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Dialysis and conservative management: ethical and deontological issues in the decision-making process

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Abstract. Hemodialysis, peritoneal dialysis and conservative care are nowadays the main treatment options to help persons suffering from advanced kidney diseases. The Authors intend to deal with ethical issues concerning decision-making process about these treatments. Data confirmed that among patients who have the choice between two medically accepted and available options that are believed to have a chance of promoting the patient's welfare some patients prefer a treatment option; the other option is the treatment of choice for the others. In decision-making process, a prominent role must be given to patient's values and his/her judgment about the impact of the treatment options on his/her quality of life, in personal assessment of benefits and burdens. Thus, share decision-making is the recommended model for decision-making in this context; the physician has the important role to guide this process, ascertaining the patient's preferences and personal values.

Key words: decision-making process, communication, informed consent, advanced kidney disease, dialysis, conservative management.

Introduction

The development of increasingly refined technologies has made accessible treatments allowing the survival to a high number of uremic patients (1). However, the use of these techniques implies significant ethical and deontological implications, including the decision-making relating to treatment options and to the patient central role. In this context, the concept of "quality of life" takes on a central role in conducting care choices based on the personal, family and social life of the individual.

Choices promoting patients quality of life can not be separated from the specific evaluation of the single case, both from the clinical point of view and from the subjective dimension. The quality of life is not predictable, because the individual component is a priority in defining expectations and the perception of quality of life (2). The decision-making process related to treatment needs to be focused on the principle of therapeutic proportionality. This principle is based on a prior assessment of the balance between potential benefits and possible risks.

Furthermore, the dialysis treatment is an essential care instrument in nephrology. The discussion about its implementation in a specific case must also consider the clinical status and the intention of the patient: i) a patient can not tolerate the dialysis, ii) for another patient this treatment can not ward off death and iii) for another patient therapeutic alternative options can be considered. The dialysis allows the survival period of the uremic patient; however, it involves symptoms and problems that have an important effect on the patient quality of life: fatigue, fluctuations in blood pressure, dizziness, cramps, related problems and complications for the placement of vascular or peritoneal access, depression, difficulties in time management.

Dialysis awakes ambivalent feelings in patients and in their family: the reassurance at the prospect of continuing life and the discomfort for the total dependence that binds the patient to the dialysis itself (3). Decisions in nephrology should be the result of a shared decision-making process (4,5), that promote both the patient health and its decisional autonomy. Knowledge is a fundamental

prerequisite to the exercise of the right to self determination. The patient must be informed about the treatment or alternative treatment options available, the method of execution, the expected benefits, the possible risks, disadvantages, complications, the consequences of the possible choice to refuse treatment indicated, the possibility of withdrawing the consent, the assistance and support of physicians in case of treatment refusal. This information will allow the patient to assess the compatibility of each possible choice with its own reference values, their beliefs and then to express a conscious choice.

In this perspective, physicians play an important role as guide and orientation, but also the enhancement of the patient own preferences (5).

In a recent document, the National Bioethics Committee (NBC) (2008) pointed out:

"Firstly, the wish to avoid undergoing a health treatment can be brought back to two fundamental hypotheses: i) when the treatment has not begun yet and the patient refuses to undergo it; ii) when the treatment has already begun under doctor's responsibility or the responsibility of a medical team, therefore the patient shows the intention to renounce it when the patient-doctor relationship is in fully developed".

The document continued: "The issue of the conscious refusal/renunciation to medical treatment can give rise to different issues according to the particular context that surrounds it. Various factors come into play: from the nature of the pathology the patient is suffering (light, acute, chronic etc.), to the typology of the proposed treatment (of brief or long length, invasive or non-invasive, statistically efficient or poor/uncertain efficacy, pharmacological or surgical, such that it requires hospitalization or not, etc); from the accessibility of the medical and welfare services to the quality / quantity of the available resources; and still, the existential situation the patient find him/her going through (situation that can in itself be quantified differently according to a variety of parameters: the age of the patient; the context of his/her family, as well as the socio-cultural, economic and ethical contexts; the health and welfare context within which he/she should receive the treatment etc.).

The document highlights: "I cannot see any ethical and legal reasons that are contrary to the decision of a patient that, finding himself/herself in dialysis for a time without improvements and without decline, feeling as extremely painful and heavy the situation of total dependence, and having the doctor's confirmation that the situation is not reversible, would avoid the therapy or ask and obtain its suspension, even in the certainty that the outcome is lethal."

Material and method

In order to investigate these issues a research was started (after Ethical Committee's favorable opinion) in the Ma.Re.A (Advanced Renal Disease) Nephrology Department of Spedali Civili di Brescia.

This perspective research was carried out by filling a form for each new patient access. This study lasted for one year. Subjects were uremic patients, over 18 years of age. This form is composed of a part to be completed at the first access, a part related to the third visit, and a part related to the revaluation after three months from that visit. The form collects information about sex, age, diagnosis, treatment (dialysis and/or conservative therapy) and preferences expressed by the patient during visits.

The research also provided an update (fourth phase) in patients non-responsive to conservative therapy after a year of treatment, when a switch to the dialysis therapy becomes necessary.

Results

During the study 77 forms were compiled (44 men, 33 women). Patients predominantly belong to groups 61-80 years (36 cases), more than 81 years of age (23 cases), 41-60 years (15 cases); 3 patients are younger than 40 years.

In this study, 70 patients are fully capable, and in most cases (60 patients) they were accompanied to the hospital by a family member or a trusted person; 7 patients were partially capable and all of them were accompanied to the clinic by a family member or a trusted person.

Only 64 of the 77 patients included in the study filled the form in the part related to the third visit, and only 46 patients were able to upgrade the board in the part related to the revaluation after three months from that visit. This is essentially due to functional deteriora-

tion resulting in the beginning of the dialysis treatment (10 patients) or of conservative treatment (4 patients), death cases (8 patients), improvement of functional situations (2 patients), patient transfer to another hospital (3 patients), failure patient presentation to the scheduled visits (3 patients), intervened transplant (1 patient).

In the first phase, 39 patients had the clinical indication to dialysis, 7 patients to conservative treatment; both dialysis and conservative therapy could be indicated for the remaining 31 patients. For one of these last cases, physicians preferred conservative therapy, because of his pluri-pathologies and social issues. He was an eighty-one years old man, partially capable, accompanied by his brother.

These indications are mostly confirmed at the third visit; the evolution of patient's conditions caused some clinical changes during re-evaluation three months after the third visit. At the time of the third visit, almost all of the patients involved appears to have accepted the proposal to treatment submitted by the treating physician. One patient did not express any choice; a patient refused the proposed treatment.

All 33 patients expressed their consent to the dialysis treatment proposed: in particular, 18 patients indicated a preference for the hemodialysis technique, 13 for peritoneal dialysis. 5 patients candidate for only conservative therapy accepted the treatment, while one patient, ninety-four year old, capable, accompanied, rejected the proposal, because of the difficulty in following a strict diet; the person concerned would have rather given his consent if the proposed treatment was dialysis. With regard to 24 patients to whom was envisaged in the alternative dialysis/conservative therapy, 13 have expressed the consent to dialysis (4 expressing a preference for hemodialysis and 8 for the peritoneal dialysis), 3 have given consent for the conservative therapy, a patient has given consent for both treatments, and 7 patients expressed a preference for conservative therapy, with the availability to the dialysis treatment, in the case in which the first treatment hypothesis was not feasible or fails.

During the revaluation, three months after the third visit, in the majority of cases (40 patients) the original clinical indication was confirmed.

Relating to patients' choice, one patient expressed a different preference than dialysis method, one patient specified the preferential dialysis method; two patients with indication to both therapies, changed their choice in favor to conservative treatment.

None of the enrolled patients expressed the necessity of transferring, over a year after enrollment, from conservative therapy to the dialysis treatment.

Discussion

Choices expressed by patients during medical examinations reveal that they are in accordance to the treatment proposals submitted by physicians. Furthermore, the different choice of patients in front of the possibility to choose between two different types of treatment for the same illness (dialysis treatment and conservative therapy) or their decision to change the treatment in time, in relation to the type of treatment or in relation to the specific implementation of the dialysis (hemodialysis or peritoneal dialysis), highlight the different perception of the impact of these important therapeutic treatments in the personal, family, social life of each individual.

The refusal of dialysis treatment could be put in relation to the greater impairment of quality of life, a concept whose determination is essential in reference to the different attitude of the individual involved (6).

Some authors (7-11) identified the most frequent reasons underlying choices of patients. Older patients could not probably choose dialysis treatment for these reasons: their advanced age and the perception that it is a treatment for younger people or in better health condition; the difficulty to go to the hospital three times a week; the distance of the hospital from home; the fear to depend on relatives; the loss of autonomy; the burden of treatment, both for transfers and comorbidity etc.

On the one hand, the important limitations that the dialysis treatment involves determining changes in daily life; on the other hand, the choice of accepting this proposal is justified in patients who express the desire to continue to appreciate what life offers, the chance to prolong life, perhaps waiting for a transplant, the ability to assist a partner or a sick or disabled child.

In this context the establishment of a therapeutic trusted relationship is fundamental, through interviews that allow the patient to express his doubts concerns, preference to physicians, and to receive the necessary

information to form their will. Only in this way every choice is actually reasonable and informed.

The choice of the type of dialysis therapy should result from a shared decision-making process, based on information and communication with the patient. In fact, factors that can direct the choice between hemodialysis (passive treatment, to be performed three times a week) and peritoneal dialysis (workable by the patient at home) are different: age, distance from the hospital, family situation (12-13).

Elderly uremic patients often suffer from co-morbidities such as diabetes, heart failure, vascular disease. In these cases, the decision-making process may also extend to the conservative diet (14-15) that can not be defined as the absence of dialysis treatment. In fact, the conservative diet implies active management of the disease, for example through the treatment of anemia, acidosis, or fluid balance or supportive therapies. The goal should be to delay the need to start the dialysis treatment.

Evidently, also the decision-making process to conservative therapy for a patient should take into account the variables of the case, the prognosis, the possible negative effects of a possible dialysis treatment, patient preferences, his lifestyle, his concept of quality of life.

Conclusions

In this research, only one refusal to the conservative therapy proposed was registered; no patient refused the hypothesis of dialysis treatment proposed by the physician as the sole therapeutic hypotheses.

In the presence of both therapeutic possibilities (dialysis and conservative treatment), the majority of patients preferred the dialysis therapy compared to that conservative. However, conservative treatment was substituted by dialysis in case of its failure.

These different choices confirm the need to contextualize the decision-making process in a context of a confident doctor - patient relationship.

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