
PSYCHOLOGICAL AND SOCIAL PROBLEMS OF CHILDREN WITH CHRONIC KIDNEY DISEASE

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Abstract

The chronic kidney disease patient is dealing with the medical problems caused by the disease and its limitations (physical activity, dialysis sessions, food and fluid restrictions or drug intake) and with the psychological and social problems that are developing during the disease stages (depression, anxiety or other psychological troubles, sexual problems linked to the libido, educational difficulties, relationships, low-self-esteem, social abilities, professional restriction etc). Children with chronic kidney disease are developing specific problems due to the difficulty of the age stages, to the family dependency and physical and emotional development. Survival is not enough so identifying problems, according medical, psychological, educational and social support is a must in order to improve their quality of life. Because the psychological factors are important predictions for patient outcomes, some of the reasons and consequences are presented.

Keywords: depression, dialysis, health belief model, kidney disease, psychological problems

1. Introduction

The ultimate goal of contemporary Medicine is to overcome life-threatening barriers and offer superior survival chances to certain patient categories with terrible destinies. This idea is understood best, in its truest sense, by those who assist patients with an end stage organ failure (be it kidney, liver, heart, etc.).

End stage renal disease, defined as the terminal evolution stage of several renal diseases, currently has a few evolutionary alternatives: death, renal replacement therapy (artificial kidney - haemodialysis, peritoneal dialysis) and kidney transplant. If the first alternative is unacceptable in the 21st century, the patient is left with the other alternatives (renal replacement therapy, kidney transplant).

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The cutting-edge haemodialysis or peritoneal dialysis findings are remarkable from a technical and medical point of view; however, the consequences of organ insufficiency are unfortunately just partially corrected, with major repercussions on general health and quality of life [1].

Most patients find it impossible to continue their education, profession and have a perturbed family life, their loved ones being put through significant efforts. Integrating the chronic kidney disease patient into a haemodialysis schedule leads to long-term adaptive changes, both physiological and pathological, as a response to chronic stress, and also to dialysis-specific changes. The unfortunate consequences of terminal chronic renal failure negatively reflect upon somatic, mental and intellectual growth and development.

Disabling osteodystrophy and protein-caloric malnutrition associated to end stage chronic renal disease are severe in children and bear strong debilitating potential. A peculiar perception of pain and of the workmanship of the dialysis session, coupled with somatic changes, shape the particular character of the chronic kidney disease child. In this sense, medical therapy of the chronic kidney disease must be backed by adequate psychological support.

In brief, assisting the terminally ill is limited to people of balanced mental structure, ready to control their reactions and manifest a behaviour adapted to the special conditions of this sort of activity.

Treating the dialysis children need a multidisciplinary care including medical, psychological, family, educational and religious support.

2. Important factors in the developing psychological problems

The patient with known or unknown renal disease is informed that he needs to undergo weekly sessions for renal function support. This causes a variety of psychological reactions: denial of the illness, irritability, despair, feelings of helplessness, hatred, fear of death, aggressiveness, anxiety symptoms, depressive symptoms, and even suicidal tendencies. The feeling of loneliness at the loss of a patient should be counteracted by immediate resumption of work and establishment of contact with other patients in need of assistance. Western hospitals feature psychologist-led support groups aimed at medical staff involved in assisting terminal patients. The doctor often enters a mutually supportive emotional relationship with the patient's family. This may be beneficial, by the provision of information necessary for the doctor's communication with the patient, both for technical and psychosocial reasons.

Different studies showed that correlation analyses identified a number of important factors associated with poor adjustment to dialysis and/or anxiety and depression in children and parents. Particularly at risk are parents in lower socioeconomic status households, parents with large families, parents with limited support and parents of young children [2]. Personality structure and family support seem to be the most important factors for the quality of life of dialysis patients.

2.1. Time of diagnosis

Time of diagnosis of chronic renal failure and the predialysis care may be important factors related to the quality of life of patients on dialysis treatment. Late diagnosis of chronic renal failure and the consequent lack of predialysis care adversely affect the quality of life of haemodialysis patients. Early diagnosis and regular predialysis care should be encouraged to improve the quality of life during dialysis treatment [3]. The study of Jungers et al provides suggestive evidence that longer duration of regular nephrological care in the predialysis period, at least for several years prior to the start of dialysis, is associated with a better long-term survival on dialysis. Such data strongly support the argument for early referral and regular nephrological care of chronic renal failure patients [4].

2.2. Depression and other psychological problems

The personality profile is very important for the survival rate of the chronic renal failure patient. Psychological support is necessary in order to avoid or diminish the severity of the following depressive syndrome.

Depression is generally accepted as the most common psychological problem in chronic renal patients. Although depressive symptomatology is commonly encountered in dialysis patients, the syndrome of clinical depression includes sadness, guilt, hopelessness, helplessness and changes in sleep, appetite and libido [5].

Depression in chronic renal patients is seen as a predictable and frequent complication. Somatic factors such as uremic toxicity, atherosclerosis, neurological disorders, anaemia, cardiovascular disorders and metabolic disorders are also involved in the aetiology of the depression [1]. As the impact of depression on survival was maximal in the first few years of dialysis, monitoring for depression should be incorporated into routine care from the start of dialysis together with evaluative interventions that might enhance survival [6].

The dialytic stage has several periods. The patient initially develops feelings of fear of either the machine or the medical staff, that may lead to anxiety, aggressive behaviour, emotional instability. Later, in advanced stages, the chronic patients who undergo haemodialysis develop doctor/medical team-patient-machine relationships with new rejection and attachment facets.

Both during dialysis sessions and in the family environment, the depressive disposition manifests itself by: irritability, affective indifference, multiple somatoform complaints: headaches, dizziness, heart palpitations, paresthesia, insomnia, feeling useless, devaluated, incurable, vegetative symptoms: sweating, appetite loss, faintness, constipation, weight loss, aggressiveness, suicidal ideation, culpability and self-accusation, sexual dynamics disorders, attention, memory, focus disorders [1; U.S. Department of Health And Human Services. National Institutes of Health School & Family

Problems of Children with Kidney Failure, NIH Publication No. 06–5165, June 2006, online at www.kidney.niddk.nih.gov].

Chronic kidney disease patients lead profoundly changed lives. Apart from the problems caused by the organ's disease (progressive nephropathy, emergence of comorbidities – anaemia, hypertension, cardiovascular disease, malnutrition, renal bone disease, dyslipidemias, metabolic acidosis), before the introduction of renal function replacement therapies, patients undergo external pressure comparable to that affecting other chronic patients (dietary and hydro-electrolytic restrictions, drug intake, the effects of the illness itself, multiple loss – of independence, life expectancy, social role, job, sexual function -, the altering of future plans, uncertainty, damaged self-image and self-esteem).

2.3. The cognitive deficit

The prevalence of cognitive deficits is particularly high in subjects with end-stage renal disease (ESRD). While it is sufficiently well documented that ESRD is linked with a change in cognitive function, little is known about the influence of different dialysis modalities on cognitive function. Some data suggest that patients with ESRD treated with chronic ambulatory peritoneal dialysis (CAPD) had consistently better cognitive function than patients treated with haemodialysis [7, 8].

2.4. Addiction to the machine

Those who undergo haemodialysis, continuous cyclic peritoneal dialysis or nocturnal intermittent peritoneal dialysis manifest an addiction to the machine without precedent in the history of medical technology. Those treated by continuous ambulatory peritoneal dialysis are tied to a repetitive circadian ritual of dialysis exchanges. All these patients are severely dependent on a medical procedure and on certain medical staff. On the whole, a patient's psychological response to the illness depends on his premorbid personality, on the level of family and social support and on the progression of the underlying disease.

2.5. The Model Health Behavior and Quality of Life (QOL)

Data on the morbidity and mortality of this patient category offers an incomplete image of the efficiency of the medical act, given that the concept of chronic kidney disease management is in full development, one of its key components being the patients' perception of their own health [9]. This is because, when a chronic disease cannot be cured, maximizing the quality of life becomes an essential goal of medical treatment.

The goals of the chronic kidney failure treatment are currently grouped into two large directions: decreasing morbidity and mortality and increasing the patients' quality of life.

Quality of life is an evaluative concept [10]. As a result, it has a dual structure, based on the following two distinct components:

- state – the state of an individual's or a community's life, as a whole or as its various components, at a certain moment;
- a set of evaluative criteria (values) by which life is appreciated as good or bad.

Health-related quality of life refers to the measure of a patient's functioning, well-being, and general health perception in each of three domains: physical, psychological, and social.

Patient QOL is a very important indicator of the effectiveness of the medical care they receive. QOL of patients with end-stage renal disease is influenced by the disease itself and by the type of replacement therapy. Numerous studies have identified the effect of such factors as anaemia, age, comorbidity, and depression on QOL. Most of these factors appear during the predialysis period, and the adequate management of some of them could influence patient outcomes. Depression, sleep disorders, ethnicity or transplant possibility are factors that affect the QOL score. Leaving with a chronic kidney disease can be seen as a success from the medical point of view but survival is not enough for a patient looking for a life more close to a normal one [11, 12].

Treatment with haemodialysis affects patients' quality of life more intensely than heart failure, diabetes, chronic lung disease, arthritis and cancer. The study of Tjaden et al described that children undergoing dialysis experience impaired growth, invasive procedures, school and social constraints. They often have poor self-esteem and a pervasive sense of losing their identity, body integrity, control, independence and opportunity. Interventions are needed to equip children with the capacity to manage their health, participate in community, engage in 'permissible' recreational activities, progress in their studies, and remain vigilant in dialysis and treatment responsibilities, for improved health and treatment outcomes [13].

The paediatric patient undergoing a dialysis session lacks the autonomy to decide on this workmanship, parents and the medical team being the ones who eventually make the decision [14].

2.6. Stress

The cause of so much distress is the sum of stressors associated with end-stage renal disease and its treatments: illness, family changes, dietary constraints, time restrictions, functional limitations, financial constraints, changes in employment, change in sexual function, medication effects and awareness of impending death etc.

Even minor stress was significantly predictive of changes in dietary compliance. The results suggest that minor stress may affect health status in the chronically ill by reducing compliance behaviours [15].

2.7. Noncompliance

The compliance has a major role in the treatment of haemodialysis patient. It requires committing considerable time (several hours/session, many sessions/week), adjusting their food and drink behaviour (fluid restrictions and diet) and taking pills regularly. The noncompliance among patients (especially teenagers) is a major problem. Studies are describing that noncompliance is inversely related to survival and that patient characteristics may be predictive of compliance under certain circumstances [16].

2.8. Family support

The child's illness is causing a lot of problems into family life. Psychological problems were revealed also in parents' profiles (anxiety and depression) and relationships with other families are also affected. Mothers seemed to be more touched. Internal family relations and couple/marriage is influenced by the child disease. Family support has an important impact of child's QOL.

3. Guidelines intervention for helping children with chronic kidney disease

Having kidney failure influences a child's self-image and relationships with peers and family. It can lead to behaviour problems and make achieving goals more difficult. Being aware of these problems can help you recognize that your child may need some additional guidance or understanding at times.

The most important areas of intervention are presented below.

3.1. Family support

Studies revealed that parents showed greater levels of anxiety and depression than a normal sample and more psychosomatic problems than a control group consisting of parents of children with other chronic physical conditions. Positive correlations were found between age on diagnosis of renal failure and fathers' depression and anxiety scores. Mothers' anxiety and depression scores were also positively correlated with those of father [17].

The child's illness was reported to have caused disruption in family life by most parents in the dialysis group (77%) significantly more often than by parents in the non-dialysis group (31%) ($p = 0-002$). Disturbance was commonly explained in terms of the restrictions imposed by the child's condition or treatment, including dialysis, which made family outings or holidays difficult to organize. Higher family conflict predicts also more externalizing symptoms and higher number of prescribed medications; higher family cohesion predicted fewer hospitalizations. Non-traditional family structure predicted higher number of prescribed medications [18].

Appreciably more parents in the group on dialysis (65% compared with 27% of parents in the group not on dialysis; $p = 0.05$) reported that their marriage had been affected (financial stress, overprotection of the ill child, changes in siblings' attitudes towards the ill child including being worry, protectiveness, and giving in to the ill child). Many studies reported stress on the marriage in families with a child with kidney failure but there is no evidence of raised divorce rates [19].

In addition to 'normal' parental roles, being a parent of a child with chronic kidney disease demands a high-level health care provider, problem solving, information seeking, and financial and practical skills at a time when the capacity to cope is threatened by physical tiredness, uncertainty, and disruption to peer support within and outside the family structure. Parents of children with chronic kidney disease need multidisciplinary care, which may lead to improved outcomes for their children [16, 20].

3.2. School

Assuring a normal life is very important for dialysis child. Negative consequences include the impossibility of continuing to attend school. With a schedule including 3 dialysis sessions per week, such children find it impossible to continue their formal studies, being doomed to illiteracy and the impossibility of socio-professional insertion. Learning problems could be the consequence of missing classes or the impossibility to focus during tasks. Data on school performance have shown that children with CKD are at risk for impairment. The aetiology of this deficit appears to be multifactorial, with the neurological side effects of the disease itself and the associated treatments, as well as school absences, all potentially playing a role. Tutoring or vocational rehabilitation could help [www.kidney.niddk.nih.gov, 21].

3.3. Dealing with low self-esteem

Learning problems and physical consequences of the illness contribute to a lower self-esteem. They could feel depressed and powerless. Children who have as much control and responsibility as possible over their own care can feel empowered (peritoneal dialysis, for example or taking care about pills and doses) [www.kidney.niddk.nih.gov, 17]. They often have poor self-esteem and a pervasive sense of losing their identity, body integrity, control, independence and opportunity. Interventions are needed to equip children with the capacity to manage their health, participate in community, engage in 'permissible' recreational activities, progress in their studies, and remain vigilant in dialysis and treatment responsibilities, for improved health and treatment outcomes [13].

3.4. Following medical instructions

Children can refuse the medical treatment or dialysis program. In case of noncompliance or non-adherence, the psychological therapy is a must. The teenagers are usually difficult patients, due to their age's psychological, physical and social needs [www.kidney.niddk.nih.gov, 17].

3.5. Engaging sports or physical activity

Usual limited, the physical activity is important for two aspects: integrate the child in social activity (play, games, competition, fun etc) and having benefits on the physical and psychological life (feeling powerful and independent).

3.6. Making friends

Children with kidney disease may have trouble in making friends. The physical activity restrictions (and sometime the smaller stature) the drug treatment or the dialysis program, the food and drinks restriction could limit them for socializing. Most children in this situation are choosing friends among those who are hospitalized with or among those in the same medical situation (peritoneal or haemodialysis). Special camps or extracurricular activity could be a solution for integrated them in a group of children of their own age [www.kidney.niddk.nih.gov, 14].

3.7. Working

To enter in the workforce is difficult for persons with kidney problems. Few of them are succeeding in finishing college or university. Most of them are graduating schools, elementary schools or high-schools, if the dialysis programs are permitting them to reach classes or support teachers are provided to their homes. Missing classes or school abandon is frequent. Family support and school policies are important for the child.

3.8. Religious/spiritual coping

Among other variables that influence the health behaviour, religious/spiritual coping mechanisms are an important strategy to cope with the disease. Important studies showed that religious practice (attending church every week) is influencing the quality of life of patients with kidney chronic disease in dialysis program [22]. Positive religious coping was associated with better overall, mental and social relations Religious struggle was an independent correlate of worse overall, physical, mental, social relations and environment health quality of life [23]. The effects of spirituality may be mediated by social support and social support is correlated with survival [24]. Spiritual aspects

seem to be more important than religious aspects in children with dialysis treatment. As studies are proving, spiritual/religious coping correlate with age, gender, financial high status and religious practices [22, 25].

4. Conclusions

Treating children with chronic kidney needs a multidisciplinary care: medical, psychological and social intervention. The medical problems are doubled by the psychological effects and factors reflecting the personal profile, the age difficulties, the family type and educational level. Involving into the specific age activities with the limits imposed by the disease could create a suitable style according to their needs. Restrictions in food and liquid diet, physical activity, sexual activity and emotional stability are feeling like an unsupportable board. Risks are joining the dialysis program (like school abandon or difficulty to socialize due to the dialysis schedule) but psychological and family support is an important factor for quality of life and survival.

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