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editorial

Advance care planning before starting dialysis

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Nefrología 2009;29**(4):**285-287.

In recent years, due to having enacted the law that regulates carrying out **living wills** (Spanish Law 7/2002 of 12 December, regarding living wills in the health care system), the legislation permitting effective implementation of rights supported by the law has been promulgated throughout Spain's autonomous communities. Although later than in other western countries where this right has been exercised for years, we feel that there is a need to make aware the general population and the patients with advanced chronic kidney disease (ACKD) in particular, of this right, since knowledge about living wills and how to make use of them is generally quite limited. Knowledge of the law is also limited among health care professionals, which is why we need to make an effort to publicise this information.

A living will, also known as **advance directives**, includes a set of documents in which the patient explains his/her wishes for a life plan and end-of-life plan. Living wills contain two fundamental components. One is the **advance statement,** a document that reflects the individual's wishes regarding the care that he/she would like to receive in the event of becoming incapacitated, and provides care providers with specific instructions regarding different aspects of the end of his/her life. The second component is the **choice of a representative** (a proxy or PoA), who will act in the name of the patient should he/she become incapacitated. This representative should have ample knowledge of the patient's wishes.

In general, doctors resist "giving bad news", meaning that in many cases, doctor-patient communication is not adequate, and the patient has only partial information about the true scope of his/her disease. It is important to establish a multidisciplinary approach in which doctors, nurses, bio-ethicists and social workers participate. Involvement the family in this dialogue is fundamental. It has been stated that the quality of family relationships determine whether or not there is a living will in many cases.[1] We must determine how much the patient knows and wishes to know. If the patient does not want very much information, we speak about treatment plans, and if the patient does wish to know, we provide information according to what is agreed. We must respond to the patient's feelings and establish means of communication that will be important for planning a future strategy. The patient and the family should participate in this process, but we must always remember that the patient's feelings and wishes are the most important.

The doctor's responsibility in the decision process will vary according to the patient's level of competence. If the patient is mentally competent, the decision will always be his or hers. If the patient is mentally incapacitated, this will depend on whether or not he/she has made wishes known through a living will or the designation of a representative. If there is no will or representative, the decision must be made by the doctor and the family together. This is the most common situation at present.

LIVING WILLS AND ACKD

Currently, developed countries place no limits on the use of renal replacement therapy (RRT). As a result the suitability of treatment in each individual patient is often not evaluated properly, although it is known that not all patients benefit equally from RRT. The excessive number of patients on RRT in countries such as the United States has been attributed to issues such as patients having limited knowledge of their disease, poor communication between the patient, the family and the doctor and the fact that there is no policy for restricting treatment. Whether or not there are available slots in the dialysis unit often influences the decision.

On the other hand, despite the high mortality rate of patients with ACKD, these patients do not see themselves as having a terminal illness and think that they can stay alive on dialysis

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indefinitely. Many patients do not consider expressing their end-of-life wishes until it is late and they have lost a large part of their cognitive function. In the USA, only 30% of patients on dialysis have a living will or have discussed or expressed their position regarding dialysis, and of these, 66% do not know the role of a representative, 42% do not know what legal status their living will has, 77% have discussed their wishes with the family or a close friend, only 17% have discussed their wishes with their doctor, and 51% think that living wills could influence the doctor's attitude toward their treatment. One aspect that highlights the lack of awareness about the seriousness of the disease is the fact that the position regarding discontinuing dialysis is not usually expressed in living wills.[3]

The existence of a living will can be very important in some patient groups, such as those who are incapacitated and for whom starting or discontinuing dialysis is being evaluated; the patients with prolonged impaired consciousness; patients with severe, irreversible dementia or severe mental deterioration; patients incapable of cooperating with the dialysis procedure or communicating with the doctor and patients with a low life expectancy (< 60 days) due to terminal illness or end-stage lung, liver or heart disease who are bed-ridden and who need assistance for daily life activities.[4]

However, despite their insufficient knowledge of living wills, when patients are asked what they want in hypothetical situations, their opinions are quite clear. In a questionnaire given to 532 patients who were potentially eligible for dialysis, 86% of patients stated that they wanted to undergo dialysis in their current state of health; 84% would want it in the event of a mild stroke, 60% after a moderate stroke and 21% after a severe stroke; 41% in the event of having a terminal illness, 14% in severe dementia and 10% in the event of a permanent coma.[5]

Planned arrival at the dialysis stage makes decision-making easier by allowing the patient to receive information on the illness and treatment options during pre-dialysis appointments, and in this case, he or she has the opportunity to decide on the conditions and level of acceptance for that treatment. Lack of planning implies conditioning and diminishing the freedom of choice.

ADVANCE CARE PLANNING FOR ACKD

For all patients starting RRT, nephrologists should recommend and obtain a living will, since these documents serve as an excellent tool for future medical care and decision-making.

Discussions about end of life tend to be late for patients on dialysis, and with time, cognitive function decreases. This matter should be broached early in order to be able to respect the patient's autonomy and values. It is necessary to consider the patient's feelings through in-depth dialogue, and plan his/her future care in its entirely taking into account ethical and psycho-social aspects and any other issues related to starting, continuing, maintaining and discontinuing dialysis treatment.[6] The planning process should be carried out at the time when the patient is given education and information on dialysis options. This process should be complementary to the consent process for choosing dialysis options, except perhaps in patients with low comorbidity or who will be receiving transplants in the near future.[7]

The clinical approach to the decision-making process implies evaluating the patient's decision-making capacity and whether the patient is aware of his/her situation and the consequences of the decision, and if he/she has informed loved ones and the medical staff about the decision. The doctor must check whether or not a living will exists, particularly for incapacitated patients who have previously expressed in writing that they do not want to be on life support, or those who do not have a living will but who have clearly stated that they do not want dialysis, and verify whether there is a representative or not.

Likewise, it is necessary to evaluate potentially reversible factors, and the nephrologist should rule out the existence of depression, dementia, or uraemic or toxic encephalopathy that might condition a patient's decision.

On some occasions, or if the patient is having doubts, you might agree on a "trial period"; some patients with terminal illness (metastasised cancer) might need "temporary dialysis" in order to resolve personal and social problems before their foreseen death. Involvement by the team and the family is fundamental. The majority of patients prefer to discuss these decisions with their families rather than with their doctors (50 vs. 6%).[8] If the patient clearly refuses dialysis, post-decision palliative care measures that contribute to the dignity of the death should be planned.[9] Documentation plays an important role, given that the patient's preferences should be clearly reflected in the clinical history, should accompany the patient, and must be known by all who are involved in the decision process.

DIFFERING SITUATIONS FOR PATIENTS WITH ACKD

Conservative treatment: patient refuses to go on dialysis

It is important to follow a proper decision-making process, since patients should understand what their decision means and provide a life plan and state how the end of life should be managed in writing. It is necessary for the patient's care providers to understand the patient's needs and be supportive of their decisions, and arbitrate the means for palliative care of the patient.[9,10]

Conservative treatment: patient not indicated for dialysis

This is a very frequent situation in clinical practice. It is possibly more frequent than discontinuing dialysis, and is the case of 25% of all patients referred for dialysis in Canada.[11] Many patients who are seen in a primary care centre are not referred to Nephrology because they are not considered candidates for dialysis, due to being incapacitated by serious dementia, being unconscious, or having a severe mental disability. Other patients, however, who are competent (those with terminal illnesses and intense, continuous pain) and have the ability to make decisions should therefore be included in the living will protocol. We cannot overlook the fact that all people have the ethical and legal right to refuse treatment after receiving adequate information regarding the nature of the disease, and all aspects of treatment, and who are aware of the consequences of their decisions. We must stress that for competent patients, the decision to accept or reject treatment legally belongs to the patient, and not to the doctor.

Treatment trial period

This situation occurs in patients with high comorbidity. For these patients, the nephrologist can propose dialysis during a trial period to attempt to improve the patient's quality of life, and discontinue dialysis if there is no improvement. This situation requires a high level of doctor-patient communication, and the treatment must be re-evaluated at the pre-established time.

Advantages of advance care planning

Exercising this right has advantages for all involved. The advantages for patients include enabling them to take charge of self-determination helping them to die with dignity and permitting them to choose a trusted representative for making important decisions. It also has advantages for the family, who are greatly aided by having discussed and defined the patient's position before the end of life and are relieved of part of their responsibility for making difficult decisions; in addition, it clarifies dialogue with the health care professional. Thirdly, there are advantages for the health care personnel, because it makes decision-making simpler, ensures that the patient's wishes are respected regarding his/her life and end-of-life plan, and improves dialogue with the family.

To sum up, nephrologists involved in treating patients with ACKD have to face the challenge of developing this right which, although recognised by law, is infrequently exercised due to being largely unknown by patients and health care professionals. Nephrologists should assume an active role in recognising this right. This is a challenge, but if we meet it, we will increase our patients' autonomy and magnify their ability to choose. We must develop protocols for advance care planning, improve the training and involvement of health care personnel and develop information systems to enable the practical application of patients' advance decisions.

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