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# DOCTOR-PATIENT RELATIONSHIP IN CHILDREN'S CHRONIC KIDNEY DISEASE AND ITS IMPORTANCE FOR THE QUALITY OF LIFE FOR THE DIALYSIS PATIENT

Magdalena Starcea<sup>1</sup>, Magdalena Iorga<sup>2,3\*</sup>, Laszlo-Zoltan  
Sztankovszky<sup>1</sup> and Mihaela Munteanu<sup>3</sup>

<sup>1</sup>Gr. T. Popa' University of Medicine and Pharmacy, Gen Berthelot 2, Iași, 700483, Romania

<sup>2</sup>Technical University Iasi, Department of Teacher Training, Bd. D. Mangeron 71, Iasi, Romania

<sup>3</sup>Emergency Hospital for Children 'Sfanta Maria', str. Vasile Lupu 62, 700309, Iasi, Romania

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## Abstract

Chronic kidney disease (CKD) is defined as an irreversible loss of renal functions, which results in a decreasing glomerular filtration rate. Chronic kidney disease is prevalent in 18.5–58.3 out of every million children around the globe. The incidence of CDK varies for different age groups, between 19-33%. 70% of children suffering from CDK develop terminal stage by the age of 20. Except renal transplantation, which is desideratum of life of these patients, the dialysis represents the only way to stay alive. A transplant patient will not fully meet the WHO definition of health, but will get the chance to enjoy life, so increase the quality of life. In this reason the medical staff who treats chronic patients must to be fully involved into solving his patients' medical and psychosocial problems.

*Keywords:* dialysis, kidney disease, medical staff, patient, quality of life

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## 1. Introduction

Chronic kidney disease (CKD), or, as formerly termed, *chronic renal failure*, is defined as an irreversible loss of renal functions, which results in a decreasing glomerular filtration rate. Its stages are [1]:

- *Early renal failure* (ERF) = the decrease in renal function, with a glomerular filtration rate ranging between 50-80% of normal values;
- *Chronic renal insufficiency* (CRI) = the decrease in renal function, with a glomerular filtration rate between 25-50% of normal values;
- *Chronic renal failure* (CRF) = the decrease in renal function, with a glomerular filtration rate between 10-25% of normal values;
- *End stage renal disease* (ESRD) = the decrease in renal function, with a glomerular filtration rate below 10% of normal values.

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\*Corresponding author, e-mail: magdaiorga@yahoo.com, tel.: +40722800936

The aetiology of chronic kidney disease in children is dominated by obstructive uropathies, renal hypo/dysplasia and reflux nephropathy, followed by chronic glomerulonephritis evolving towards segmental or focal glomerulosclerosis, polycystic kidney disease or autoimmune diseases [2]. Chronic kidney disease is prevalent in 18.5–58.3 out of every million children around the globe. The incidence of the chronic kidney disease varies for different age groups. According to NAPRTCS (The North American Pediatric Renal Trials and Collaborative Studies), it is 19% for the 0–2 age group, 33% for the 2–5 age group, 17% for the 6–12 age group and 31% over the age of 12. An increased incidence of chronic kidney disease accompanies extreme prematurity [2, 3].

Incidence is similar in the two sexes. 2.7 times more black children reach end stages of the renal disease, on the one hand, because of genetic susceptibility, and on the other hand, because of their socio-economic conditions, which often limit their access to medical assistance. Approximately 70% of children suffering from chronic kidney disease develop terminal stage by the age of 20. Excluding kidney transplants, the survival rate of children who reach end stage renal disease is 80% at the age of 10, with a mortality rate 30 times higher than that of children not suffering from chronic kidney disease. The main cause of death is cardiovascular pathology [2, 3].

Statistic data shows that 5–27% of these children suffer from chronic diseases. For this reason, their risk of developing psychopathological disorders is double/triple, compared to that of healthy children. The quality of life for the families of chronically diseased children decreases continually, due to chronic disease conditions and the stress associated with being a carer (57% of mothers and 30% of fathers develop depression) [4].

## **2. The medical team**

The General Practitioner (GP) has got special status, being prepared to offer primary care. He is the one who best knows the biological features, as well as psychosocial problems of his patient. Each person has the legal right to choose his own GP, a fact that favours trust and good doctor-patient relationships from the start. Interdisciplinary cooperation is the natural result of specialization. It increases the quality of the medical act, but has the disadvantage of exposure to the risk of diluted medical responsibility. The collaboration between clinicians, laboratory doctors, anatomic pathologists and imaging specialists plays an essential part in the success of medical assistance.

The nurse represents the doctor's closest support. At the hospital, the nurse takes direct care of the patient under her supervision, harvests pathological products for investigations, and applies treatments. Nurses acquire more and more knowledge in various domains, being capable of independent activities to the benefit of the patients and relieving doctors of some time-consuming activities, such as getting patients involved in their own treatment. The nursing

activity is extending, more and more, into the area of home care of the chronically ill, of the elderly and of children.

Psychologists are in charge of the patients' psychological evaluation, by establishing their psychological profile. By means of (individual or group) psychotherapy, they get involved in solving conflicts generated by the stress of illness or of hospitalization. Patients, their families and also medical staff exposed to stress equally benefit from the psychologist's intervention.

The social worker solves the patient's social security and financial resource issues, and offers support for his disrupted social relationships (family, school, and workplace).

The priest offers religious assistance, starting from the assumption that ill people are in greater need of spiritual support. As there is a great variety of confessions, the organization of religious service in hospitals must be ecumenical. The spiritual aspect of the patient's life is usually neglected, but a lot of studies proved that incorporating religion and spirituality in patient's treatment helps patients improve their quality of life [5, 6].

The technical staff is prepared to handle the increasingly sophisticated technology used for diagnosis and treatment. The imaging services, dialysis stations and operating rooms are relevant examples of sectors where equipment manipulation and maintenance is important. In contrast to the industrial domain, for instance, technical staff members in hospitals have to be aware that, working with human subjects, their behaviour must be different based on epidemiological requirements, on ethical rules and medical deontology.

### **3. Doctor/medical staff-patient relationship**

The doctor-patient relationship is the central element of medical practice and the means by which medical care is provided [7].

The paternalist type of relationship, in which the patient had perfect trust in his attending physician, whom he considered omniscient and infallible, has gradually been replaced by the partnership, in which the doctor and the patient become the core members of a team formed in order to fight against illness. Within this team, the doctor proposes treatment strategies, while the patient is the deciding factor, choosing the conduct that he deems optimal to his own set of values.

The informed consent signed by the patient represents the legal basis of the medical act – the diagnosis and/or therapy. According to the WHO (World Health Organization) definition, “the aim of the patient's therapeutic education is to help the patient and his/her family understand the illness and its treatment, actively collaborate and learn to maintain his/her capacities needed to harmonize his/her lifestyle with the constraints brought by the illness” [8].

The imperative need for these constraints, which limit the freedom of his/her lifestyle, must be explained and justified by the ulterior reward of a higher quality of life (by avoiding complications and decelerating the decline of

functional capacities), as well as by prolonged life, by comparison with the natural evolution of the illness.

Szasz and Hollender [9] described the first model of the doctor-patient relationship:

- *The activity-passivity model* describes a doctor-patient relationship in which doctors are responsible for carrying out medical interventions, and patients are passive recipients of medical treatment. This type of relationship is considered adequate in case of medical emergencies, when patients are unconscious and therefore lack decision-making capacities.
- *The assistance-cooperation model* implies a doctor who indicates to the patient what he/she should do, and he/she follows the instructions and obeys the physician. According to the authors, this model is adequate in case of serious medical conditions, when the doctor holds the solution.
- *The mutual participation model* refers to a partnership between the doctor and the patient. This model may be applied especially well to manage chronic diseases and in psychoanalysis.

#### 4. Quality of life

Chronic diseases are caused by irreversible pathological phenomena which lead to a deterioration of the body and, ultimately, to death. Medical progress has radically changed the evolution and prognosis of many illnesses, facilitating long-term survival, often with minimal disabilities, which, however, require highly qualified, specific and perseverant assistance. A study carried out by the Public Health Service revealed the dimension of the chronic disease problem: around 50% of the population of the USA suffers from at least one chronic disease, which results in around 95 million patients, of whom a portion have limited activity because of their illness, and 2% are incapable of independent activity [10].

The 'quality of life' notion is equivalent to WHO's definition of health, in the sense of physical, mental and social wellbeing, which, however, is not complete and implies the presence of illness [World Health Organization, WHOQOL-BREF Introduction, Administration, Scoring and Generic Version of the Assessment, 1996, online [http://www.who.int/mental\\_health/media/en/76.pdf](http://www.who.int/mental_health/media/en/76.pdf)].

The modern 'quality of life' concept is defined by the individual's subjective perception of his own health condition, which includes:

- control over symptoms,
- the body's biological functions,
- the role function (the capacity to integrate into a workplace, family, society).

Society secures the material conditions necessary for the assistance of the chronically ill by financing healthcare units (qualified staff, adequate environment and means of investigation, drugs and sanitary supplies), socially

and materially supporting the ill, encouraging and supporting biomedical research [[http://www.who.int/mental\\_health/media/en/76.pdf](http://www.who.int/mental_health/media/en/76.pdf)].

Health programs are complexes of specific measures aimed at reducing morbidity and mortality in a particular pathology, but especially to secure the highest possible accessibility to the optimal therapeutic means available. These differ based on the socio-economic level of the society. For example, the healing rate for children's cancer is 60% in developed Western countries. Worldwide, however, hundreds of thousands of children die from cancer, because only 10% of them have access to adequate treatment.

The behaviour of the chronically ill is decisive in its own treatment; thus, he needs motivation and preparation. He must admit to his illness, accept it, face the crisis brought on by physical and mental affliction and by the altering of his self-image, and become an active member of the treatment team.

Compliance is the patient's observance of medical checks, of the prescribed treatment and diet, and it represents a mandatory premise of therapeutic success.

Communicating the (potentially lethal) chronic disease diagnosis is mandatory in order to ensure the patient's participation in his therapy and treatment.

The environment is the hospital, but an intimate atmosphere is chosen so that the patient and those close to him may openly express their reactions and psychological shock.

The attending physician is responsible for communicating the diagnosis, which is not a mere verdict, but a complex process, to be carried out in successive stages. The doctor must offer his patient a clear image of his illness and its prognosis, and be prepared to offer competent answers to the emerging questions. The tone of discussion should be moderate, optimistic, in order for the patient to understand that the treatment he is to undergo has a curative aim and will improve the quality of his life. In any case, the first reaction is rejection, and it should be respected. Details about the illness are to be provided during the next meetings, in the guise of a dialogue, with answers adapted to the patient's level of comprehension and degree of anxiety.

The chronically ill's adaptation was studied through the interview method by Kubler-Ross [11] who identified five evolution stages.

1. Rejection or minimization of the seriousness of the illness is a normal initial behaviour, because it is a defence mechanism against the shock caused by illness. In this phase, the patient takes part in his treatment passively, but, if his reaction is exaggerated, there is the risk of treatment refusal or non-compliance. For instance, a chronic renal insufficiency patient will accept dialysis, but initially refuses to believe that he will need to undergo dialysis three times a week, for the rest of his life.
2. Searching for information about the causes and manifestations of the illness, treatment options and future perspectives is the second coping mechanism. This moment should be exploited, as the patient is extremely receptive to his preparation for following the right diet, the adequate

treatment and, finally, to the inherent change of his lifestyle. From this moment on, he becomes an active part of the treatment team and acquires his own opinions about his illness, highly depending on the quality of the information he receives.

3. Solace, another coping mechanism, means asking for support and reassurance from medical staff, family and friends. The patient expects to be told his illness will not radically change his life, in the sense of a possible stigmatization. The success of this stage lies on social support.
4. Progressive activity resumption also functions as a coping mechanism. The patient's discovery that he has not lost his dexterities allows for regaining trust in himself, rebuilding his self-image and motivates him to accept his illness and therapy.
5. Readjustment of future plans, taking into account the new situation and its evolution possibilities, allows the patient to confront future complications, being a long-term coping mechanism in the face of irreversible illness.

The model proposed by Kubler-Ross is important for understanding the reactions of the chronically ill and, taking these into account, for satisfying his needs.

Improved quality of life is the objective of assisting the chronically ill and its quality measure. The first contact with the patient has dual purpose: technical and psychosocial. Doctors are generally pressed for time, so the therapeutic doctor-patient relationship is virtually non-existent. Although biotechnology has developed a lot in recent years, more and more patients are in need of psychotherapy, partially because a doctor will spend an average 7 minutes with each patient, whereas a therapist - at least 30 minutes. Competence and patience are the means by which a doctor may earn his patient's trust.

Informing the patient in accessible terminology is the result of a dialogue carried out through successive meetings. The patient's questions reveal his level of comprehension and his need for information, which should be satisfied adequately. The importance of communication with the ill is acknowledged, as the patient must sign an informed consent.

The chronically ill are largely treated as outpatients, or at home, a fact which does not relieve the doctor of responsibility, but makes him share it with his patient. The chronic patient returns to the hospital on a regular basis, for check-ups and treatment. It is important that he perceive the hospital environment as familiar, that he feel like a privileged guest and he be given the possibility to reveal both his strictly medical and his psychosocial problems.

Another typical issue with the chronic patient is related to invasive investigations and treatments. The patient repeats the experience of invasive technique pain and side effects, which may increase his anxiety and repulsion. This is why it is important that all measures be taken for a psychological and analgesic preparation from the first of such experiences, in order for the side effects anticipated by the patient to be minimal. Small concessions made to the patient, such as the time of day, his favourite position and even the person who

carries out the painful manoeuvre, have beneficial effects, contributing to the patient's increased compliance.

In brief, the doctor who treats chronic patients does not have any right to fall into habits; he is fully involved into solving his patients' medical and psychosocial problems and must win them over in the complex treatment process.

The child with a chronic/lethal disease is a special case. Parents are prepared to raise their child and witness the development of his skills until he becomes independent. Understanding the death of a child brings up two major psychological aspects: the perception of death during childhood and the reaction of the family to the child's terminal illness. The child's perception, depending first and foremost on the basic processes of cognitive development (i.e., on age), should be understood and respected.

Children under the age of five do not acknowledge death as an ending, but rather as prolonged sleep, monotonous and uncomfortable, and their anxiety is linked to the separation from their loved ones.

From five to nine years old, the child acquires a new perspective on death, perceiving it as something or someone that can tear him down. Though the child understands death as an ending, he bears a strong ego-protective trait, believing that it may be avoided.

After the age of ten, the child fully understands the concept of death, acknowledging it as something final and inevitable. The child's separation and loneliness anxiety may be diminished by the presence of his loved ones and by intense focus on the present.

In the teenager, chronic disease evokes a pattern of conflict between two antagonistic sets of forces: the former rises from the pubertal transformation that stimulates a behaviour of attempts, expressing one's sexuality and, in fact, the beginning of emancipation; the latter is generated by illness and its repercussions on personal development.

On a psychodynamic level, the situation of the teenager who suffers from a long-evolving chronic disease is very different from that of the teenager who has previously enjoyed perfect health, but now develops a serious, or chronic, illness. In the latter situation, an *affective regression* is often noted, along with self-deprecatory and self-rejective feelings.

In order for the teenager suffering from a chronic disease to enjoy an age-appropriate affective life, identical to his healthy peers, a natural cooperation should exist between teenagers-parents-medical team. The mere covering of medical needs is not enough; discovering the teenagers' wishes and emotions is also necessary.

We may distinguish three health necessity levels for teenagers suffering from a chronic disease: illness-related necessities, adolescence-related necessities and psychosocial necessities, linked to the interactions between the illness, the teenager and his environment.

Parents require psychological support in order to overcome their despair and culpability feelings. Correct information from the medical staff is absolutely necessary for assuming an essential role in the treatment of a terminally ill child.

The medical team's behaviour (doctor + nurse) should be the expression of education and self-education. Medical staff reacts in a very emotional way to a chronic/terminal patient, due to their disappointment with the limitations of medicine and feelings related to the futility of their work. Expressing these emotional reactions must be reduced to a sober compassionate attitude, without reaching indifference, which would be contemptible.

Controlling one's reactions requires timely preparation and is based, firstly, on avoiding to identify oneself with the patient, and secondly, on getting involved in a professional, rather than sentimental, assistance of the chronic/terminal patient.

The medical, social, ethical and moral arguments above support the assertion that renal transplant represents the only therapeutic alternative that may save the end stage renal failure patient.

Extending patients' lives is not everything; this desideratum must be backed by an optimal quality of life. A transplant patient will not fully meet the WHO definition of health, but will, however, get the chance to enjoy life even under the restricted conditions of an immunosuppressive therapy.

Organ transplantation has been made possible by lengthy essential medicine research, which has overcome physiological barriers, perfected transplant surgery techniques, introduced new immunosuppressive drugs capable of modulating the immune response in order for the transplanted organ to be accepted, improved the tracking and monitoring methodology for transplant patients.

Almost 40 years have passed since the first successful kidney transplant. Over 40.000 patients are currently waiting for a kidney transplant in Western Europe, while the number of kidney transplants remains under 12.500, less than 6.000 of which included a cerebral death donor. This supply and demand discrepancy stands true for other continents. In the USA, at the end of January 2006, there were 31.200 patients on a waiting list, whereas the number of transplants performed yearly was under 10.000 (the data is offered by the UNOS – United Network for Organ Sharing – Organization). In countries with a tradition in kidney transplantology and with real economic possibilities, the waiting time does not exceed 2 years [<http://www.unos.org/>].

Unfortunately, Romania finds it difficult to align to countries with a tradition in kidney transplants. Economic, social and religious reasons keep Romania far behind such countries, in spite of its remarkable professional training in this activity field. Statistic data from 2001 showed a total of 3.789 end stage renal failure patients signed up for kidney replacement, of whom only 233 got a transplant (statistically, 6.14% of patients obtained a transplant). The expansion and support of a kidney transplant program should be a priority concern of all health programs. It is desirable that the proportion of transplant patients reach 20-25% in 2013, with a yearly average of 400 transplants. The

first kidney transplant in Romania was carried out in 1980, at the Fundeni Hospital, followed by a lengthy interruption of this activity. In 1992, a solid kidney transplant centre was founded in Cluj. Since the year 2000, kidney transplants have been carried out successfully in Iași as well, at the 'C.I. Parhon' Nephrology, Urology and Transplantation Institute.

Given the disastrous effects of paediatric chronic kidney failure and the inconvenient of chronic dialysis programs, the question arises if the child is or is not compatible with the 'priority' term, if he may or may not become a donor when death criteria are met.

In France, for instance, two ministry decrees have offered the child under the age of 16 national priorities for kidney transplants. These decrees resulted in the immediate reduction of dialysis duration for children to an average of 9 months on a waiting list. In addition, a significant percent of the paediatric patients obtained a transplant without preliminary dialysis: a preemptive transplant.

Romanian legislation unfortunately does not stipulate the issue of paediatric priorities.

Below are the rights of the chronic patient [12]:

- Adequate time for check-up and communication;
- The right to the best care of choice (treatments, doctors, procedures);
- The right to complete information about the diagnosis, treatment and prognosis;
- The right to give or withdraw consent for various procedures, treatments, psychological counselling;
- The right of access to one's own medical files;
- The right to intimacy;
- The maintenance of European quality standards for medical services;
- Access to the most up-to-date medical technologies available;
- Treatment according to clinical guidelines;
- Quality health insurance;
- The right to a second opinion;
- Waiting lists reduced to a minimum;
- Access to clinical trials as often as possible;
- Assistance in taking informed decisions;
- The right to participate directly in taking decisions about one's treatment;
- Access to supportive, palliative and pain management therapies, as well as the integration of adjuvant therapies and conventional treatment;
- The right to personal data confidentiality, the respect of dignity;
- The right to involve one's family members in a relationship with medical staff (if requested).

The relationship patient–health professionals must develop in terms of mutual respect and trust and be based on well-defined rights and responsibilities.

- The access to information for patients and their families should be promoted with a view to a better understanding of the illness and its

treatments, in order to diminish anxiety and go through this stage of life with as little stress as possible. Informing patients should be carried out by health professionals.

- Psychological support is essential to the patients' and their families' emotional needs in all evolutive stages of the illness, during and after treatments. Social and financial support is also necessary. In this sense, the social worker provides counselling for obtaining social welfare and support both during and after the completion of treatment, specific support for certain family members when necessary, workplace protection (reduced hours, dismissal avoidance).

## 5. Conclusions

Sanitary behaviour involves the acceptance of the illness, active participation in one's treatment and the activation of coping mechanisms.

Health must come first, without turning into an obsession.

The medical team's behaviour should include certain particularities when treating a chronic patient. Dissatisfactions are common, whereas success is tardy and less striking. Novice doctors feel less interested in chronic pathology, as they want to witness immediate and spectacular effects of their activity.

The treatment of chronic, life-threatening affections such as cancer or end stage renal failure is a major challenge, which requires special training, perseverance and patience, and satisfaction resides in the trust relationship that the attending doctor and his entire team share with the patient.

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