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# Psychological and Ethical Aspects Related to Dialysis

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*Abstract: The development of new medical technologies and drugs has led to the possibility of prolonging the lives of many patients suffering from chronic diseases. In the last decades, dialysis and transplant have been subject to bioethical criticism, adding psychological, social, cultural, religious or economical points of view. If the medical goal refers to the length of the survival, the patient is interested by its quality. Autonomy, social integration and work are parts of a normal life. Apart from these aspects related to quality of life of patients' needs, society adds its own. Numerous disputes referring to the effectiveness and cost related to cover the expenses with kidney chronic disease patients. The paper presents different approaches of this topic in the scientific literature, identifying if medical guidelines must be applied for all types of patients, or they should or may be adapted for individuals or smaller groups.*

*Keywords: kidney chronic disease, ethics, dialysis, transplantation, patient.*

## Introduction

For more than two decades, the wide-spread patient-centered care has promoted patient's autonomy. In case of patients with chronic disease,

health care professionals must share the decision making process, providing to patients and their families all the information needed for making the best decision. Share decision making is the optimal way to assure an informed consent process. Doctor-patient relationships must be characterized by a good communication, which shapes the best treatments proposed by the medical team, the values and preferences expected by the patient; a negotiation reveals the proper alternatives in order to be accepted by both of them (1).

In case a kidney chronic disease (CKD), dialysis and transplant are the treatments provided for the patients, in order to achieve their quality of life and to assure survival. Prolonging life using dialysis or transplants has raised a lot of dilemma, religious, cultural, psychological or financial reasons being involved. Data revealed

by studies showed that rates for dialysis and transplants are not similar in different countries. Cultural differences regarding stopping dialysis are registered and explained by some studies. In the Western countries, stopping dialysis is directly related to age. In the Japanese culture, it is inversely related to the same variable. Japan has a lower rate of transplantation, it seems like the religious and cultural mixture hindered the increase of rejection of organ donation (2).

Kidney disease is “common, harmful, and treatable” with a consequent impetus on kidney disease screening, detection, surveillance, prevention, and research (3). Over the last 50 years, kidney chronic disease has pushed the medical industry to develop and high profits were registered. In the United States, the prevalence of CKD in adults may be as high as 13.1% of the population (4). The constantly increasing costs for dialyzed patients were subjects to many studies focusing on ethical aspects related to this kind of treatment. Higher costs supported by society, higher incomes for industry and non-ethical behavior of nephrologists (like trying to recruit patients for their own clinics) were pointed by research and discussed by professional in this area. Social, ethical, and economic relationships among dialysis patients,

nephrologists, dialysis providers, and third-party payers were identified, described and analyzed, in order for better policies to be proposed (1, 5, 6).

In the case of kidney chronic disease and dialysis treatment, refusal is usually leading to the end of patient’s life. Despite optimism regarding future medical discoveries, according to Moss, the application of the ethical principles of respect for patient autonomy, beneficence, non-maleficence, justice, and professional integrity, and the ethical process of shared decision-making must represent important issues to be discussed in the process of considering starting, withholding, continuing, and stopping dialysis. Patients and families must be involved and become members of the team. All of them must take part in the decisional process, in order to identify when the burdens of dialysis can be predicted to substantially outweigh the benefits (7). In 1991, the Institute of Medicine Committee to Study the Medicare ESRD Program recommended the development of a clinical practice guideline. The members of the committee appreciated that were “an increasing number of [dialysis] patients with limited survival possibilities and relatively poor quality of life.” Apart from patient autonomy and the principles of non-maleficence and beneficence, an acute recognition that

health care financial resources are limited directed the bioethical discussions to the topic of the fair allocation, highlighting the importance of distributive justice (8).

In 2005, the World Health Organization (9) emphasized the importance of controlling chronic non-communicable diseases as a neglected global health priority. In 2007, the U.S. Renal Data System projections estimated that more than 500,000 people will undergo dialysis by 2020 with an additional 250,000 living with a transplant (10).

Kidney chronic disease is a highly prevalent disease with high collective costs and important public health consequences. Despite advances in the technology of dialysis, mortality in patients who develop acute renal failure remains high. Decisions to withhold or withdraw dialysis in seriously ill patients are difficult for all partners involved: patients, families, and health care providers. The clinical practice guideline, *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*, provides evidence-based recommendations having the purpose to aid nephrologists in discussions and the process of medical decision-making about starting and stopping dialysis. None of the approaches is easy. None of them could be taken unilaterally.

### **Dialysis dilemma**

Although dialysis can extend life, there is substantial mortality rate associated with this method, studies proving that about 25% of patients die within their first year and 60% at 5 years (11).

A new model proposed by Vandecasteele & Tamura in 2014 (12) presents three types of dialysis. The first type is dialysis as bridging or long-term maintenance treatment. It is provided for patients considered to have a good prognosis and whose goal is transplantation or long-term maintenance dialysis, preferably self-care. The second is dialysis as final treatment destination, referring to patients with a low probability of recovering independent social functioning and those at high risk of imminent death or recurrent hospitalizations. The third type is dialysis as a final destination - active medical management without dialysis - refers to patients who have high levels of co-morbidity or unclear prognosis be managed with the understanding that they are undergoing palliative dialysis. For some patients, the disease and its treatment limit their social and professional integration and they are not eligible for transplantation (13). In such conditions, where poor survival and low quality of life define the situation of some patients, applying

the same medical standards to all patients is nurturing ethical dilemmas.

The appropriateness of dialysis has been subject for numerous disputes, even if it is about infants and children, old age, mental disabilities or other co-morbidities or palliative stages. The border between doctor's decision and patient's choice is not settled half way. Many criteria must be taken into consideration in favor or against dialysis use (14, 15).

Co-morbidities, like mental diseases, determine a lot of controversial opinions regarding the most appropriate medical care plan for this kind of patients. They have a decreased ability to communicate symptoms during treatments or dialysis or to comprehend diet and follow indication regarding medication restrictions. Factors refer to the current societal trend toward technological imperative (a term shaped in 1968 by Victor Fuchs pointing to the fact that dialysis is being overused in patients who are unlikely to benefit from the treatment because of societal expectations and pressures), social costs, premature fatalism, survival benefits, quality of life and the implications of providing care to patients who are unable to express their tolerance for symptoms associated with the treatment or lack of treatment (16, 17).

Another aspect revealed by some studies proved that nephrologists are under emergency unit staff pressure, being expected to give such assistance. Intensivists often expect that consulted nephrologists will provide dialysis when asked to do so, without considering whether it is likely to benefit the patient and therefore it is medically and ethically appropriate (18).

A recent article has launched an acute request to the nephrologists. In "Survival by Dialysis Modality-Who Cares", published in January 2016, the authors are asking doctors and researchers to stop studies on dialyzed patients. In their opinion, over the years all studies proved similar survival between patients undergoing peritoneal dialysis and those receiving conventional hemodialysis three times a week, with differences only for specific subgroups. The authors suggest that expected survival is a variable with no importance compared to the quality of life and their unmet needs. Not just duration of survival is a major priority but the quality of survival, too (19). A study found that 63% of patients who chose to start dialysis regretted the decision, and 52% stated they initiated dialysis owing to the "doctor's wish" (20).

Other studies shaped the personal reasons regarding refusal of

treatment: the desire not to burden others and the personal experience of a deteriorating quality of life. These are important elements in the decision to stop or decline dialysis (21).

### **Dialysis for children and adolescents**

Since 1960, the majority of pediatric patients have undergone dialysis. Some studies offer controversial approaches related to the quality of life of certain groups such as children with multiple co-morbid conditions, children and families with few social and economic resources, and neonates and infants, presenting the dilemmatic decision of whether to proceed with dialysis (22).

In case of adults, refusal seems to be carried by the patient himself. For children and especially adolescents, things change, because they are not the only ones charged with treatment and dialysis. Parents and caregivers are part of the team. In the case of children, the paternalistic way of treatment is more often used and children find themselves more obliged to adopt a decision regarding their disease.

In what concerns adolescents, things seem to me more complicated, because the physical and psychological transformations of the patients have a great impact on their decisions. At this age, body image and social interactions are more likely

to guide a teenager's life than reasons related to health.

The restrictive therapy including dialysis, exercise, diet, fluid restriction are frustrating and keep them away from their group of peers. The limits imposed by the physical activity or going out to have a drink with their friends increase the rates of depression, anxiety and suicidal thoughts. Adolescents should be part of the team and, even if most of the time they follow their parents' decision, their implication in the treatment must offer them the certainty about their degree of control. Control does not refer only to decision-making, but also to taking medication, being involved in the decision of choosing treatments, measuring the amount of liquids and paying attention to diet. The desire to be involved in the decisional process changes over the years, the older the patient is, the more duties and power to decide are present (23, 24). Coping with problems related to dialysis demands a lot of effort, withdrawal from dialysis and refusing treatment sometimes being an issue to be discussed.

### **Refusal of treatment**

Refusal was defined as the overt rejection by the patient, or his or her representative, of medication, surgery, investigative procedures, or other components of hospital care

recommended or ordered by the patient's physician. Applebaum and Roth (25) identified that reasons for refusal were usually multifactorial, the most common causes being: organic brain syndromes, type of personality, and failure to inform the patient about the purpose of the treatment or procedure. The study revealed that 15% were potentially life endangering, the majority of cases being related to refusals with minor impact on life (refusing medication, diagnostic tests or adjunctive care). For example, no refusal was referred to surgical intervention.

The most common physician responses to refusal were: re-informing patients (28%), forcing treatment in incompetent patients (14%), permitting proper refusals (12%), and forcefully persuading or coaxing (10%). The most common outcomes of refusal were: no treatment given (34%), delayed acceptance (31%), and forced treatment (17%)

Conneen et al. (26) identified, in their study during a period of seven years, four types of patients among those who withdrew from dialysis: patients suffering from a terminal illness, patients suffering from dementia, patients presenting progressive disability and patients with no other than end-stage renal failure. The study presented the

hypothesis that some of the deaths related to this kind of decision might have been preventable. In this case, authors presented as a conclusion the fact that behavioral expert intervention is very important for guiding and treating patients on chronic dialysis. Many studies shaped the importance of psychological intervention for patients who want to cease dialysis. Related ethical problems rose from this situation: the first of those mentioned was referring to the right of the patient to decide about continuing or not the dialysis program. The other one referred to the influences that the medical team could have on the patient's decision, taking into account that patients have their own experiences and life context and they can appreciate by themselves what is right or wrong.

Refusing treatment seems to be related to the communication between doctor and patient or family (e.g.: the illness was not clearly explained). Another aspect is caused by the lack of trust in the medical team and the opinion that nothing good is going to happen in their future life related to their disease. An important aspect explained by Applebaum and Roth is that the refusal of treatment is most common to patients suffering from hospital fatigue syndrome, meaning that patients who registered many weeks of hospitalization were more likely to tend to refuse medical

treatments. Most of them expressed their desire to end medical treatment or to go home and return for new investigation after a period of time spent at home (25).

Every decisional process that involves a patient and a medical team should be doubled by psychological assistance. Any decision taken will activate the patient's coping mechanisms. The motivations to start or retire from dialysis are the results of personal analysis, psychological traits, family structure, professional duties, and specific factors related to age, gender, mental health, life experience or expectations. Personal filters will sift life choices and decisions could change over the years, the psychological interventions being proved to empower the patient's resources to manage the disease (27-31).

Ethical or unethical, dilemmas appear on both sides. No patient or medical team could guarantee that decision to remain solid over the years.

### **Conclusions**

As medical technology evolves in a continually changing environment with personal and societal values, a more understandable attitude considering ethical values during their medical intervention enables the clinician to systematically negotiate

and optimize difficult ethical situations. The ideal therapy does not exist. The main goal is to assure the best for the patient, available at a present moment and provide assistance to assure a high quality of life. The best therapy is not in guidelines, but guidelines could direct the doctor to propose the best therapy and the patient to deal with it.

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