Advances in Ethical, Social, and Economic Aspects of Chronic Renal Disease in Bolivia

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ABSTRACT

Since 2005, great progress has been made in health care provision to patients with terminal renal failure in Bolivia. Access to dialysis and transplantation is regulated by the Ministry of Health, based on clinical criteria, applied equitably, without favoritism or discrimination based on race, sex, economic means, or political power. Until December 2013, there were no restrictions in dialysis and transplantation in Health Insurance institutions, but they covered only 30% of the population. Now the remaining 70% has access to free dialysis funded by the communities where patients live, with funds coming from the government and taxes on oil products. More than 2,231 people are getting dialysis, reaching a population growth of >60% annually. The number of hemodialysis units has increased by >200% (60 units), making access easier for end-stage renal failure patients. Treatment protocols have been drawn up to guarantee the best quality of life for the patients. The Law on Donation and Transplantation was enacted in 1996, and Supplementary Regulations were enacted in 1997 with various amendments over the past 5 years. A National Transplant Coordination Board, working under the National Renal Health Program, supervises and regulates transplants and promotes deceased-donor transplantation in an attempt to cover the demand for donors. Rules have been drawn up for accreditation of transplant centers and teams to guarantee the best possible conditions and maximum guaranties. Since January 2014, the National Renal Health Program has been providing free kidney transplants from living donors.

THE CONCEPTS contained in this communication were initially presented by the author in July 1991 at a cycle of conferences organized by the Court of Justice of Cochabamba, about medical issues that should be legislated in Bolivia. Later, the paper was submitted to the leaders of the political parties represented in Congress at the International Symposium on Prevention and Treatment Chronic Renal Failure in Developing Countries, held in Cochabamba in March 1993, sponsored by the International Society of Nephrology and the Latin American Society of Nephrology. In 2002, the concepts laid out this paper were submitted to the leaders of the political parties for consideration, to be taken into account in their government programs vis-a-vis the elections held in June 2002. Since that time, and particularly in the past 10 years, great progress has been made in health care provision to patients with end-stage chronic renal disease in Bolivia.

TERMINAL CHRONIC RENAL DISEASE IN BOLIVIA: AN IMPORTANT HEALTH PROBLEM FOR THE 21ST CENTURY

Since, over the past years, transmissible diseases and maternal and child morbidity have decreased, there has been an increase in the prevalence of chronic degenerative diseases, including diabetes, hypertension, and progressive kidney failure. The incidence of chronic renal disease that requires dialysis and transplantation is estimated at 160 new cases per million inhabitants per year. This means that, if Bolivia has 10 million inhabitants, there are over 1,600 new patients with chronic renal failure that require renal

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replacement therapy. These 1,600 new patients, added to the already existing cases that are still alive, represent a large group of patients whose comprehensive health care should not be ignored and, on the contrary, must be taken into account by national health authorities and society as a whole.

A patient with chronic renal disease that has reached the terminal phase (stage 5) has only two options: to die or to go on living. Medical conditions, family support, the will to live, and economic support permitting, the second option—to go on living—is the right one, and then chronic dialysis and a kidney transplant will have to be considered as the existing alternatives.

In the past 70 years, extraordinary scientific advances and notable technologic accomplishments have been achieved in the field of chronic renal disease that, despite making comprehensive health care of patients complex and costly, have made possible the physical and social rehabilitation of hundreds of thousands of sick people around the world, including Latin America and Bolivia, in the past 10 years [1].

The yearly cost of hemodialysis in Bolivia reaches $20,500 USD, including additional medication that consists of erythropoietin to correct anemia, calcitriol to prevent skeletal complications, blood pressure medication, and calcium, folic acid, and vitamin B complex supplements.

The cost of a kidney transplant in the first year reaches $14,000.00 USD, including patient and donor assessment and conventional triple immunosuppression with prednisone, mycophenolate, and cyclosporine. In the event that rejections occur that require the use of other therapeutic alternatives to reverse them, such as thymoglobulin, intravenous immunoglobulin, or plasmapheresis, or to prevent them, such as basiliximab, the cost can rise by an additional $5,000–$10.000 USD.

ADVANCES IN THE LEGAL ASPECTS OF DIALYSIS AND TRANSPLANTATION

Unfortunately, owing to the cost of high-technology programs, such as dialysis and transplantation, to select patients with stage 5 chronic renal disease for replacement therapy, a purely economic criterion had taken precedence up until 10 years ago, with the exclusion of ethical principles of higher hierarchy, such as the patients' age and intelligence, their cultural and environmental condition and their motivation to follow the program, the availability of technologic and human resources in the area, the therapeutic modalities to choose from, the emotional stability of the patients and their families, the soundness of the family setting, and the availability of suitable and motivated donors.

Until 2003, dialysis and transplant programs in Bolivia benefited a few patients under the age of 60 years, who did not present any clinical contraindications and who had Health Insurance support. However, in the past 10 years, access to programs has been regulated by the Ministry of Health, based on clear and objective medical criteria, applied equitably, and with extensive knowledge not only by the patients and their next of kin, but also by the public in general, without favoritism or discrimination, as mentioned earlier, based on race, sex, economic means, or political power [1,2].

In Bolivia, where the availability of resources for health never sufficed to cover demand, up until 3 years ago nephrologists both in private and in state-run or Health Insurance institutions, faced the decision every day of "who will live when not everyone can," because we had scant life-saving resources available.

In the 1960s, during the initial phase of the Terminal Chronic Renal Disease Program in the United States, given the shortage of skilled staff, dialysis machines, and the lack of organs donated for transplants, Medicare decided that the potential candidates had to be assessed by a selection committee that decided who were the most suitable patients to benefit from the new technology. The increase in available resources in the past 40 years allowed a greater liberality in the selection criteria and patients with other systemic diseases, including AIDS, patients with mental disorders, women, the elderly, poor, black, Latino, and other minority racial groups, which would have been considered as "unsuitable" to go on living in other times, are presently accepted without restrictions.

For the past 10 years, there have been no restrictions in dialysis and transplant programs in Health Insurance institutions in Bolivia, but they covered only 30% of the population. Nonetheless, recently, thanks to Law 475 on Comprehensive Health Insurance enacted in December 2013, the remaining 70% of the population, which until then lacked insurance, now has access to free dialysis funded by the communities where patients live, with funds coming from the government and a tax on oil products [3,4].

According to data of the National Renal Health Program, over 2,231 people are currently getting dialysis therapy in Bolivia, reaching a population growth of >60% annually. Dialysis has evolved a lot in the past 10 years. The number of hemodialysis units has increased by >200% (60 units), making access easier for the population that suffers this clinical condition. Standards regulating the infrastructure conditions and diagnosis and treatment protocols for patients with kidney disease that require dialysis have been drawn up to guarantee the best quality of life for the patients.

Practically all countries have laws and supplementary regulations that govern the performance of organ and tissue transplants, organ procurement, and the conditions required for their implantation. In Bolivia, that law was enacted as number 1,716 in November 1996 [5]. Supplementary regulations were enacted in June 1997 [6], with various amendments throughout the years, particularly over the past 5 years [7,8].

From the organizational viewpoint, and according to the provisions of the law's regulations [6–8], we have presently a National Transplant Coordination Board, working under the National Renal Health Program, and 3 Regional

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