

Psychosocial Effect of Chronic Kidney Disease on Children and Their Families

Dr Samah Al-Jbour

Pediatric Nephrology Consultant

- In recent years, medical care and the management of children and adolescents with chronic kidney disease (CKD) have significantly developed. As a consequence, there have been considerable changes in the prognosis of these patients and survival has extended.

- However, there is still great difficulty in the management of stress and the responsibilities that accompany CKD, as these patients deal with a life of limitations. Additionally, their quality of life (QoL) is significantly impaired due to the demands and restrictions brought on by the clinical condition and treatment.

- 1. Rosenkranz J, Bonzel KE, Bulla M et al. Psychosocial adaptation of children and adolescents with chronic renal failure. *Pediatr Nephrol* 1992; 6:459-63.
- 2. Reynolds JM, Morton MJ, Garralda ME, Postlethwaite RJ, Goh D. Psychosocial adjustment of adult survivors of a pediatric dialysis and transplant programme. *Arch Dis Child* 1993; 68:104-10.

- CKD affects many life aspects of these children. On a daily basis, they are submitted to dietetic and hydric restrictions, difficult and invasive treatments, with complex drug treatments and even hospitalizations. It has been observed that they present a higher risk of worse psychosocial performance than their healthy peers.
- Lavigne JV, Faier-Routman J. Psychological adjustment to pediatric physical disorders: a meta-analytic review. *J Pediatr Psychol* 1992; 17:133-57.
- Holden EW, Chmielewski D, Nelson CC, Kager VA, Foltz L. Controlling for general and disease-specific effects in child and family adjustment to chronic childhood illness. *J Pediatr Psychol* 1997; 22:15-27.

- Literature data have shown that these emotional alterations in patients with CKD and their caregivers can also persist in the adult phase.
- Thus, it can be perceived that the management of these patients represents a challenge for the healthcare team, for the patients and their caregivers.
- Fielding D, Brownbridge G. Factors related to psychosocial adjustment in children with end-stage renal failure. *Pediatr Nephrol* 1999; 13:766-70.
- Aldridge MD. How do families adjust to having a child with chronic kidney failure? A systematic review. *Nephrol Nurs J* 2008; 35:157-62.





- The presence of chronic diseases (CD) during childhood and adolescence significantly increases the risk of emotional and behavioral disorders.
- Although many CD are considered rare in childhood, it has been estimated that they affect approximately 15% of the pediatric population. Of this total, approximately 5% are persistent or recurrent organic CD.
- Reynolds JM, Garralda ME, Jameson RA, Postlethwaite RJ. How parents and families cope with chronic renal failure. *Arch Dis Child* 1988; 63:821-6.
- Eiser C. Psychological effects of chronic disease. *J Child Psychol Psychiatry* 1990; 31:85-98.
- Mendonça MB, Ferreira EAP. Adesão ao tratamento da asma na infância: dificuldades enfrentadas por cuidadoras. *Rev Bras Crescimento Desenvolv Hum* 2005; 15:56-68.

- Children with CD can present psychological disorders caused not only by the disease itself, but also by the treatment.
- These children can also have their daily life modified by several limitations, mainly physical ones, due to the characteristics of the disease that require continuous re-adaptations in the presence of new situations, in addition to the development of strategies for coping with the disease.
- Jones JG. Compliance with pediatric therapy. A selective review and recommendations. *Clin Pediatr (Phila)* 1983; 22:262-5.
- La Greca AM. Issues in adherence with pediatric regimens. *J Pediatr Psychol* 1990; 15:423-36.
- Eiser C, Berrenberg JL. Assessing the impact of chronic disease on the relationship between parents and their adolescents. *J Psychosom Res* 1995; 39:109-14.

- These emotional alterations can be associated with the neurological alterations inherent to the diagnosis itself. However, it can be observed that the emotional disorders presented by the patients are essentially associated with the innate difficulties of living with a CD.
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- CKD is invariably quite stressful and has a high impact on the lives of patients and their families. Therefore, it constitutes a predisposing factor for the development of psychiatric pathologies in these patients and their family members, notably in their main caregivers.
 - On the other hand, the presence of psychiatric comorbidities worsens the prognosis of patients with CKD. Burton et al. found an association between major depression and premature death in CKD patients.
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- Eiser C. Psychological effects of chronic disease. *J Child Psychol Psychiatry* 1990; 31:85-98. .
 - Burton HJ, Kline SA, Lindsay RM, Heidenheim AP. The relationship of depression to survival in chronic renal failure. *Psychosom Med* 1986; 48:261-9.

- The medical care given to CKD patients have advanced substantially in the last decades.
- However, the treatment remains quite invasive, requiring profound behavior, cultural and life style changes.
- The clinical condition of these patients brings on several daily difficulties and limitations.
- Thus, their increased survival is many times accompanied by the presence of psychiatric comorbidities.
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- Normally, these children present anemia, hyporexia and a tendency toward decreasing their activities, with a worsening in school performance. Bakr et al. demonstrated that these emotional consequences are not explained by socioeconomic or clinical factors. In this study, the emotional involvement was associated with the difficulty to live with the disease and with altered renal function.
- Fukunishi I, Kudo H. Psychiatric problems of pediatric end-stage renal failure. *Gen Hosp Psychiatry* 2005; 17:32-6.
- Fukunishi I, Honda M. School adjustment of children with end-stage renal disease. *Pediatr Nephrol* 2005; 9:553-7.
- Bakr A, Amr M, Sarhan A et al. Psychiatric disorders in children with chronic renal failure. *Pediatr Nephrol* 2007; 22:128-31.

- The patients with CKD reported high levels of stress, depression and feelings of hopelessness related to worries concerning their own health and the perception of their limitations.
- Brownbridge et al. demonstrated that high levels of depression and anxiety and altered results in personality tests in these patients were associated with a worse therapeutic adherence.
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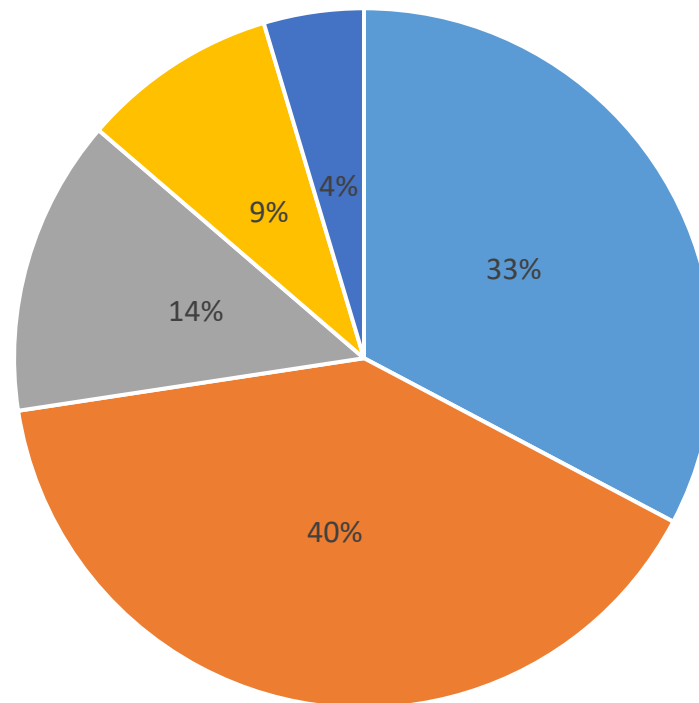


- Thus, an important point to be discussed is that the understanding and re-channeling of stress in children with CKD constitute an effective form of relief of their emotional suffering and improvement in their treatment adherence.

- Brownbridge G, Fielding D. An investigation of psychological factors influencing adherence to medical regime in children and adolescents undergoing hemodialysis and CAPD. *Int J Adolesc Med Health* 1989; 4:7-18.
- Wolcott DL. Organ transplant psychiatry: psychiatry's role in the second gift of life. *Psychosomatics* 1990; 31:91-7.

- Children with CKD normally present a negative self-image and a feeling of inferiority in relation to their peers.
- The study by Bakr et al. used the SCICA, a semi-structured questionnaire that globally evaluates the patient's functionality in nine areas, such as school, friends and family relations in 38 pediatric patients with CKD undergoing conservative treatment and hemodialysis (HD).
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Prevalence of mental disorders 52.6%



■ Behavior ■ Depression ■ Neurocognition disorders ■ Anxiety ■ Elimination disorders

- The prevalence of mental disorders was 52.6%, divided as follows: behavior 18.4%; depression 22.4%; neurocognition disorders 7.7%; anxiety 5.1%, and elimination disorders, 2.6%. When comparing the incidence of psychiatric disorders in patients undergoing dialysis and conservative treatment, the prevalence was 68.4% and 36.8%, respectively.

- Several hypotheses have been suggested to explain this increase in the prevalence of mental disorders.
- In addition to the stress inherent to CKD and its treatment, studies have pointed out to other factors that contribute to the predisposition to psychiatric disorders in this group. Among them, we can mention the decrease in the levels of the brain-derived neurotrophic factor (BDNF) and the low serum levels of serotonin in CKD patients.

- They also present uremia, which can be associated with irritability, restlessness, insomnia and delayed development of secondary sexual features.

- The cognitive function of patients with CKD seems to be worse than that of their healthy peers. This impairment seems to be related to the time of exposition to the disease. The cognitive alterations are mainly related to learning and intelligence.
- Bale JF, Jr., Siegler RL, Bray PF. Encephalopathy in young children with moderate chronic renal failure. *Am J Dis Child* 1980; 134:581-3

- The young adults with CKD since childhood, particularly those that have undergone dialysis for longer periods, present impaired cognition and reading skills, when compared to their peers.
- In the study by Bawden et al., patients with CKD showed mild deficit at tests of intelligence and fine motor skills, when compared to siblings. However, surprisingly, no differences were observed regarding the academic results, memory, behavior and self-esteem.
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- It constitutes noteworthy information the fact that the consequences of CKD, its treatment and the psychiatric and clinical comorbidities persist after childhood.

- Groothoff JW, Grootenhuis M, Dommerholt A, Gruppen MP, Offringa M, Heymans HS. Impaired cognition and schooling in adults with end stage renal disease since childhood. Arch Dis Child 2002; 87:380-5.
- Bawden HN, Acott P, Carter J et al. Neuropsychological functioning in end-stage renal disease. Arch Dis Child 2004; 89:644-7.

- In the study of Rosenkranz et al., 50% of the participants informed that the CKD negatively affected their social life. Among these, approximately one-third had sought medical help in the previous five years due to psychiatric and emotional disorders.
 - Few patients reported a stable relationship with the opposite sex.
 - In this other study, the level of dependence found in patients with CKD was high. Growth and sexual development delay was also observed, as well as a much lower fertility rate, when compared to that of the general population.
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- Rosenkranz J, Bonzel KE, Bulla M et al. Psychosocial adaptation of children and adolescents with chronic renal failure. *Pediatr Nephrol* 1992; 6:459-63

- Therapy adherence constitutes another challenge for these pediatric patients. To follow the proposed treatment means to be submitted to hydric and dietetic restrictions, complex posologic regimens and invasive therapies.
- The study by Wolff et al. emphasized psychosocial factors related to adherence. It was observed that the patients with worse emotional and social performance usually demonstrated a tendency to not follow medical recommendations.

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- This author explains that the adolescent with CKD many times does not adhere to the treatment in an attempt to demonstrate autonomy and treatment adherence very often worsens when there is a family crisis.
- Wolff G, Strecker K, Vester U, Latta K, Ehrich JH. Noncompliance following renal transplantation in children and adolescents. *Pediatr Nephrol* 1998; 12:703-8.

- Transplanted children need to deal with the necessity to continuously use immunosuppressive drugs and deal with their side effects. These patients fear the loss of the functioning graft.
- It is important to work with the families on the actual expectations of the caregivers and transplanted patients. Although it represents a huge evolution in terms of QoL, the transplant can become a frustrating experience, as the patients and their family members often expect a totally healthy and autonomous life after the procedure.
- Grimm PC, Ettenger R. Pediatric renal transplantation. *Adv Pediatr* 1992; 39:441-93.
- Griffin KJ, Elkin TD. Non-adherence in pediatric transplantation: a review of the existing literature. *Pediatr Transplant* 2001; 5:246-9.

- The phase immediately after the transplant is a delicate one, marked by the presence of depression symptoms, low self-esteem and difficulty to understand and deal with the treatment.

- Reynolds JM, Garralda ME, Postlethwaite RJ, Goh D. Changes in psychosocial adjustment after renal transplantation. Arch Dis Child 1991 ;66:508-13.

- Among the social effects of CKD is the significant schooling impairment. Usually, the degree of schooling in these patients is lower than that of their healthy peers.
- It has been demonstrated that children and adolescents with CKD present a higher degree of school absenteeism.
- The parents of children with CKD undergoing hemodialysis (HD) report a worse academic performance of their children in comparison to those undergoing conservative treatment and in the control group.
- Eiser C, Eiser JR, Town C, Tripp JH. Discipline strategies and parental perceptions of preschool children with asthma. *Br J Med Psychol* 1991; 64:45-53.

- Another point to be considered is the association between the worsening in the QoL and the morbimortality of CKD patients.
- QoL is a multidisciplinary concept that consists in the perception of the individual of his/her position in life, in the context of the culture and system of values in which he/she lives and in relation to his/her objectives, expectations, standards and concerns.
- QoL worsening interferes with the prognosis of these patients.
- In relation to the type of treatment used, the worse scores of QoL were observed in patients undergoing dialysis, in most studies.

- In the study by Gerson et al., adolescents undergoing dialysis with end-stage CKD reported a worse QoL, with worse impairment of the physical domain in relation to transplanted patients with functioning graft.
- Gerson AC, Riley A, Fivush BA et al. Assessing health status and health care utilization in adolescents with chronic kidney disease. *J Am Soc Nephrol* 2005; 16:1427-32.
- Gerson A, Hwang W, Fiorenza J et al. Anemia and health-related quality of life in adolescents with chronic kidney disease. *Am J Kidney Dis* 2004; 44:1017-23.

- In a study by Buyan et al., in which 211 children with CKD were compared to healthy controls, the first presented significant impairment of the QoL in relation to the latter.
- Buyan N, Turkmen MA, Bilge I et al. Quality of life in children with chronic kidney disease (with child and parent assessments). *Pediatr Nephrol* 2010; 25:1487-96.

- Regarding the type of treatment, the transplanted patients presented a higher degree of self-esteem and preserved social skills in comparison to those undergoing dialysis.
- In the study by McKenna et al. 39 the PedsQL was used to measure the QoL of 64 children with CKD, of which results were statistically lower in all domains in comparison to healthy controls. Similar results were obtained at the study by Goldstein et al., which used the same tool.

- McKenna AM, Keating LE, Vigneux A, Stevens S, Williams A, Geary DF. Quality of life in children with chronic kidney disease-patient and caregiver assessments. *Nephrol Dial Transplant* 2006; 21:1899-905.

- Goldstein SL, Graham N, Burwinkle T, Warady B, Farrah R, Varni JW. Health-related quality of life in pediatric patients with ESRD. *Pediatr Nephrol* 2006; 21:846-50.

- The study by Fadrowski et al. showed a probable association between an increase in height and QoL improvement in relation to the physical domain.
- In this study, adequate levels of hematocrit and albumin were associated with a better QoL. On the other hand, a decrease in the glomerular filtration rate (GFR) was associated with a significant impairment of the QoL in adolescents with CKD.
- This author associated a worse performance in the psychosocial domain of the QoL to the dialysis treatment and older age.
- Fadrowski J, Cole SR, Hwang W et al. Changes in physical and psychosocial functioning among adolescents with chronic kidney disease. *Pediatr Nephrol* 2006; 21:394-9.

- In patients with CKD, adolescence usually brings about a worsening in clinical control and therapeutic adherence.
- Moreover, there is an additional stressor, which is the change in the healthcare team that cares for the patient.
- A worsening in the clinical control has been demonstrated when these patients were referred to healthcare teams that treated adult patients.

- Reynolds JM, Morton MJ, Garralda ME, Postlethwaite RJ, Goh D. Psychosocial adjustment of adult survivors of a pediatric dialysis and transplant programme. Arch Dis Child 1993; 68:104-10.

- In the study by McDonagh, the CKD itself, plus the side effects of the medications, the school absenteeism and the psychosocial alterations, notably the low self-esteem observed in these patients, resulted in growth and development retardation, pubertal delay and worse cognitive performance.

- In this study, the adolescents with CKD presented worse social and sexual performance than the control group.

McDonagh JE. Child-adult interface. The adolescent challenge. Nephrol Dial Transplant 2000; 15:1761-5.

KEY MESSAGES

- Pediatric patients with CKD are frequently affected by mental disorders at higher frequency when compared to the general population.
- This fact is due to the disruptions in the family dynamics, the troublesome treatment and the chronic disease itself.
- These patients also demonstrated a worse school performance, low self-esteem and difficulty to establish relationships with their peers.

- The reviewed studies showed that the children undergoing dialysis treatment had a worse emotional performance in comparison to those undergoing the conservative treatment and transplanted patients.
- The mental and emotional health of the pediatric patients with CKD is a determinant factor on the disease course, prognosis and therapeutic success.





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ما يبذل ؟
الأمامية ؟
كلما عرفت المزيد عن صحتنا

حمام

معلومات سريرية

Thank you