

Thoughts on the start and withdrawal of dialysis

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ABSTRACT

Increased life expectancy and the availability of treatments provided by modern medicine have given rise to a new situation in which survival may be prolonged without the patient having an acceptable quality of life. Renal replacement therapy (RRT) to treat End Stage Renal Disease (ESRD), may involve the use of aggressive techniques designed to improve and prolong the lives of patients with high comorbidity and very low short term survival expectancy. RRT often means lowering patients' quality of life, it is a significant burden on families and survival expectancy is low. Patients must actively participate in decision-making, but to do so, the information about the prognosis of their disease and how the treatment will affect their quality of life must be more comprehensive. As nephrologists, we will be able to contribute better to decision-making by improving prognostic tools and participating collectively with the patient and their family in the final decision. It is necessary to offer appropriate care to patients who opt for conservative treatment by implementing multidisciplinary teams within ESRD units.

Keywords: Withdrawing dialysis. Withholding dialysis. Advance directives. Palliative care.

GENERAL

The increase in life expectancy, especially in developed countries, and the availability of possible treatments

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Reflexiones sobre la entrada y la retirada de diálisis **RESUMEN**

El aumento de las expectativas de vida y la disponibilidad de tratamientos proporcionados por la medicina actual han dado lugar a nuevas situaciones en las que se puede prolongar la supervivencia en condiciones de calidad de vida inaceptables. El tratamiento sustitutivo renal (TSR) para el tratamiento de la enfermedad renal crónica avanzada (ERCA) puede implicar el uso de técnicas agresivas, diseñadas para mejorar y prolongar la vida, a pacientes con elevada comorbilidad y expectativas de supervivencia muy limitadas a corto plazo. Con frecuencia, el inicio de TSR implica un empeoramiento de la calidad de vida de los pacientes y una importante sobrecarga familiar, con una limitada supervivencia. Los pacientes deben participar activamente en la toma de decisiones, pero para ello han de disponer de una información más completa sobre el pronóstico de su enfermedad y cómo va a influir el tratamiento en su calidad de vida. Los nefrólogos podremos contribuir mejor en la toma de decisiones perfeccionando las herramientas pronósticas y participando de forma colegiada con el paciente y su familia en la decisión final. Es necesario ofrecer a los pacientes que opten por el tratamiento conservador una adecuada asistencia mediante la implantación de equipos multidisciplinarios dentro de las unidades de ERCA.

Palabras clave: Suspensión de la diálisis. Rechazo de la diálisis. Voluntades anticipadas. Cuidados paliativos.

provided by modern medicine have led to new situations, which can prolong survival in unacceptable quality of life conditions. Renal replacement therapy (RRT) for the treatment of End Stage Renal Disease (ESRD) may involve the use of aggressive techniques designed to improve and prolong life in patients with high comorbidity rates and very limited short-term survival expectations.

The concept of “dysthanasia” word of Greek origin meaning “difficult or agonising death”, defines a not sufficiently justified application in certain patients of treatments that worsen their quality of life, even more than their illness. It is associated with inappropriate use, during the dying process, of treatments that have no objective except the prolongation of the patient’s biological life. In recent years, the use of the term “therapeutic obstinacy” has become extended, which in general is not an accurate expression, as it suggests the existence of a will or intention to do something inappropriate and harmful to the patient, which is not typically the doctor’s intention. Therefore, it is more appropriate to use the term “dysthanasia” which is more clearly related to unnecessarily prolonging life using life support means.

There are circumstances in which the patients’ condition is irreversible, but not end-stage, and is subjected to therapeutic interventions for correcting specific aspects of their diseases, losing sight of their overall situation, their suffering and their quality of life. The decisions taken by the medical team are frequently conditioned by a culture and an environment that fosters the adoption of “dysthanasic” attitudes and behaviours, and sometimes this situation is favoured by family pressure to “do everything humanly possible”. The usual absence in our environment of a living will puts the family under severe emotional pressure, which makes taking decisions on ending life very difficult. On other occasions, there is difficulty in establishing a clear short-term prognosis in some cases and the doctor resist “giving up” without exhausting all the possibilities and treatments available.¹

THE PRINCIPLE OF NON-MALEFICENCE

One of the fundamental principles of Hippocratic ethics is “primum non nocere” (first, do no harm), a principle which should be considered as a priority in medical practice. Based on this principle of non-maleficence, no treatment should be started or should be discontinued when, according to generally accepted clinical practice, it fails to improve patient survival in acceptable quality of life conditions. A treatment is unnecessary when it is not indicated, according to medical literature and clinical guidelines, because it is clinically ineffective or does not improve prognosis, symptoms or intercurrent diseases. Non-indicated aggressive treatment can cause harmful effects, or not provide the expected benefit for the patient, or will seriously damage family, economic and social conditions. At present, most of deaths occur in hospitals, in shared rooms with no privacy, or in intensive care units. Death at home, with the support of family and friends, is increasingly rare. We have

progressed to a situation of “medicalised” death. There are no longer “hopeless” patients. There are critically ill, irreversibly ill, terminally ill, but no “hopelessly” ill patients.²

“Dysthanasic” behaviours produce unnecessary suffering for patients and family, healthcare team frustration and unnecessary increases in health spending. It is necessary to bear in mind that benefit to the patient is a main and unavoidable priority. Not all possible treatments are indicated to prolong life, even if focused on the disease process, if they do not provide the patient with an improved survival under minimum quality of life conditions. A terminally ill patient may feel threatened not only by the disease itself, but also for useless activities that bring more pain than relief. Unnecessary suffering is an evil that should be avoided in civilised societies. One of the worst professional misconduct in specialised medicine consists in not regarding human beings in their entire complexity but solely considering them from the perspective of an organ or a system.²

THE PRINCIPLE OF AUTONOMY

Current society considers individual have a fundamental right to freely choose a dignified death. The Spanish Constitution mentions human dignity, together with freedom, among the highest values of our legal system, Article 1.1 and 10.1, which protect personal dignity and the right to free personality development, or 16.1, which guarantees freedom of ideas, or Article 15, which states the fundamental principles that have to be taken into consideration in establishing a correct relationship between the prohibition of killing and an individual’s right to self-determination.^{3,4}

When making decisions, practitioners should consider important aspects as the impact of measures taken on patients’ quality of life and, if they are able to make decisions, consider their values, attitudes and the degree of information available to them. The assessment of quality of life can be subjective for each patient, so that in circumstances in which their wishes are known, the doctor must strictly comply with them. Doctors sometimes underestimate the quality of life of patients, so it is very important, especially in chronic patients who are adequately informed of the prognosis of their disease, to let them decide what quality of life they are willing to accept. If a patient is competent, they have the right to freely refuse treatment, if they have been duly informed and understand the scope and consequences of their choice. In cases where it is not possible to know the patient’s will, it is necessary to establish appropriate communication channels with the immediate family, or

person delegated, when making tough decisions, always respecting legal and ethical requirements.

THE DOCTOR'S RESPONSIBILITY

However, although the doctor must respect the patient's autonomy, he cannot leave aside his convictions as to what is best for the patient nor can he betray the goal of medicine, designed to protect health objectively, based on corresponding assessment. However, the doctor must maintain sufficient objectivity to know when prolonging treatment is useless and will only lengthen suffering for patient and family. It is necessary to make decisions, often difficult ones, based on knowledge and professional experience, despite the existence of opposition from family and friends, providing prior information and attempting to make joint decisions: when this situation occurs, it is desirable that the underlying rationale for decision-making and contacts with family are reflected appropriately in a patient's medical history. The decision must be discussed collectively and consensus must be achieved. Doubts of a single team member involved in the decision making process must cause postponement of the same.³ If the situation is very complex, impeding decision making, it is appropriate to consult the Hospital Medical Ethics Committee and their answer must be detailed in the medical record. In general, professionals find more difficult to interrupt a treatment than not to start it, but conceptually there is no difference. There are even confessional states, such as Israel, in which discontinuing vital support is banned.⁵

ADVANCE DIRECTIVES

Citizens have a recognised right to accept or reject proposals of health personnel. When a patient is fully conscious, the expression of his will is decisive. In the event that a patient is unable to communicate their will, there are two basic instruments, such as the signing of a living will (advance directives document), as provided in our legislation, or the previous designation of a representative or agent to take relevant decisions, according to instructions. The appointment of a representative must be validated legally and properly drafted and recorded, and has legal validity in court. In all cases, it is necessary to consider the boundaries between curative treatments, those only seeking to prolong life, and symptomatic treatments. However, when a patient refuses treatment, practitioners should provide all the information needed to eliminate irrational fears and clarify the situation. If an appropriately informed patient holds to his decision, it should be accepted while simultaneously providing treatment options to limit the consequences of the disease and impaired quality of life.

Commonly, patients with ESRD or on dialysis are not aware of the severity of their illness and do not consider making their wishes known on end of life situations until it's too late and they have lost a great part of their cognitive functions. Despite the existence of legislation that regulates and promotes the expression of previous living wills, this practice is not widespread in Spain. In a survey by the Ethics Group of the Spanish Society of Nephrology in five hospitals in Spain, it was found that only 9% of patients had signed a document, although a higher percentage itself had expressed their desires orally to their closest relatives. However, the lack of an express statement on specific aspects of end of life decisions poses serious problems for both family and professionals. When patients were asked about their wishes about certain practices, nearly 70 % expressed their refusal to be intubated, dialysed or resuscitated if they were in irreversible coma, had severe untreatable dementia or were suffering from serious illness (cancer, refractory heart failure, refractory liver failure, etc.). Therefore, a high percentage of patients have a clearly formed opinion with regards to these issues, but the absence of a statement *expressed* in writing or verbally prevents both family and medical team from knowing their wishes.⁶ This situation is not very different from that found by other studies in other countries.⁷ It is possible that a patient may have made an advance directive under different circumstances to those currently affecting him. In this case, it is necessary to reassess the situation by providing the patient with more adequate information to enable him to be fully informed.

PALLIATIVE CARE

Since 1970, we have witnessed a growth of movements which try to develop laws that promote "helping patients to have a good death". One of them is an advocate of voluntary active euthanasia, and the other, of the implementation of modern palliative care techniques and programmes (hospice movement). Euthanasia (good death) has a Greek root and hospice is a word derived from Latin (hospitium, "hospitality") used in the Middle Ages.⁸ There is a very active movement in Western countries in favour of the regulation of euthanasia largely favoured by the fear that modern technology will make patients undergo aggressive unlimited not justified medical measures. People want to preserve their autonomy and how and when they will face their "end of life". The progressive introduction of palliative care units has made it possible to provide adequate facilities and trained personnel to reduce the suffering of patients, and help patients and families in the final moments of life. If an adequate palliative care programme is in place, voluntary active euthanasia loses force, as virtually all patients can have a dignified death.

A patient without an indication of renal replacement therapy (RRT) or who voluntarily chooses a conservative treatment should be guaranteed health care that supports their needs and allows them to maintain a good quality of life. It is necessary to have available support alternatives for conservative treatment, through CKD Conservative Treatment Units formed by multidisciplinary teams (inpatient and ambulatory palliative medicine, primary care, social work, psychologists) acting jointly with the nephrology team (nephrologists and nurses). There are already several experiences in our country⁹ with protocols for this process, mainly centred in palliative care. This perspective consists in organising conservative treatment for patients, so that they are not denied full nephrology care (excluding dialysis) and provided with adequate health care by supporting other professional teams which provide knowledge of “end of life” care and a support infrastructure that facilitates outpatient home care. There is not yet much experience with these teams, but it is an initiative that may be extended to most Nephrology Units in the next years.

DECISION TO START OR WITHDRAW DIALYSIS

Renal replacement therapy (RRT) techniques, haemodialysis and peritoneal dialysis are aggressive techniques designed to improve and prolong the lives of patients with ESRD. The use of RRT can be questioned if it fails to improve quality of life of patients with limited life expectancy. The percentage of patients who die as a result of the discontinuation of dialysis is clearly specified in some records and this percentage is growing. There is an increasing number of patients who begin RRT with a limit indication and in which it is necessary to suspend the treatment. In a study performed in 1986, Neu showed that 9% of 1766 dialysis patients suspended treatment and these patients accounted for 22% of all deaths.¹⁰ The withdrawal was more frequent in older patients and in young diabetics versus nondiabetics, but also was more frequent in patients with degenerative disorders, in intermittent peritoneal dialysis and in patients living in nursing homes. Of these patients, 50% were competent to make a decision and when the patient was incompetent, the physician recommended withdrawal in 73% of cases and the family in 27% of cases. When analysing the evolution over five year periods, it is increasingly seen that the patients themselves take the initiative to change their treatment conditions (1970-75: 30%; 1976-79: 40% and 1980-83: 50%). This change requires the establishment of protocols and hospital facilities for “end of life” care, since 80% of patients who are withdrawn from dialysis die in a medical centre.

One of the few prospective studies was performed in West Virginia¹¹ comparing the percentage of patients

with CKD treated by a primary healthcare doctor and nephrologists who were not included in RRT (22% vs. 7%). The reasons given by the primary healthcare doctors for not starting RRT were several and among them the main ones were the presence of heart failure or liver disease, lung disease, older age, end-stage cancer, patient refusal, dementia, frailty, severe neurological deterioration and rejection by the family. This high number of patients suggests that the incidence of end-stage CKD may be 20% greater than that collected in common registers. It was also seen that dialysis was discontinued in 12% of patients in public health centres and in 6% in private ones, and a higher percentage of the first had a living will document. The reasons for discontinuation of dialysis were an unacceptable quality of life for the patient (41%), acute complications (21%), dementia (12%), stroke (10%), permanent unconsciousness (7%), cancer (6%) and others (3%). Patients not receiving RRT lived an average of 20 months (range 1-108 months). Median survival in patients who withdrew from dialysis was 12 days (range 0-150 days). The existence of an advance directives document facilitates the work of the doctor, since in this case it is the patient who takes the initiative, while if the document does not exist it is, in general, the doctor who initiates the process through discussions with family and patients in 62% of cases.

Evidence of the interest in this problem is the development by The Renal Physicians Association and the American Society of Nephrology, in collaboration with other health professionals, patient organisations, bioethics and public health experts, of a document entitled “Clinical Practice Guideline on Shared Decision- Making in the Appropriate Initiation of and Withdrawal from Dialysis”. These guidelines provide recommendations relating to the initiation and withdrawal of dialysis in adult patients with acute renal failure and ESRD.¹² Shared decision making between doctor and patient is strongly recommended and informed consent that includes complete information about diagnosis, prognosis and treatment options (modalities, conservative treatment, testing time-limited dialysis and dialysis withdrawal and end-of-life care). It is recommended to withhold or withdraw dialysis in patients with full capacity to decide, patients without capacity but that have previously stated their refusal to undergo dialysis by means of a living will or whose legal representatives request this, and patients with profound and irreversible neurological damage or non-renal terminal disease. In those patients who require dialysis but have an uncertain prognosis or when it is not possible to reach consensus, consensus test dialysis is a good alternative. It is important that those patients refusing or rejecting dialysis receive palliative care from appropriate professionals. Palliative care should include medical, psychosocial and spiritual end-of-life care. Patients may decide to die in a health

care institution or at home, supported by palliative care. You may obtain a copy of these clinical guidelines at rpa@renalmd.org.

THE UNCERTAINTY OF VITAL PROGNOSIS

One of the most important problems faced by nephrologists is an appropriate estimate of the patient's prognosis. This is a fundamental aspect for the patient to decide based on sufficient information. Although there are many approaches to this problem and different scores have been defined, there are no definitive studies. Most of the indices include different variables such as age (2-4% increase per year of life),¹³ race (7-38% increase for whites over blacks),¹⁴ sex (5-73% increase for women compared to men),¹³ serum albumin (33-81% decrease for each gram increase in serum albumin),¹⁵ nutritional status (25-36% increase due to malnutrition),¹⁶ functional status (52-158% increase if the decline is moderate and 100-216% if severe),¹⁴ comorbidity (congestive heart failure [11-41% increase], ischaemic heart disease, diabetes [10-74% increase], peripheral vascular disease, chronic obstructive pulmonary disease or cancer).^{14,15,17} However, despite these calculations there is always an underlying degree of uncertainty. There are studies providing a very high degree of validity, in risk estimation, to answer nephrologist's queries such as: "Would you be surprised if the patient died in the next six months?"¹⁸ The Charlson comorbidity index seems to present a good correlation with survival prognosis when groups of patients are analysed, but it is more difficult to apply this predictive tool in individual patients.¹⁹ The current scoring systems provide good information when analyzing prognosis for groups of patient, but not when applied to individual patients, in which case the prediction is not as good. It is therefore necessary to develop new prognostic projection systems that take into account multiple aspects of each individual patient, since prognosis systems are better if they are of increasing complexity, including values for joint comorbidities and complications and disability aspects, social and family aspects, frailty, quality of life and others.^{20,21} Future progress in this direction will allow us to improve the prognostic value of our initial clinical assessment and provide the patient with more reliable information about the future to enable them to make properly informed decisions.

In short, nephrologists are aware that the high rate of comorbidities seen in many patients with ESRD is a factor for poor survival of this group of patients when they start RRT. Often the start of RRT involves deterioration of patients' quality of life and severely burdens families, with limited survival. Patients should be actively involved in decision-making, but

they must have complete information on the prognosis of their disease and how treatment will influence their quality of life. Nephrologists can best contribute to improving decision making by improving prognostic tools and participating jointly with patients and families in their final decision. It is necessary to offer patients opting for conservative treatment appropriate care provided by multidisciplinary teams in ESRD units.

Conflicts of interest

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

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