in 34 cases, diabetic in 33, polycystic renal disease in 12, interstitial nephropathies in 15, of unknown origin in 24, and other nephropathies in 17 cases, especially glomerular nephropathies.

The educational level of the patients was: 14 patients do not know how to read or write, 91 have elementary studies, 23 secondary studies, 5 intermediate grade, and 2 high grade.

One hundred and thirty-four out of 135 administered questionnaires were returned. Only one twenty-eight years old female patient, with very limited elementary studies and important familial uprooting did not return the questionnaire.

Sixty-eight (50.7%) patients manifested some kind of written will, 48 did not manifest any, and 18 wrote down other possibilities, which will be commented further on. Sixty-four out of 68 patients manifesting some kind of written will expressed their will of limiting therapeutic actions in case of disability provided that permanent coma, vegetative state, irreversible dementia, or end-stage disease with very poor would occur. The remaining four patients expressed their will of having full therapeutic actions (resuscitation measures in case of CA, artificial feeding by nasogastric tube, intubation and mechanical ventilation, continuation of dialysis) under the same clinical circumstances.

Four patients out of the 64 had already elaborated an ADD and their representatives were aware of that. Of the 68 patients writing down their wills, 36 (52.9%) declared having appointed a representative, 26 (38.2%) did not, and 6 (8.8%) expressed that they would do so. In 23.9% of the cases, the designated representative is the couple, in 55.2% the sons/daughters, in 16.4% another relative, in 3% a physician, and 1.5% a nurse.

Table II. Reasons given by 48 patients (35.5% of the whole) for not answering the questionnaire on written living wills

Reason for not answering	Frequency	%*	%** of the whole
They rather not think about	26	54.2	19.4
They have informed a representative	8	16.7	6
Other culture/language	3	6.2	2.2
They manifest their inability or that of their family	2	4.2	1.5
Distrust	9	18.7	6.7

*Percentage calculated based on the number of patients not answering the questionnaire on living wills, n = 48. **Percentage calculated based on the total number of study patients, n = 135.

Eighty-five patients in total (the 68 answering by written and 17 others) assured having a representative, in 69 cases the representative was aware of it and in 16 cases he/she was not.

Thirty-six (26.7%) patients were given the questionnaire in Catalan and 99 (73.3%) in Spanish. Fourteen patients lived by themselves, four of them in nursing homes.

The reasons for not giving an answer in 48 patients and returning back the questionnaire without filling it out are shown in Table 2, whereas Table 3 shows the reasons given by the 18 patients expressing their wills in case they would become disable for deciding by themselves.

Table 4 shows the therapeutic limitations to be applied in case of disability expressed by 64 patients (47.8% of the whole) provided that permanent coma, vegetative state, irreversible dementia, or end-stage disease with very poor prognosis (life expectancy shorter than 3 months) would occur.

Th SPSS version 14.0.1 statistical package has been used for the statistical analysis. When comparing those patients expressing their written wills to be taken into account in case of future disability with those not doing so, there were no statistically significant differences between both groups by gender (p = 0.674), primary nephropathy (p = 0.815), comorbidity (p = 0.824), or educational level (p = 0.288). About the educational level, we would like to highlight that a higher educational level is not related

with any particular attitude towards expressing the living wills: virtually the same percentage of patients not knowing how to read or write (57.1%) elaborated an ADD than those having secondary studies (54.5%), although those patients with intermediate or high educational level do think more frequently about other possibilities as the ones described.

About comorbidity due to the number of ESCRF-associated diseases, we did not observe either any significant difference since 44.4% of the patients with no associated diseases elaborated an ADD, 53.6% of those having one or two associated diseases, and 46.8% of those having more than two diseases.

By contrast, there are differences by patient's age when expressing the will of elaborating an ADD (Figure 1) since the mean age of the patients wishing therapeutic limitations was 71.2 years and that of those not doing so was 62.2 years (p = 0.002).

Another remarkable fact is the language as a cultural factor influencing the will of elaborating by writing the living wills; considering the 4 patients expressing their will of wanting full therapy under any circumstance and the 48 patients that did not elaborate an ADD we observed that 61.8% of the questionnaires administered in Catalan are answered with the will of limiting the therapeutic maneuvers, 23.5% against such limitation, and in 14.7% the patients offered other possibilities. Forty-four point eight percent of the questionnaires answered in Spanish expresses the will of limiting the maneuvers, 41.7% are against,

Table III. Reasons given by the 18 patients (13.3% of the whole) to whom the questionnaire on living wills is administered

Reason given	Number of patients	% of the whole
They have discussed the issue with a representative, although they rather not express their opinion in writing (distrust)	12	9
They manifest properly their will. They delegate to representatives and physicians if disability present	2	1,5
They delegate to the medical team	4	3

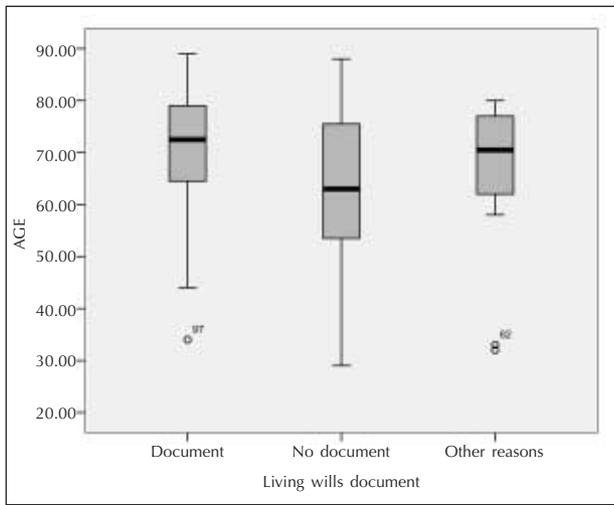


Fig. 1.—Box diagram with extreme values for age of the patients according to manifesting or not a living wills document.

and 13.5% offered other possibilities. However, the differences are not statistically significant ($p = 0.155$).

Eight patients expressing their will of limiting therapeutic efforts live by themselves, three of them in nursing homes, whereas six patients rejecting limiting therapeutic maneuvers live by themselves, one of them in a nursing home.

Sixty-four out of 134 returned questionnaires expressed the will of limiting therapeutic maneuvers under certain clinical conditions. We may highlight that the situation that patients seem to reject a priori more frequently is artificial feeding by nasogastric tube in all possible conditions such as permanent coma, permanent vegetative state, irreversible dementia, and end-stage disease. The will of discontinuing dialysis in case of coma or vegetative state is expressed by 40.3% of the patients documenting by writing some will of limiting therapeutic maneuvers, by 35% in case of profound irreversible dementia, and by 33.6% in case of end-stage disease with a life expectancy shorter than 3 months.

During the 16-months follow-up period, 6 out of the 64 patients expressing their will of limiting therapy under the clinical situations described died because of dialysis discontinuation. They were 4 men and 2 women, with a mean age of 76 years (58-81). One 86-years old patient that had elaborated an ADD expressing his wills died after a dialysis session having informed his representative (daughters) about of his decision of discontinuing dialysis just 20 days before. One of the women died by her own decision not wanting to keep on being treated with regular HD, even before a medical indication had been expres-

sed. Another patient was also discontinued from dialysis by his own decision and that of the medical team (he was diagnosed with pulmonary neoplasm with widespread metastases and was on palliative oncologic therapy). This patient and another one died at the Palliative Care Unit, four and five days after admission, after six days without dialysis. Thus, four patients died under a situation of mental disability to take their own decisions. Three patients died at their homes, and the other one at the Nephrology Department. The wills of these four patients were respected, without conflicts with their representatives (the sons/daughters in most of the cases).

A 79-years old patient, belonging to the group of patients having not elaborate an ADD, died because of dialysis discontinuation being mentally disabled, with worsen pain due to ischemia of the lower limbs and on upper limb after amputations of the digits. We died at home several days after the medical decision that was accepted by their representatives (spouse and son). Dialysis discontinuation was proposed to the daughter of a 91-years-old woman having not answered the questionnaire; the patient died 25 days after the proposal but having not discontinued renal replacement therapy. A proposal about dialysis discontinuation was not made to any other patient (or representative) of this group.

After the 16-months follow-up period, no patient to whom the questionnaire was administered elaborated a true ADD stating that the thoughts they had expressed by means of the questionnaire validated their will in case of disability since they had been verified with their representatives and the physician/interviewer in charge.

DISCUSSION

Dialysis discontinuation is a common death cause of ESRF patients treated by means of permanent dialysis. The number of deaths has been increasing in recent years, likely due to the fact that more aged people with greater comorbidities are being treated; it has changed from 10% of death causes 30 years ago to 20% nowadays.^{3,5,10} This decision of discontinuing dialysis is frequently being made in patients unable to take their own decisions at that time,⁵ so that it would be very helpful when making a choice to know their opinion about the possible clinical situations making them mentally disable.

Dialysis discontinuation is not a euthanasic maneuver but rather an action aimed at avoiding useless therapy within a clinical condition with a very poor prognosis in the short term.^{1,11,12} Our non-religious center has been pioneer in our country when dealing

Table IV. Therapeutic limitations expressed by 68 patients in case of disability and diseases with very poor life expectancy (four of them expressed their will of no limitations)

Clinical condition	Case	Number of patients	% of the whole
Permanent coma/Vegetative state			
Mechanical ventilation	No	55	81
	Yes	8	11.8
	Doubtful	5	7.3
Artificial feeding	No	63	92.6
	Yes	5	7.3
Cardio-respiratory resuscitation	No	53	78
	Yes	15	22
Dialysis continuation	No	54	79.4
	Yes	11	16.2
	Doubtful	3	4.4
Irreversible dementia			
Mechanical ventilation	No	46	67.6
	Yes	10	14.7
	Doubtful	12	17.6
Artificial feeding	No	51	75
	Yes	7	10.3
	Doubtful	10	19.7
Cardio-respiratory resuscitation	No	45	66.2
	Yes	11	16.2
	Doubtful	12	17.6
Dialysis continuation	No	47	69.1
	Yes	11	16.2
	Doubtful	10	14.7
End-stage disease			
Mechanical ventilation	No	45	66.2
	Yes	11	13.2
	Doubtful	12	17.6
Artificial feeding	No	49	72
	Yes	9	13.2
	Doubtful	10	14.7
Cardio-respiratory resuscitation	No	42	61.8
	Yes	16	23.5
	Doubtful	10	14.7
Dialysis continuation	No	45	66.2
	Yes	13	19.1
	Doubtful	10	14.7

with this potentially conflictive issue, from both the health care professionals and the patients viewpoint, by elaborating a consensus protocol bringing together physicians, nurses, non-medical personnel, and patients' representatives from the Nephrology Department and the Health Care Ethical Committee of the Hospital.⁵ This protocol has been a reference for many other nephrology departments from other hospitals. However, there are potentially conflictive situations between the health care personnel and the representatives of disable patients.¹³

Under these circumstances, an ADD elaborated by the patient according to his/her own criteria and lifestyle could be very useful. A project for elaborating an ADD requires a planning comprising ethical, psychological, and for many people, religious issues.¹⁴

According to the Hippocratic principles of beneficence and nonmaleficence, physicians are always due to the criterion of preserving life. However, technological and scientific advances make that the life of people with many health deficits, and thus deficits in their quality of life, may be maintained. Thus, more and more the ethical dilemma of whether treating patients and their diseases for just prolonging their lives without improving their quality of life (therapeutic futility) emerges. There are experiences showing that the elaboration of an ADD by dialysis patients facilitates a «good death» when complications arise.¹⁵ However, there is a lack of education on these issues, not only on the part of the patient but also on the part of the physician.¹⁶

In order to avoid conflicts between physicians and other health care personnel on the one side, and pa-

Appendix. Summary of the questionnaire administered to all patients suffering from end-stage chronic renal failure on regular hemodialysis for longer than 3 months

- 1) *Who is the representative?*
 - 0 = couple
 - 1 = son/daughter
 - 2 = other relative
 - 3 = friend
 - 4 = physician
 - 5 = nurse
 - 6 = social worker
 - 7 = priest or similar
 - 8 = other
 - 2) *SHave you already told him/her?*
 - 0 = No
 - 1 = Yes
 - 2 = Not said, but with the intention of telling him/her
 - 3) *Language for the Living Wills Document*
 - 0 = Catalan
 - 1 = Spanish
 - 4) *In case of not elaborating the document, what is the reason?*
 - 0 = I would rather not think about it
 - 1 = Given the case, the family/medical team will take a decision
 - 2 = Distrust in given the information by writing
 - 3 = Verbally manifested to the representative
 - 4 = different culture, language
 - 5) *In case of permanent coma, I would like to have: Patient answers = 0; Patient does not answer = 1*
 - a) Mechanical ventilation. No = 1, Yes = 0, No answer = 2
 - b) Artificial feeding. No = 1, Yes = 0, No answer = 2
 - c) Dialysis. No = 1, Yes = 0, No answer = 2
 - d) Resuscitation in case of cardiorespiratory arrest. No = 0, Yes = 1, No answer = 2.
 - 6) *In case of vegetative state, I would like to have: Patient answers = 0; Patient does not answer = 1*
 - e) Mechanical ventilation. No = 1; Yes = 0; No answer = 2
 - f) Artificial feeding. No = 1; Yes = 0; No answer = 2
 - g) Dialysis. No = 1; Yes = 0; No answer = 2
 - h) Resuscitation in case of cardiorespiratory arrest. No = 1, Yes = 0, No answer = 2.
 - 7) *In case of dementia, I would like to have: Patient answers = 0; Patient does not answer = 1*
 - a) Mechanical ventilation. No = 1; Yes = 0; No answer = 2
 - b) Artificial feeding. No = 1; Yes = 0; No answer = 2
 - c) Dialysis. No = 1; Yes = 0; No answer = 2
 - d) Resuscitation in case of cardiorespiratory arrest. No = 1, Yes = 0, No answer = 2.
 - 8) *In case of end-stage disease, I would like to have: Patient answers = 0; Patient does not answer = 1*
 - a) Mechanical ventilation. No = 1; Yes = 0; No answer = 2
 - b) Artificial feeding. No = 1; Yes = 0; No answer = 2
 - c) Dialysis. No = 1; Yes = 0; No answer = 2
 - d) Resuscitation in case of cardiorespiratory arrest. No = 1; Yes = 0; No answer = 2
-

tients and their representative, on the other, several steps must be followed,¹⁷ which we try to apply at our Center: 1) an adequate information on all therapeutic possibilities for ESCR, including that of not dialyzing

or transplanting the patient (before the prognosis of bad clinical course in the short term); 2) an informed consent on acceptance of the replacement therapy chosen in which an adequate information on therapeutic options is certified; 3) the estimated prognosis of both the patient and his/her disease; 4) the forecast of possible conflicts that may arise and their resolution; 5) an ADD verifying the patient's opinion in case of disability; 6) the precaution of dialysis continuation or discontinuation according to the clinical course in order to avoid therapeutic futility; 7) the possibility of special care groups according to religion, social class, other culture, marginalization, etc.; 8) the possibility of limited dialysis therapy for a certain time in case of diseases with unknown prognosis (neurological, psychiatric, etc.) to observe the patient's clinical course; and 9) the offer of palliative care in case of dialysis discontinuation.

The Latin culture is less experienced with the issue of dialysis discontinuation and documents of living wills, although there are some previous experiences.^{5,18} On December of 2000, the Parliament of Catalonia set rules for the patients rights and elaborated the first law on Living Wills in Spain; later on, on April of 2002, the Parliament of Aragon set rules on the ADD, and further on, during the following years, all other autonomous regions but Asturias, Ceuta, and Melilla, have done so. Besides, Catalonia, Aragon, Navarra, Cantabria, the Basque Country, Valencia, Andalusia, Castile la Mancha, and Murcia have available a Registry where these wills can be registered, as well as other city councils (Logroño, Vitoria, Sant Andreu de la Barca, Lleida, Sant Boi, etc.). Our experience shows us that patients prone to elaborate an ADD are those having had the experience of a loved one having suffered from therapeutic savagery or prolonged agony that they would have not wish for them. The Health Care and Social Security Office of Catalonia states that this is one of the reasons why people seek information about the elaboration of a Living Wills Document.¹⁸ Other characteristics of these people are advanced age, chronic health care problems, thorough thinking about this requirement, and a profile of people with an important familial or friend bounds.¹⁸

The response to the questionnaires administered at our center shows us that the population suffering from a chronic disease such as ESCR, is very heterogeneous when expressing their wills on a written document since about half of them express their will of limiting some therapeutics efforts on them under certain clinical circumstances, and the other half does not do so. About the characteristics of the former, age is the only factor making a significant difference as compared to the latter (older patients are more in

agreement with limiting therapeutic efforts). Contrary to other authors,¹⁹ the degree of comorbidity, the gender, and the educational level do not contribute to this difference. We have asked ourselves about religious beliefs: people reasoning more thoroughly their responses without expressing themselves on therapeutic limitations more frequently alleged having stronger religious beliefs. They also had higher educational level, although the will of writing down therapeutic limitations was not correlated with the educational level. Belonging to other cultures, generally with few years of living in our country, makes more likely not to answer the questionnaire, and we suspect that mistrust on how their answers could be interpreted (or even more, on how their could be treated under those circumstances) lies at the heart of this fact.

Duffy et al.²⁰ state that in those societies with many different ethnicities, such as in the United States, the answers may differ depending on cultural differences: the Arabs see these barriers as insurmountable, Afro-Americans feel these barriers are due to unequal care practices, and Caucasians feel there is difference by people's age. The decision of contemplating the cultural differences at the time of making a decision on limiting therapies may increase the confidence in health care systems and the satisfaction from the patients and their relatives.²¹

In our work, few patients (10.3%) live by themselves; most of them live with their couple or sons, so that we have not found significant differences by family structure. Other authors have found that widowers and widows and nursing home residents tend to more frequently express their will on limiting therapeutic efforts under particular circumstances.²²

These questionnaires on possible therapeutic limitations not only promote the patient-physician relationship but also may promote trust on the patient's daily perspectives if they are done with the appropriate correct information and detailed prognosis, highlighting the positive aspects for the patient's hope.¹⁴

In our experience, of the patients responding to the questionnaire, 16.2% would like to stay on dialysis in case of permanent coma or vegetative state, 16.2% in case of irreversible severe dementia, and 19.1% in case of irreversible end-stage disease. These percentages are lower than those expressed by patients from other countries: 25% would stay on dialysis in case of severe thrombosis, 19% in case of severe dementia, and 14% in case of profound coma, in Canada;¹⁹ eighteen percent would do so in case of dementia and 45% in case of terminal cancer, in Japan.²² With the exception of terminal diseases, our data are fully comparable to those found among Japanese patients.

The attitude of the patients towards resuscitation in case of CRA at the HD Unit is wanting to be resuscitated in spite of being in permanent coma or vegetative state in 22% of the patients answering the questionnaire, in 17.6% in case of profound dementia, and in 23.5% in case of end-stage disease. In the United States, globally 87% of the patients would want to be resuscitated in case of CRA; older patients, those with higher comorbidities, widows/widowers, and nursing home residents are less prone to resuscitation.²³ Usually, the health status sets the will of limiting therapeutic actions, although we have not found significant differences by comorbidity index: the value of 87% of the dialysis patients wanting to be resuscitated in case of CRA goes down to 10% in case of being in a situation of permanent coma.¹⁹ In Japan, less than 20% of dialysis patients would like to be resuscitated from CRA in case of terminal cancer.²²

It seems that of all situations, the one being the worst tolerated is artificial nutrition by nasogastric tube. By contrast, other authors report that dialysis discontinuation is the circumstance about which PHD patients have more difficulty in expressing themselves.⁶

Cultural differences may have their importance at the time of writing down an ADD. As compared with American patients, German and Japanese patients, but not their nephrologists, less frequently use an ADD as useful tool on which to support the decision of dialysis discontinuation.⁸ However, this should be interpreted taking into account age, comorbidity, and social aids, since generally German and Japanese dialysis patients are younger and with less comorbidity.⁸ Social support for the patients, which in our country basically lies on the family, may decrease the importance of the comorbidity factor reflected in our results. In this context, the only definitive factor would be age when thinking about limiting therapeutic actions in our setting.

Moss et al.²³ reported that, in the United States, Afro-American people answer affirmatively, with a significant difference as compared with Caucasians, when they are asked about being resuscitated in case of CRA. These differences should be again interpreted from the perspective of age, comorbid conditions, and socio-cultural and religious factors, and family support, etc. Under this angle should be interpreted the differences found between the questionnaires administered in Catalan and in Spanish, which were not significant. The paramount DOPPS study²⁴ considers these issues and gives importance to quality of life and socio-economic factors that may have an influence on the orders of no-resuscitation from CRA and dialysis discontinuation in dialysis units.

Our patients have not make a difference between the situations of deep coma and persistent vegetative state, answering exactly in the same manner to the different questions. Considered from the ethical and medical perspectives, there are regulations to confront the situation of vegetative state,²⁵ with the recommendation of following some basic guidelines for discontinuing dialysis under such situation. We have no direct experience with such kind of patients.

The ADD can facilitate a good death¹⁵ and also must give importance to palliative care, which must not be forgotten. Whenever the patient or his/her relatives wish to do so (due to several reasons, from avoiding organic symptoms to approaching strictly psychological issues), referral to the Palliative Care Department is promoted where patients and their relatives may have a satisfactory experience, in agreement with what have been reported by other authors.^{26,27} Thus, Cohen et al.²⁶ report a high level of satisfaction from the relatives of deceased patients. In our experience, in most of the cases that dialysis is discontinued at the hospital, this is done at the Nephrology or Palliative Care departments.⁵

According to what has been mentioned, the ADD should a mandatory document done by the patients and regularly consulted by the physicians treating those patients with ESCRf, although it does not occur like this. Almost 50% of the patients have answered the questionnaire. This fact is positive by itself. A similar questionnaire undertaken among Internal Medicine physicians about clinical conditions in which a decision had to be taken about applying a therapy or not based on limiting the therapeutic efforts, was answered by only 41% of them.²⁸ Therefore, it seems that there is no big difference between patients and physicians when expressing an opinion on these issues.

Physicians are somewhat reluctant to talk about the issue of advanced directives with patients, and probably even between them;⁶ this is due to several reasons requiring further investigations, although what seems obvious is that it will become a more and more indispensable issue with time; not the ADD itself, but rather the discussion about patients death and how to face it. It seems obvious, as well, that these patients cannot be left alone and their opinion on the burden they represent for their relatives, their quality of life, etc. must be taken into account.^{27,29,30} Patients' age will continue on going up due to life expectancy perspectives in the western world, which will lead to the dilemma of whether applying or not treatments under certain circumstances and poor prognoses.²⁹ A priori and according to some publications, it would seem that younger and less experienced physicians would be more prepared to more easily respect the

patients' wills and their possible desire of discontinuing from dialysis.³⁰

Physicians need to know their patients' opinion and it is clear than more than 75% of them prefer to make a decision on their future, either they manifest it or not.⁶ They choose a representative, who usually is a family member rather than a physician.³¹ In our experience, we found the same results, highlighting those cases that have not written down an ADD but state having talk about planning their future with a relative, firstly their sons/daughters and the couple in the second place. We feel there is an undertone of mistrust in the health care system and personnel since, given the case, these could take decisions not in the full interest of the patient and financial interest could be prioritized given the burden they represent to the public health care system. Counseling and influence from another patient may be more helpful than the medical work itself regarding these issues.³²

The thoughts expressed by the patients by means of this questionnaire validated their wills in case of disability since they have been meditated together with their representatives and with the physician posing the possibility of therapeutic limitations in case of extreme situations. In fact, the elaboration of an ADD must be a dialogue between the person who is trying to get ready for his possible death, rather than his disability, and the person that will represent him in case of disability, since in this way the patient will understand that the representative understands him trustworthily and will act as if he were the patient himself.⁹ It should not be just a manifest for the health care team. This did not happen in the case we mentioned above, in which the representatives (the patient's daughters) more likely acted moved by their believes than as true representatives since they did not respect their father's opinion, expressed when he was fully able.

We physicians also need more education on these topics in order to being able to appropriately discuss therapeutic limitations that our patients may present.^{7,16} There are cultural differences that may define some medical attitudes.⁷ These are completely subjective in many cases, although these opinions may completely change such an important decision implicating the patient's life or his/her level of discomfort.³³

It maybe that we physicians need to learn to say no when renal replacement therapy is to be offered to elderly people, with important comorbidities and an evident lack of quality of life.⁴ Conservative management of chronic renal failure should be considered and it may yield satisfactory results, especially regarding patients' quality of life. Age alone should not be a determinant factor when offering the possibility of

renal replacement therapy; other factors that may have an influence on the decision of not offering renal replacement therapy should be weighed, such as social isolation, late referral to the nephrology department, the Karnofsky's index, and diabetic status.³⁴ Besides, other aspects influencing the old patients' ability to take their own decisions, such as mental capacity, family burden they feel they may represent, and suffering, should also be weighed.³⁵

The ADD is a helpful instrument for physicians and other health care workers for taking clinical decisions, but it may also represent an aid if is socially seen. It is a dialogue or discussion tool between patients and their representatives that may facilitate dying with dignity while avoiding futility and therapeutic savagery at the end of life. The important thing is to manifest one's opinion to one or more representatives according to one's lifestyle so that these premises guide therapeutic actions in case of disability.

For the health care workers, especially for the nephrologists, the thinking must comprehend the patients' integral care at the end of their lives. Nephrology training and clinical guidelines on chronic renal failure should include this thinking.

We are far from reaching these goals since we, as physicians, cannot express an ADD and even less talk about this issue with our colleagues for our own diseases.³⁶ If we were to believe this need, it would be easier for us to convince our patients.

To conclude, in our setting, and taking into account the issues discussed: 1) 48% of patients on regular HD are for limiting therapeutic efforts in case of disability and associated irreversible severe conditions; 2) older patients are more prone to limit such efforts.

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