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### **FAMILY SUPPORT AND QUALITY OF LIFE OF CHILDREN WITH KIDNEY CHRONIC DISEASE**

Magdalena IORGA, Laszlo-Zoltan  
SZTANKOVSKY

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# Family Support and Quality of Life of Children with Kidney Chronic Disease

Magdalena IORGA<sup>1</sup>  
Laszlo-Zoltan SZTANKOVSKY<sup>2</sup>

## Abstract

*For the child with kidney chronic disease, the psychological effects and factors reflecting the personal profile, the age difficulties, the family type and educational level double the medical problems. Involving into the specific age activities with the limits imposed by the disease could create a suitable style according to their needs. Family is an important factor for the quality of life and studies reveal the major influence on treatments and the evolution of disease and comorbidities.*

**Keywords:** *quality of life, chronic kidney disease, dialysis, family support.*

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<sup>1</sup> Lecturer, PhD, University of Medicine and Pharmacy “Gr. T. Popa” Iasi, Romania, magdaiorga@yahoo.com.

<sup>2</sup> PhD student, University of Medicine and Pharmacy “Gr. T. Popa” Iasi, Romania, sztankovszky@yahoo.com.

### **1. Problem Statement**

The quality of life (QOL) is an evaluative concept expressed by its dual structure: the state of an individual's or community 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 patient's functioning, well-being and general health perception in each of three domains: physical, psychological and social (Noordzij et al., 2005).

According to the Kidney Disease Outcomes Quality Initiative of the National Kidney Foundation, chronic kidney disease is defined by structural or functional abnormalities of the kidney for more than 3 months, with or without decreased glomerular filtration rate or by a glomerular filtration rate under 60 mL/1.73 m<sup>2</sup> for more than 3 months. (Hogg et al., 2003)

Treating children with chronic kidney needs a multidisciplinary care: medical, psychological and social intervention. The therapeutic approaches in childhood present a challenge due to the different characteristics of each period of growth and development, having the aim to minimize renal damage and reduce complication. (Sztankovszky, Iorga, 2015) Medical interventions are adopted according to the type of damage: renal replacement therapy in the form of hemodialysis, peritoneal dialysis or renal transplantation.

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 (Sesso, Yoshihiro, 2014).

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 (Jungers et al., 2010).

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 (Iorga et al., 2014).

## **2. Social support and Quality of life**

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. (Iorga et al., 2014)

Social support is a concept recognizing patients exist to varying degrees in networks through which they can receive and give aid, and in which they engage in interactions. Social support can be obtained from family, friends, co-workers, spiritual advisors, health care personnel, or members of one's community or neighbourhood. Several studies have demonstrated that social support is associated with improved outcomes and improved survival in several chronic illnesses, including cancer and end-stage renal disease. The mechanism by which social support exerts its salutary effects are unknown, but practical aid in achieving compliance, better access to health care, improved psychosocial and nutritional status and immune function, and decreased levels of stress may all play key roles (Patel et al., 2005).

Social support is an understudied, yet important, modifiable risk factor in a number of chronic illnesses, including end-stage renal disease. Increased social support has the potential to positively affect outcomes through a number of mechanisms, including decreased levels of depressive affect, increased patient perception of quality of life, increased access to health care, increased patient compliance with prescribed therapies, and direct physiologic effects on the immune system. Higher levels of social support have been linked to survival in several studies of patients with and without renal disease. Higher perceived spousal support among women on dialysis was linked to improved compliance and survival in subgroup analyses (Cohen et al., 2007).

The functioning of the family is affected by the child's disease. 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 (Fielding et al., 1985) Personality structure and family support seem to be the most important factors for the quality of life of dialysis patients.

The HRQoL in children with chronic kidney disease is lower than in healthy children. This is already observed in the early stages of the disease. The disease itself influences the child's mental state. Children on hemodialysis require special support on account of the lowest demonstrated overall HRQoL. Children's lower rating of the quality of life observed by their parents may render the patients unmotivated and adversely affect their adjustment to life in later years. It may also create conflicts between the parents and the children (Kiliś-Pstrusińska et al., 2013).

In a study of Piazza-Waggoner (2008) results indicated that children with mild illness reported less adaptive coping, and their caregivers reported more maladaptive coping compared to the other groups. In addition, children in the mild severity group were reported to have higher levels of internalizing behaviour problems.

Treatment should be adjusted to the age and to the social possibilities and the main goal is to provide good treatment and provide equal chances to it. Social network could contribute significantly to it. Despite significant interest by pediatric transplant patients in meeting others who have undergone transplantation, geographic distances combined with their daily routines make this difficult. In a mixed-method study describes the use of Zora, (researchers used a Web-based virtual community designed to create a support system for these patients). The Zora software allowed participants to create a graphical online virtual city with houses expressing their individuality and objects conveying their concerns and personal stories. Zora allowed real-time chat between participants further facilitating communication. Qualitative data show the preliminary success of the project, as three major themes emerged:

- increased sense of normalcy for the patients,
- enhanced sense of self and contribution to the community, and

- increased social network.

There were no instances of harmful interactions in the virtual world. This study demonstrates the feasibility and safety of a virtual community as a potential psychosocial intervention for post-transplant adolescents (Bers et al., 2010).

### **3. Family support in chronic kidney disease**

The relationship between family and child is often disturbed. The child is affected by the family perception of the disease and its adaptive (or not) response to it. On the other hand, the family is influenced by the child's self-perception, by the coping strategies and the psychological profile that determines every child to come over the disease very differently and to face all consequences (life style, school, food restriction, physical limits etc.).

The family involvement is determined by the dialysis type: most commonly, the hemodialysis is less empowering the family to be part of the treatment. In the case of peritoneal dialysis, the family is the main responsible partner in the intervention: helping during the process, taking care about sleep conditions, and being responsible about home conditions (hygiene, keeping medical materials in good conditions or not disturbing the child etc.) or joining the child during the hospitalizations.

The family becomes a partner of the medical team who should respect all rules and schedules. But the partnership is not limited only to it. The members of the family should support the child during the daily activities and to encourage attending school. A higher rate of socialisation increases the parents autonomy. Good education could lead to a proper and adequate job (limited by the physical condition and by the treatment's dependence). Even if most of the studies showed that cognitive deficit and depression are the most common for the kidney chronic disease, this is not an impediment for the patient to develop a career.

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. Nontraditional family structure predicted higher number of prescribed medications (Soliday et al., 2001).

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 (Reynolds et al., 1988)

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 (Tong et al., 2008).

In their family environments, mothers of ESRD children reported significantly lower independence and achievement orientation than mothers of control children (Fukunishi et al., 1993). Mothers seem to be more often the caregiver, charged with the medical aspects, the diet, the school problems, the protection against tasks which overpass the child's possibilities.

Entire family should readjust the activity if the child has chronic kidney disease and is included in a dialysis program. Many changes should be taken into consideration, like: relocation, joining the child to the hospital, joining the child during divers activities in order to protect him/her against suprasolicitation or change their own schedule to cover the child program, re-prioritization of the expenses in order to keep the financial balance.

The concept of 'caregiver burden' has thus been used to capture this impact. Caregivers can be identified as the individual(s) who during the course treatment are most closely involved in caring for the patient and helping the patient cope with and manage his chronic illness

The difficulties presented in providing adequate support for both old and young patients with any chronic disease, such as chronic kidney

disease, have been emphasized. These difficulties impose a substantial burden on those directly responsible for giving care, especially for family members (Belasco et al., 2006). The caregiver burden increases significantly as functional and cognitive impairments imposed by the chronic disease limit the ability of the patient to care for himself. Additional factors associated with caregiver burden include the relationship between caregiver (and their career) and patient, behavioural and psychological symptoms displayed by the patient, gender and adverse life events. A multi-factorial role and inter-dependence of these factors must be assessed to measure the impact of the caregiver burden (Gayomali et al., 2008).

The impact of the disease on family members is not insignificant: anxiety, fatigue, depression, deterioration in family relationships, social isolation and stress can occur when caregivers take charge of home dialysis for either adult patients or children. This in turn may result in a more negative impact on the emotional and social aspects of caregivers' lives.

The importance of caregivers in the success of peritoneal dialysis has been noted; psychosocial and family problems contribute significantly to technique failure rates in elderly patients maintained on peritoneal dialysis. Unfortunately, the caregiver become a "patient" for the multidisciplinary team and caregiver lifestyle and psychosocial problems become, on their turn, a problem for the entire medical team and measuring the caregiver burden in pediatric chronic disease is nowadays a goal (Parham et al., 2014).

A lot of studies are recommending that mothers with the more severely ill children may be the ones most likely to benefit from regular social or parent groups, where there is an opportunity for contact with other parents in the same predicament.

Other authors have reported work problems in fathers or feelings of resentment when work prevented them from being concerned with treatment and with the child at the hospital. It is worth considering whether a special effort to involve fathers more in various aspects of the ill child's care might result in an increase in their sense of satisfaction with other areas in their lives.

#### 4. Conclusion

Quality of life for children with chronic kidney disease depends very much from the family support and caregivers and all aspects of life are deeply influenced by the family help and involvement in the treatment (medical and psychosocial support, economical aspect, school support, sociability, ordinary activities etc.) so, on the one hand, family is one of the most important health providers at home.

On the other hand, family itself needs support because of lot of studies proved that members of the family or caregivers developed themselves a lot of consequences of the child's disease. Mothers and fathers are differently affected by the child's disease and they are differently involved in the child's treatment.

Social support is proved to be important for both child and family even if the help is coming from parents' job, school, NGOs, hospital.

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### **Biodata**

#### **PhD Lecturer Magdalena IORGA**

Magdalena IORGA is PhD lecturer University of Medicine and Pharmacy “Gr. T. Popa” of Iasi and clinical psychologist at Santa Maria” Child Hospital of Iasi. Interested in the area of clinical psychology, psychotherapy, children medical problem and family support in case of children with chronically diseases. She published articles related to the quality of life of children in medical need, psychological and social difficulties of children with chronically disease, psychotherapy.

#### **PhD Student Laszlo-Zoltan SZTANKOVSZKY**

Laszlo-Zoltan SZTANKOVSZKY, MD, PhD student at University of Medicine and Pharmacy “Gr. T. Popa” of Iasi. He is interested in chronically disease related problems and ethical aspects of doctor-patient relationship. He published articles on chronically disease, vulnerable population and ethical problems in the medical area.