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Can you explain and modify the differences in the perceived quality of life, between patients incident and prevalent in dialysis treatment?

¿Se pueden explicar y modificar las diferencias en la calidad de vida percibida, entre pacientes incidentes y prevalentes en tratamiento de diálisis?

In the medical literature, there are frequently publications that refer to the quality of life of patients on dialysis. However, it is not usual to find a work that demonstrates, with statistical strength, the difference in the perception of the quality of life among the incident patients, who are studying the first three months of their hemodialysis treatment, and prevalent, who have overcome this term, in many cases with prolonged periods. This difference, precisely, has been demonstrated in the enlightening article prepared by Varela and colleagues, entitled “Quality of life in incidents vs. prevalent patients. Is there a difference in the quality of life?”

In this way, there is a strong need to find explanations that make it possible, in the first instance, to understand the phenomenon and, subsequently, act and provide the sanitary solutions that allow these results to be modified. For this, it is wise to remember the historical and evolutionary path achieved by humanity in the control of diseases and to confront it, in general terms, with the quality of life reached by the different population masses. Fundamentally, in the most unprotected regions of the globe and, especially, in many regions of Latin America and the Caribbean.

We know that medicine and medical treatments have evolved over the centuries and transformed rudimentary treatment techniques, of traditional origin, into the great therapeutic achievements that scientific knowledge has incorporated. These continue transforming and extending the life expectancy of the human being also today, at the beginning of the XXI century^{1,2}.

We continually attend, absorbed, to new developments in pharmacology and biotechnological research, whose tenuous limits impose, necessarily, the essential containment of bioethics. Simultaneously, epidemics are controlled, disease control is improved, life expectancy is prolonged, but diseases and chronic patients, among them, patients with chronic kidney disease, also grow exponentially.

Ironically, these novel situations revealed the inequality of the current world. In particular, the profound differences in access and quality of life among those populations with adequate living standards, legal inhabitants of countries and/or developed regions, compared to the large population masses who live in conditions of sanitary vulnerability, or even extreme poverty, imply differences in access to care, including the absence of educational strategies for the promotion and prevention of diseases as well as self-care for the restoration, recovery and rehabilitation of health.

The absence of accessible infrastructure conditions the communities to arrive late to health care. However, those of us who have worked in the field for many years have been able to appreciate that, even when the health center is available, the most solid barriers to access to the health system are ignorance, severe educational deficiencies and, often, culturally models of some areas of Latin America and the Caribbean, where “witches”, “healers” and similar are used³⁻⁵.

Latin America, at the regional level, is a clear example of these great differences, which are growing when, within the national territories, there are concentrations of population with enormous distributive differences in the available resources. In similar situations, society faces the dilemma of the allocation of economic resources, usually scarce in less developed countries.

Chronic kidney disease has a negative effect on the quality of life, the economy of families and health systems, depending on the rate of progression of the loss of renal function. Rapid progression leads to in-

creased costs, reduced quality of life and premature death. Mortality in stage 4 (glomerular filtration rate of 30-15 ml/minute) is higher than 45% ⁶, which adds to the deaths that occurred in the previous stages of the disease, almost always due to cardiovascular causes. Survivors, the remaining percentage of stage 4, will enter dialysis, usually in emergency situations and/or clinical decompensation, without prior anticipatory or preparatory controls for substitution therapy, whichever is chosen. In such cases, therapeutic salvage techniques are required, such as the placement of transient catheters for emergency hemodialysis. This explains sufficiently, the difference in quality of life and survival of these incident patients, of great clinical instability, and without the adequate psychological preparation, neither for their illness nor for this new situation of dependence on technological processes as life support of his existence⁷.

In this context, it is easy to understand that quality of life, as a holistic and absolutely subjective concept, cannot be comparable between people from different ethnic groups, countries and population groups, with their particular conditions. Even within the same country, there are asymmetries. I consider it important to reaffirm conceptually that it is a mistake, in language, to declare a patient terminal when he is in advanced stages of his kidney disease. It is advisable, then, to modify in the medical nomenclature the concept of terminal chronic renal failure for patients in stage 5 D.⁸, and transform it for permanent chronic renal failure. This would also generate a positive externalization among health funders, since the permanent ceases to be terminal.

When patients are controlled early and can achieve regression and/or remission of kidney disease, they begin to modify the alternatives of global control of homeostasis, in its biological and emotional aspects. Thus, the subjective perception of quality of life is impacted, beyond the objectivity of altered clinical-chemical values. In addition, there are also schemes for the absence of systematized health programs articulated with society, under the concept of transdisciplinarity, with health professionals committed to their development.

Therefore, it is necessary to review, in each country, the financing policies of the health programs and the macro-budgetary allocations secondary to differentiated population groups with specific coverage needs. For example, in the programs articulated between renal health and other prevalent chronic pathologies, with a holistic and integral conceptualization⁹.

Latin America, through the Latin American Society of Nephrology and Hypertension, has been a pioneer in propel and promoting these public policies, providing evidence of the need and importance of acting comprehensively in the prevention and control of kidney diseases¹⁰⁻¹². These efforts have not been crystallized nor included in the public policies of the countries, with the result of a lower quality of life in the incident patients than in the prevalent ones. However, at first glance, better results would be expected, such as the entrance of well-compensated, controlled patients with permanent vascular access that is permeable and ready to be used. At least, failing that, prepared to start a peritoneal dialysis therapy or even a kidney transplant, in the countries where the legislation allows it.

Our considerations would be incomplete if the importance of the educational role of the health team was not highlighted. It is time that the new training models, still focused on a biomedical model, focus on a biomedical, ethical, psychosocial and economic understanding. It is necessary a global conception that seeks to achieve and maintain the quality of life, through the management and stimulation of the knowledge imparted and, fundamentally, the concern for the excellence in the quality of the practice. This last aspect must necessarily extend to the quality of interpersonal relationships, whether they are doctor/patient, doctor/family, or doctor/community. Likewise, the teaching of transversal generic competences should be included in the university curricula for teaching¹³.

Let us return, at this point, to the initial question: can the differences in the quality of life perceived be explained and modified between incidents that are prevalent in dialysis treatment? We have seen, in this

exhibition, the conditioning factors that justify such a difference. However, the most important thing to note is that, when designing and executing systematized programs, these differences can be modified. This is the case of what was published, in Colombia, by Dr. Gustavo José Aroca Martínez, with a regional risk management model for lupus nephritis, but assimilable to all renal pathologies, in its trans-disciplinary work dynamics¹⁴.

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