Revista de Pesquisa Cuidado é Fundamental Online

E-ISSN: 2175-5361

rev.fundamental@gmail.com

Universidade Federal do Estado do Rio de Janeiro

Brasil

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Revista de Pesquisa Cuidado é Fundamental Online, vol. 5, núm. 3, julio-septiembre, 2013, pp. 94-103

Universidade Federal do Estado do Rio de Janeiro

Rio de Janeiro, Brasil

Available in: http://www.redalyc.org/articulo.oa?id=505750941008

ISSN 2175-5361 DOI: 10.9789/2175-5361.2013v5n3p94

RESEARCH

PROFILE OF CHILDREN AND ADOLESCENTS WITH CHRONIC RENAL FAILURE FOLLOWED UP AT NEPHROLOGY UNITS

PERFIL DE CRIANÇAS E ADOLESCENTES COM INSUFICIÊNCIA RENAL CRÔNICA ACOMPANHADOS EM UNIDADES DE NEFROLOGIA

PERFIL DE NIÑOS Y ADOLESCENTES CON INSUFICIENCIA RENAL CRÓNICA SEGUIDOS EN UNIDADES DE NEFROLOGÍA

Ayla Costa Maciel[1], Juliana de Oliveira Freitas Miranda[2]

ABSTRACT

Objective: Characterize the profile of children and adolescents with chronic renal failure followed up at nephrology units in the town of Feira de Santana, Bahia, Brazil. **Methods:** This is a quantitative, retrospective and descriptive, research which investigated socio-demographic, clinical, and therapeutic variables in the medical records of 35 children and adolescents followed up at nephrology units by June 2010. **Results:** The main etiology was chronic glomerulonephritis (34.2%); 88.6% of patients were diagnosed and started treatment between 10 and 20 years of age. The most prevalent comorbidities were systemic arterial hypertension (51.4%) and diabetes mellitus (48.6%). The main associated clinical manifestations were systemic arterial hypertension (51.4%), uremia (48.6%), edema (42.9%), and anemia (31.4%); 97.1% of patients underwent hemodialysis. Most patients continued on hemodialysis (40%) up to 2 years of treatment (54.3%). **Conclusion:** This study allowed one to know this profile of patients, hitherto unknown, and it may contribute to the planning of care actions aimed at this clientele. **Descriptors**: Chronic renal failure, Adolescent, Child.

RESUMO

Objetivo: Caracterizar o perfil de crianças e adolescentes com insuficiência renal crônica acompanhados em unidades de nefrologia do município de Feira de Santana-BA. **Métodos:** Trata-se de pesquisa quantitativa, retrospectiva e descritiva, que investigou variáveis sociodemográficas, clínicas e terapêuticas nos prontuários de 35 crianças e adolescentes acompanhados em unidades de nefrologia até junho de 2010. **Resultados:** A principal etiologia foi a glomerulonefrite crônica (34,2%); 88,6% dos pacientes foram diagnosticados e iniciaram o tratamento entre 10 e 20 anos de idade. As comorbidades mais prevalentes foram hipertensão arterial sistêmica (51,4%) e diabetes *mellitus* (48,6%). As principais manifestações clínicas associadas foram hipertensão arterial sistêmica (51,4%), uremia (48,6%), edema (42,9%) e anemia (31,4%); 97,1% dos pacientes se submeteram a hemodiálise. A maioria dos pacientes continuava em hemodiálise (40%) com até 2 anos de tratamento (54,3%). **Conclusão:** Este estudo possibilitou conhecer esse perfil de pacientes, até então desconhecido, e pode contribuir com o planejamento de ações assistenciais voltadas a essa clientela. **Descritores:** Insuficiência renal crônica, Adolescente, Criança.

RESUMEN

Objetivo: Caracterizar el perfil de niños y adolescentes con insuficiencia renal crónica seguidos en unidades de nefrología del municipio de Feira de Santana, Bahia, Brasil. **Métodos:** Esta es una investigación cuantitativa, retrospectiva y descriptiva, que investigó variables sociodemográficas, clínicas y terapéuticas en los prontuarios de 35 niños y adolescentes seguidos en unidades de nefrología hasta junio de 2010. **Resultados:** La principal etiología fue la glomerulonefritis crónica (34,2%); el 88,6% de los pacientes fueron diagnosticados e iniciaron el tratamiento entre 10 y 20 años de edad. Las comorbilidades más prevalentes fueron hipertensión arterial sistémica (51,4%) y diabetes mellitus (48,6%). Las principales manifestaciones clínicas fueron asociadas con hipertensión arterial sistémica (51,4%), uremia (48,6%), edema (42,9%) y anemia (31,4%); el 97,1% de los pacientes se sometieron a hemodiálisis. La mayoría de los pacientes continuaba en hemodiálisis (40%) después de hasta 2 años de tratamiento (54,3%). **Conclusión:** Este estudio posibilitó conocer ese perfil de pacientes, hasta ahora desconocido, y puede contribuir con el planeamiento de acciones de asistencia dirigidas a esa clientela. **Descriptores:** Insuficiencia renal crónica, Adolescente, Niño.

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INTRODUCTION

It's estimated that the annual incidence of end-stage chronic kidney disease (CKD) in children is between 5 and 15 patients per million in the child population (PMCP) and its prevalence is between 22 and 62 per million, with wide variation in the literature.[1]

Despite a relatively low incidence, chronic renal failure (CRF) is a disease which has a slow clinical course and often silent. This way, there may be an underestimation of its rates in childhood, making it difficult to actually estimate how many children and adolescents have this disease. Latin American or Brazilian data are scarce and the exact incidence of chronic renal failure in our environment is unknown, both because of the possibility of non-recognition of this problem in economically disadvantaged regions and because of undernotification of diagnosed cases.[2]

Although the child/adolescent population presents a lower incidence of the disease when compared to the adult population, in the child CRF becomes even more dramatic, since, in addition to its clinical severity, it affects an organism in full growth process and biological, cognitive, social, and emotional development.[3] This way, the impact of CRF on the children and adolescents' health is undeniable, something which constitutes a challenge for health systems worldwide, by presenting, in addition to the usual complications to adults, unique features resulting from manifestations of the disease in individuals going through a growth and developmental process.[1]

In a census published in 2008 by the Brazilian Society of Nephrology (SBN), one estimated that there were 41,614 patients undergoing dialysis treatment modalities in the country, and, out of these, about 666 patients were aged less than 20 years; this census only had the participation of 327 of the 684 units enrolled in SBN. Furthermore, the mortality rate in children with CKD undergoing dialysis treatment is from 30 to 150% higher than the general pediatric population and the life expectancy for a child from 0 to 14 years undergoing dialysis treatment is only 20 years.[4]

This study aimed to define the profile of children and adolescents with chronic renal failure followed up by the nephrology services in the town of Feira de Santana, Bahia, Brazil, up to June 2010, in addition to identify the main socio-demographic, clinical, and therapeutic characteristics of children and adolescents with chronic renal failure. Studies like this may provide a deeper knowledge on chronic renal failure in children and adolescents and contribute to the production of scientific evidence and the planning of health actions aimed at this population.

METHODOLOGY

This is a quantitative, retrospective and descriptive, study which investigated the profile of 35 children and adolescents aged between 0 and 20 years of age with chronic renal failure followed up at the two only nephrology units in Feira de Santana by the Unique Health System (SUS) up to June 2010, through the investigation in their medical records stored in the services. The patients treated by means of health insurance plans and private clients were excluded. The instrument used for data collection was an investigation form whose variables under analysis were divided into three groups: socio-demographic, clinical, and therapeutic.

The research was prepared in accordance with the Resolution 196/96, from the National Health Council of the Ministry of Health, and the recommendations of the National Commission of Research Ethics (CONEP).[5] Data collection was

conducted under permission of the institutions' coordination and the Research Ethics Council of Universidade Estadual de Feira de Santana (UEFS), under the Protocol 044/2010.

The data obtained were computed on a database and electronically processed using the software *Statistical Package for the Social Sciences* (SPSS), version 11.0. One performed analyses of simple and bivariate, absolute and relative, frequencies through the descriptive statistics technique. The results were presented under the form of graphs and tables.

RESULTS AND DISCUSSION

Table 1. Sociodemographic characterization of children and adolescents with chronic kidney disease enrolled in nephrology units. Feira de Santana, June 2010. N = 35.

Sex	**N**	**%**
Female	19	54.3
Male	16	45.7
Age		
0-6 years	01	2.9
6-10 years	01	2.9
10-20 years	33	94.2
Education level		
Illiterate	03	8.6
Without schooling	00	00
Primary Education	23	65.7
High School	02	5.7
Higher Education	00	00
Not available	07	20
Birthplace		
Feira de Santana	09	25.7
Other	26	74.3

Table 1 displays the study population distribution by sex, age, education level, and birthplace; 54.3% of participants were female and 45.7% male, 94.3% were aged between 10 and 20 years, 65.7% were at the Primary Education, 5.7% of patients were at the High School, 8.6% of them were illiterate, and in 20% of the medical records investigated there was no record of schooling. Regarding birthplace, 25.7% were born in Feira de Santana, most of them (74.3%) were from surrounding towns, since many of these don't have dialysis services.

Table 2. Distribution of weight and height percentiles of children and adolescents with chronic kidney disease enrolled in nephrology units. Feira de Santana, June 2010. N = 35.

Weight percentile	**N**	**%**
< P3	16	45.7%
P3–P50	11	31.4%
P50–097	03	8.5%
Not available	05	14.3%
Height percentile		
< P3	10	28.7%
P3–P50	11	31.4%
P50-097	03	8.5%
Not available	11	31.4%

Regarding weight, 45.7% of children and adolescents had a weight below the percentile 3, 31.4% were between P3 and P50, and 8.5% were between P50 and P97. No patients were computed with weight above P97 and in 14.3% of the medical records this data wasn't included. These values correspond to weight after the hemodialysis session ("dry weight").

Table 2 also indicates the population distribution according to height, showing that 31.4% of patients were between P3 and P50, 8.5% were below P3 and 28.7% were between P50 and P97; 31.4% of the medical records didn't register this datum.

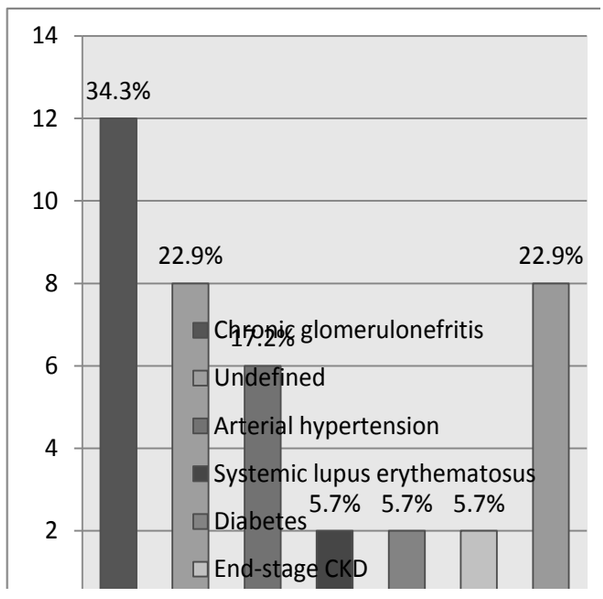

Figure 1. Main causes of chronic kidney disease in children and adolescents enrolled in nephrology units. Feira de Santana, June 2010.

Figure 1 displays the main causes of CKD pointed out by nephrologists and registered in the medical records of children and adolescents participating in this study. Chronic glomerulonephritis shows up as the main cause (34.3%) of CKD among patients. Undefined causes showed up in 22.9% of the medical records, followed by arterial hypertension (17.2%). Systemic lupus erythematosus, diabetes, and end-stage CKD presented the same percentages, being responsible for the disease in 17.2% of children and adolescents. Other causes, such as nephrolithiasis and chronic pyelonephritis were grouped in the category "others" due to the low prevalence. It's worth mentioning that some medical records had more than one cause.

Table 3. Distribution of dialysis treatment modalities and kinds of access for dialysis treatment used in children and adolescents with chronic kidney disease enrolled in nephrology units. Feira de Santana, June 2010. N = 35.

Dialysis treatment modalities	**N**	**%**
Hemodialysis	34	97.1%
Peritoneal dialysis	08	22.9%
Kidney transplantation	04	11.4%
Kinds of access for dialysis treatment		
Double lumen catheter	34	97.1%
Arteriovenous fistula	26	74.3%
Tenckhoff catheter	08	22.9%
Permicath catheter	02	5.7%

Table 3 indicates the treatment modalities and the kinds of access which had already been adopted for children and adolescents throughout the dialysis treatment. 97.1% of patients were undergoing or had already undergone hemodialysis. Peritoneal dialysis was being used or had already been used as dialysis treatment by 22.9% of patients and only 11.4% underwent kidney transplantation.

The most used kinds of accesses to perform the dialysis treatment for these patients were double-lumen catheter and arteriovenous fistula. Out of the 35 participants in this research, 97.1% were using or had already used the double-lumen catheter, while 74.3% had already undergone dialysis or were undergoing dialysis through an arteriovenous fistula. Only 5.7% of patients had already used or were using the Permicath catheter and 22.9% had already used or were using the Tenckhoff catheter for peritoneal dialysis.

Table 4. Distribution of children and adolescents with chronic kidney disease enrolled in nephrology units according to treatment time and destination described in the last record. Feira de Santana, June 2010.

	Treatment time									
	0-2 years		**2-4 years**		**4-6 years**		**6-10 years**		**TOTAL**	
Destination	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Remain on peritoneal dialysis	02	5.7	0	0	0	0	0	0	2	5.7
Remain on hemodialysis	06	17.2	05	14.3	0	0	03	8.5	14	40
Death	08	22.9	04	11.4	0	0	0	0	12	34.3
Transfer	03	8.5	02	5.7	01	2.9	01	2.9	7	20
TOTAL	19	54.3	11	31.4	01	2.9	04	11.4	35	100.0

Table 4 points out the relationship between the child and adolescent's destination and the treatment time and it shows that 40% of patients remained on hemodialysis within the study period, 34.3% died, 20% were transferred to hemodialysis services in other towns during therapy, and only 5.7% remained on peritoneal dialysis.

Regarding the patients who remained on hemodialysis, 17.2% had 0-2 years of treatment, 14.3% had 2-4 years, and 8.5% had 6-10 years; 34.3% of children and adolescents died, 22.9% were had 0-2 years of treatment, and the patients who remained on peritoneal dialysis had less than 2 years of therapy.

Socio-demographic aspects of children and adolescents with chronic kidney disease: sex, age, education, and birthplace

According to the census of 2008 released by SBN, most dialysis patients are male (57%).[6] A study with 45 children aged between 0 and 12

years, with CRF, in Botucatu, Sao Paulo, Brazil, within the period from January 1972 to December 2000, found out that 58.7% of cases involved males.[7] These data are different from those presented in this study, where 54.3% of children and adolescents with CKD enrolled and followed up in the nephrology units were female.

Concerning age, in this study, 94.3% of patients were aged between 10 and 20 years. The census released by SBN in 2008[6] indicated that 1.6% of the enrolled patients were aged between 0 and 20 years. Although the data on CKD in the pediatric age group are scarce and, therefore, can't represent reality in a reliable manner, it's known that, both in the pediatric population and among adults, CRF rates can rise with age.[1,2]

Among the various aspects changed by a chronic disease, such as CKD, school life shows to be among them.[8] This study reveals a low education level, since most of patients were aged between 10 and 20 years and should be attending High School, a fact which may be related to CKD. The young person finds it difficult to keep up with the education activities proposed by the school, because she/he is forced to dedicate her/his time in the clinical therapy.[9]

The census of 2004 from SBN portrayed that Bahia is the 6th state in Brazil in number of patients in terms of hemodialysis programs.[10] However, the number of hemodialysis units in Bahia is below the national average. This fact can lead many patients to spend an excessive time to perform their dialysis treatment, and also a physical and emotional exhaustion due to the need to transfer to reference units in other towns. In this study, most of the children and adolescents (74.3%) were living in towns surrounding Feira de Santana. In this context, it's worth taking into account the place of residence of these patients, since many of them were living in small towns, where rural houses prevail, something which further complicates access to downtown and, as a result, to the nephrology units.

The means of transport used to go to the nephrology units are usually vehicles of municipal governments, which transport patients to various destinations, passing through roads in poor condition, adding extra time to the trip. Much of the patients' time is dedicated to weekly dialysis sessions, something which can cause damages to the quality of life. Many of them and their relatives need to move from their towns of residence, they have difficulty to keep jobs, besides the social repercussions and the economic impact associated to this fact.[11]

Weight and height percentiles

The weight described in Table 2 consists in the "dry weight", because, as the disease progresses and diuresis decreases or disappears, the weight evaluation turns inaccurate and, in most cases, it's overestimated due to accumulation of fluids.[12]

Most children and adolescents in this study had weight and height below the percentiles appropriate for their age group. One thinks that many patients with CKD haven't the caloric support needed for this developmental phase. Besides, an adequate nutritional approach is one of the pre-dialysis factors which have to be prioritized.[2] Malnutrition can be due to chronic disease, regardless of the availability of care and food supply. The caloric needs of a child with renal failure are usually much larger than those of a healthy child. Before any further intervention, the caloric intake must be optimized.[12]

The protein intake needs are also increased in patients with renal failure, especially those undergoing peritoneal dialysis or those who may have increased protein losses through dialysis. An adequate supplementation of vitamins and

minerals must also be provided and, sometimes, here's a need for adding bicarbonate to the diet for correcting the metabolic acidosis.[13]

Children with kidney disease are more prone to develop growth problems, especially if they're diagnosed with progressive renal failure under 10 years of age. Among the growth problems there's also the absence of weight gain, something which can help diagnosing the disease and needs intervention. The pediatric patient may have a persistent growth failure due to various other factors. Specifically, the patient may have a disturbance in the biochemical pathway which regulates the growth hormone, and that, then, shows up as a deficiency of the functional growth hormone, usually occurring when the child's kidney function has decreased to 30% or less. However, there're other variables which can cause growth failure, such as nutritional deficiencies. These variables must be taken into account, monitored, and corrected, so that there's an optimization of the chronic renal patient's growth and development.[13]

In a comparative study between siblings without renal failure, one obtained as a result the fact that the individuals with the disorder, even keeping the usual weight/height ratio according to their age, still showed this ratio significantly lower when compared to the control group.[12] Perhaps, the change in the development of weight and height is associated to late CRF diagnosis, as well as to the metabolic and hormonal changes caused by the disease.[7]

Possible causes of chronic kidney disease

The causes of CKD pointed out by nephrologists among children and adolescents in this study were chronic glomerulonephritis, arterial hypertension, systemic lupus erythematosus, diabetes, and end-stage CKD, as well as causes undefined. A study with 45 children aged between 1 month and 12 years, from January 1972 to December 2000, found out that the two main causes of CRF were urinary tract malformations (48.8%) and glomerular diseases (40%). The causes of end-stage CRF in 13 children (the 5 remaining and 8 of the 22 children who showed malformation of the urinary tract) were, by order of prevalence: chronic glomerulonephritis, vesico-ureteral reflux, hemolytic uremic syndrome, and polycystic kidneys.[7]

Unlike adults, in whom diabetes and arterial hypertension are the most frequent etiologies, congenital causes are responsible for a high percentage of CKD cases in childhood.[1]

In the registration framework of the North American Pediatric Renal Transplant Cooperative Study (NAPRTCS) of 2005, almost half of cases are explained by patients with a diagnosis of obstructive uropathy (22%), aplasia/hypoplasia/dysplasia (18%), and reflux nephropathy (8%). Taking into account that the structural causes predominate among younger patients, the incidence of glomerulonephritis increases in individuals over 12 years.[14]

A study with 49 children who were followed up in a pediatric nephrology ward of a hospital in Sao Paulo, from November 2003 to September 2004, indicated as a characteristic the late renal failure diagnosis. It was found out that 14.3% of these children had an undetermined etiology, indicating that when they got to the service their CKD was already a late one.[15] So, often the children and adolescents arrive at the units with an advanced renal injury and, therefore, the primary cause of CKD isn't specified, something which explains the reason for the considerable prevalence of undefined causes in the medical records of the children and adolescents studied.

Treatment modalities adopted

Among the treatment modalities for CKD, hemodialysis was the most frequently adopted for

the children and adolescents participating in this study, followed by peritoneal dialysis and kidney transplantation. Not only clinical issues can be associated to the fact that hemodialysis is the most prevalent treatment modality in this study, but also socioeconomic issues, such as housing conditions, living in surrounding towns, and in predominantly rural locations, which constitute hindering factors for conducting peritoneal dialysis.

According to a census published by SBN in 2008, most patients (89.4%) in Brazil were undergoing hemodialysis, while the rest of them (11.6%) were using some kind of peritoneal dialysis, being the continuous ambulatory peritoneal dialysis (CAPD) the most frequent one (5.3%).[6] In fact, peritoneal dialysis emerged as an alternative method to hemodialysis to be especially used in low weight children (less than 20 kg), where a vascular access is difficult, or in patients who don't accept repeated venous punctures.[16] A research with 45 children aged between 1 month and 12 years, from January 1972 to December 2000, found out that peritoneal dialysis was started in 28.8% children, and most of them (69.2%) were referred for CAPD as the preferred method.

Regarding kidney transplantation, the literature registers that the first successful kidney transplantation was carried out in 1954, in order to improve the ill patient's quality of life, since, until then, there was no treatment for CKD. However, the first data on kidney transplantation in children were published only in 1966.[15] Although Brazil has one of the greatest kidney transplantation programs in the world, the annual number of transplant patients is less than the number of patients undergoing dialysis who would need a transplantation.[11]

There're a few cases of kidney transplantation for children and adolescents assisted in Feira de Santana. This may be due to the location of the transplantation centers in Bahia, which are predominantly located in the state's capital, or also to the size of the waiting list for a kidney donation, which totals more than 3,000 patients. Moreover, one must take into account the age, the weight of the child/adolescent, and the kind of donor, since these factors limit or exclude the possibility of a transplantation, its kind, and its location.[18] It's also important to highlight that kidney transplantation among this population interferes with the quality of life and it not always means a permanent cure for CKD.[18,19]

The technological increase observed in the hemodialysis and the peritoneal dialysis procedures over the last 20 years, associated to the recognition and treatment of a variety of factors (nutrition, infection, growth dialysis kinetics), improved a lot the treatment of children with CRF, providing them with adequate conditions for completion of the renal transplantion.[16]

Kind of access for treatment

The kinds of access for dialysis identified in this study were the double lumen vascular catheter, the arteriovenous fistula, the Permicath catheter, and the Tenckhoff catheter. The double lumen catheter and the arteriovenous fistula are used for performing hemodialysis and, as this was the main treatment modality, such accesses had a highlight, especial the double-lumen catheter, as it's initially used until there's an indication, construction, and maturation of the arteriovenous fistula.

The arteriovenous fistula requires some special care procedures, such as appropriate aseptic care, and it's subject to some complications, such as stenosis, thrombosis, and even hand edema. However, the double lumen catheter is a temporary access whose risk of

infectious complication is very high.[20]

The venous Permicath catheter has been an option for patients who don't have access or those using it only for a few months, and it's recommended for small children. The Tenckhoff catheter has a cuff inserted into the peritoneal cavity through a surgical route in patients with a referral for intermittent peritoneal dialysis.[20]

Treatment time and destination

The treatment time of patients in this study ranged from 0 to 10 years; some of them remained in treatment through hemodialysis and peritoneal dialysis, some were transferred to other dialysis services in other towns, and a considerable number of them, unfortunately, evolved to death in the first 4 years of treatment.

It's worth highlighting that, despite hemodialysis has suffered a major technical improvement, its use is still difficult in newborn infants and nursing infants, especially due to the high incidence of complications, and one prefers to provide these patients with peritoneal dialysis.[21]

For a large number of patients, hemodialysis is regarded, at first, as a real life possibility, having in mind that many of them start treatment in situations of extreme physical suffering and, soon after the first session, there's already a great relief in symptoms.[9] In a study conducted in São Paulo with eight children, some of them reported their preference for hemodialysis, explaining that this brings benefits, i.e. being able to eat and drink during the procedure, and also the fact of having a team to provide support and assistance when it's needed. The children who are ill for longer or those who have information and/or experience concerning the various treatment modalities wait for kidney transplantation because they know that it's the next step and that it can ensure a better quality of life.[22]

Regarding death among children and adolescents with CKD, fear of death is imminent, since the expected survival for patients aged from 0 to 14 years undergoing dialysis is only 20 years.[2] According to the census of 2008 from SBN, 15 2% of kidney patients die annually, and out of them, 0.4% correspond to patients aged between 0 and 20 years.[6]

For cases of transfer to other services, it's worth remembering that not always the nearest hemodialysis clinic has an availability of vacancy to receive them, something which leads them to be sent to units further away from their home.[11]

CONCLUSION

Characterize the profile of children and adolescents with CKD can bring technical and scientific contributions to the management agencies, services, and health teams working in this sector, because it allows someone to deepen knowledge on the population studied, as well as on its peculiarities, facilitating the planning of actions and individualized assistance, favoring a better adaptation of all subjects involved in the CKD context.

Accordingly, the health professionals working with children and adolescents with CRF must enhance their attention with regard to this population and be prepared to identify risk factors, associated manifestations, comorbidities, and possible causes of this pathology, since these characteristics influence on the therapeutic conducts adopted and on the monitoring of children and adolescents.

One believes it's of paramount importance to carry out studies mainly focusing on children and adolescents with chronic diseases, especially CKD, having in mind that there're few studies published in Brazil addressing the theme among this population. Obtain and disseminate research results brings contributions on various aspects,

from care itself to increased quality of life for children and adolescents with CRF.

In the face of chronic disease in childhood and adolescence, a reasonable level of quality of life is very relevant and, because of this, all factors involving its bearer should be discussed in search of alternatives which provide a daily life close to what is regarded as normal, avoiding as much as possible the complications, both of the disease itself and the treatment adopted.

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Received on: 13/08/2012
Required for review: No
Approved on: 27/02/2013
Published on: 01/07/2013