FAMILY’S EXPERIENCE OF LIVING WITH A CHILD’S CHRONIC RENAL DISEASE

EXPERIÊNCIA DA FAMÍLIA NO CONVÍVIO COM A DOENÇA RENAL CRÔNICA DA CRIANÇA

ABSTRACT

Objectives: to describe the family’s experience of living with a child’s chronic renal disease and verify the changes faced by the family of the sick child. Method: exploratory and descriptive study with a qualitative approach, developed in a Child’s Hospital in João Pessoa/PB - Brazil, with nine parents of children that is suffering of chronic renal disease. For data collection it was used an interview script using the following guiding questions: “How did the family reaction when knew about the child’s chronic renal failure? Tell me about your experience living with a child suffering of chronic renal disease? And what did change in the family’s routine to you can perform the accompanying of child’s peritoneal dialysis?” For the data analysis, it was used the technique of Collective Subject Discourse - Discurso do Sujeito Coletivo (DSC) , after the approval by the Research Ethics Committee of Faculdade de Enfermagem Nova Esperança (FACENE), underneath the CAAE number: 2510.0.000.351-10, and the Protocol number: 76/10. Results: DSC has evidenced how difficult it was for these families to discover the child’s disease, as well as the changes faced in order to perform the treatment, which range from behaviors changing, feelings, and family routines, in the social and scholar life of the sick child, until removals of residence, job changes to its parents, and even changes in the way of seeing life. Conclusion: the family’s care to the child with chronic renal disease implies great (heavy) changes; therefore the family structure undergoes deep adaptations to tackle with the problem. Descriptors: child; family; chronic disease; chronic renal insufficiency.

RESUMO

Objetivos: descrever a experiência da família no convívio com a doença renal crônica da criança e verificar as mudanças enfrentadas pela família. Método: estudo exploratório e descritivo com abordagem qualitativa, desenvolvido em um Hospital Infantil de João Pessoa-PB, com nove pais de crianças com doença renal crônica. Para a coleta de dados foi usado o roteiro de entrevista com as questões norteadoras: “Como foi a reação da família ao saber da insuficiência renal crônica da criança? Conteste-me sobre a sua experiência no convívio com a criança portadora de doença renal crônica? E o que mudou na rotina familiar para vocês conseguirem fazer o acompanhamento da diálise peritoneal da criança?” Para a análise dos dados foi empregado o método do Discurso do Sujeito Coletivo (DSC), após aprovação do projeto de pesquisa pelo Comitê de Ética em Pesquisa (FACENE), sob CAAE 2510.0.000.351-10 e Protocolo nº 76/10. Resultados: o DSC evidenciou a dificuldade da descoberta da doença da criança para essas famílias e as mudanças enfrentadas para a realização do tratamento, que vão desde alterações de comportamentos, sentimentos, nas rotinhas familiares, na vida social e escolar da criança, até mudanças de domicílio e de trabalho dos pais e do modo de ver a vida. Conclusão: o cuidado da família à criança portadora de doença renal crônica implica grandes mudanças, pois a estrutura familiar sofre adaptações profundas para enfrentar o problema. Descriadores: criança; família; doença renal crônica; insuficiência renal crônica.

RESUMEN

Objetivos: describir la experiencia de la familia que convive con la enfermedad renal crónica del niño; verificar los cambios experimentados por la familia. Método: se trata de un estudio exploratorio y descritivo con abordaje cualitativo, desarrollado en el Hospital Infantil de João Pessoa (Pará, Brasil), con nueve papás de niños con enfermedad renal crónica. Para la recopilación de datos se utilizó el guión de entrevista con las cuestiones de referencia: “¿Cómo fue la reacción de la familia al conocer la insuficiencia renal crónica del niño? ¿Cuánto acerca de su experiencia en la convivencia con el portador de enfermedad renal crónica? ¿Qué cambió en su rutina familiar para que puedan realizar el seguimiento de la diálisis peritoneal del niño?” Para el análisis de los datos se utilizó la técnica del Discurso del Sujeito Colectivo (DSC), tras aprobación del proyecto de investigación por el Comité de Ética en Investigación de la Facultad de Enfermería de Nueva Esperanza, bajo CAAE 2510.0.000.351-10 y Protocolo nº 76/10. Resultados: el DSC destacó la dificultad de descubrir la enfermedad del niño para estas familias y los cambios experimentados para la realización del tratamiento, que van desde alteraciones de comportamientos, sentimentos, rutinas familiares, vida social y escolar del niño, hasta incluso los cambios de domicilio y trabajo de los padres y modo de ver la vida. Conclusión: el cuidado de la familia al niño portador de enfermedad mental crónica implica grandes cambios, puesto que la estructura familiar sufre adaptaciones profundas para enfrentar el problema. Descriptores: niño; familia; enfermedad renal crónica; insuficiencia renal crónica.

Nurse, PhD student from Program of Post-Graduate in Nursing of the CCS/UFPI. Assistance Nurse of University Hospital Lázaro Wandenier/PB. Professor at Faculdade de Enfermagem Nova Esperança/FACENE, João Pessoa/PB, Brazil. E-mail: danielaantao@hotmail.com; Nurse, Master student from Program in Education Sciences of Los Angeles University and Technology University – Universidade Lusófona de Humanidades e Tecnologias - ULHT. Professor at FACENE, João Pessoa/PB, Brazil. E-mail: marquesdk@gmail.com; Nurse, Master student from ULHT, Assistance Nurse of Neonatal Intensive Care Unit of Maternidade Frei Damião. Professor at FACENE, João Pessoa/PB, Brazil. E-mail: danielaantao@hotmail.com; Nurse, PhD in Nursing. Professor of Nursing Graduation and Program of Post-Graduate in Nursing of UFPI. João Pessoa/PB, Brazil. E-mail: marquesdk@gmail.com.
INTRODUCTION

The family as a unit of research and care has received increasing interest. The foundations of centered care approaching in the family emphasize the integral role that family members play in the life and well-being of the child.¹

For the families, the birth of a child creates reasons for happiness and new expectations. When we refer to the child, it is expected that it lives situations of health to grow and develop itself; however, when confronted with it in the condition of a patient, as every human being, will probably have it behavior changed,² especially if is beneath a chronic disease.

The main characteristic of chronic diseases is the their duration; they are characterized by deterioration or malfunction of an organ or body system, the progressiveness, the impairment of functional capacity of the individual and the need for prolonged treatment lasting longer than three months in a year, or requiring hospitalization for a period longer than a month, which may often be incurable.³

In this sense, the experience of having a child hospitalized or diagnosed with chronic disease creates difficult times for the family involved in this situation. The diagnosis is a stressful time, tense, covered with uncertainty and can lead to a painful process in the lives of families, especially if the disease goes to an irreversible progression, as occurs in children with chronic renal disease.

The chronic renal failure occurs when the harmed kidneys can no longer committed to maintain under normal conditions the chemical structure of normal body fluids, with irreversible loss of renal function. There is gradual reduction of glomerular filtration rate (GFR), leading to accumulation in the body of toxic non-volatile solutes and acid-base imbalance and water-electrolyte. The progressive deterioration culminates in the clinical syndrome known as uremia. The most common causes are: congenital malformations of the kidneys and urinary tract, vesicourethral reflux associated with recurrent urinary tract infection, chronic pyelonephritis, hereditary disorders, chronic glomerulonephritis and glomerulonephropathy associated with systemic diseases, such as anaphylactoid purpura and systemic lupus erythematosus.⁴

The incidence of chronic renal failure (CRF) in children is poorly documented; its magnitude is still estimated from statistics for entrance into programs for dialysis and renal transplantation. The causes of renal disease have regional variations. In general, the etiology and the incidence of CRF vary depending on age. In children under five years, the most common causes are malformations (congenital) of the urinary tract, while at the age of five to fifteen years prevail acquired and inherited renal diseases, the acquired forms of renal disease are the illnesses with faster progression.⁵

For the family, the threat of imminent loss of one of its members, as well as constant interaction with the hospital environment and its actors enable the construction of a huge diversity of meanings and codes. In this context, the disease, and unique experience, it is also life experience, of a procedural nature, jointly lived (experienced) by the patient and the family.⁶

The family of patients with chronic disease undergoes a process of misfit in its form of organization and its functions, because it has to adapt the family dynamic to the needs and activities related to treatment and support to member carrier of the disease. The adaptation needs of the family dynamics are intense and tend to increase as the disease evolves.

Considering that the children need a family caregiver to the accompanying of the health care, it is essential that these families have knowledge and effective supports, so that care can have the best possible quality. Having this concept, it begins from the principle that it is necessary to know firstly the difficulties faced by families to play the role of main caregiver, thus that may occur later adjustments of health services and social support in the face of this problem.

For instrumentalization of this study it was evaluated the following questions: how was the family’s reaction upon knowing about the child’s chronic renal failure? Tell me about your experience when living with the child with chronic renal disease? And what has changed in family routine for you can do the accompanying of peritoneal dialysis in children?

Through the questioning, the objectives of this study are: to describe the family’s experience in living with chronic renal disease in children and to verify the changes faced by the family.

METHOD

Exploratory and descriptive study with
Family’s experience of living with a child’s chronic renal disease and the evaluation of the impact in various contexts in the first month of dialysis treatment, after explanation of the reason, objectives and procedures of the research, as well as ensuring the confidentiality of information and freedom to withdraw your consent at any stage of the investigation, that upon receipt of the information authorized its participation, by signing the consent form.

Data collection was like script of an interview with open and closed questions, to allow greater interaction between the interviewer and the subject of research. The statements were written to record information.

We performed the characterization of the participants, grouped and presented in absolute and relative numbers. For analysis of the interviews, we used the Técnica do Discurso do Sujeto Coletivo, DSC, (Technique of Collective Subject Discourse) which consists of a set of procedures for tabulation and organization of discursive data from the testimony of participants, allowing the recovery of understanding about a particular subject in a given universe. This analysis process involves the following steps: selecting the key-expressions of each particular discourse. These expressions should reveal the essence of the discursive content; identify the Central Idea (CI) for each key-expression.7

With this technique, the statements do not cancel themselves or be reduced to an unifying common category since it seeks to do is to reconstruct, with excerpts from speeches individual, like a puzzle, many synthetic discourses as are deemed necessary to express a determined way of thinking or social representation of a phenomenon. Thus, the DSC is a methodological strategy, using a discursive strategy, allowing the realization of research of redeem of the collective opinion, in which the thought, as discursive behavior and social fact individually internalized can express itself.7

The research project was submitted to evaluation of the Comitê de Ética em Pesquisa da Faculdade de Enfermagem Nova Esperança (FACENE) underneath the CAAE 2510.0.000.351-10 and Protocol n° 76/10. Moreover, the research took into consideration the ethical aspects in Research Involving Human Beings, contained in Resolution 196/96 of the Brazilian National Health Council - Conselho Nacional de Saúde (CNS) / Brazilian Ministry of Health - Ministério da Saúde (MS) and Resolution 311/2007 of the Brazilian Code of Ethics for Professional Nursing - Código de Ética dos Profissionais de Enfermagem.

RESULTS

The sample was composed of nine relatives of both sexes, the prevalence of females with 89% (8) and in males 11% (1). During the research period there were nine children enrolled in this hospital for dialysis treatment in the researched institution and the sample was composed of all the family.

The children were mostly accompanied by their mothers and 88.8% (8), which are usually the main caregivers in the accompanying of hospitalized children, however, a male child was accompanied by his father, represented by 11.1% (1) of the sample.

It has predominated in the age group of caregivers from 30 to 40 years, totaling 66.7% (6) of the participants, and then aged between 20-30 years, 50-60 years and above 60 years - all with 11.1% (1) of participants for each age group.

The predominant age group of children who were undergoing dialysis was between 11 and 14 years, with 66.7% (6), the others identified in the study were ages 2, 10 and 18 years, the context in which contained 11.1% (1) for each old respectively. Since 55.6% (5) were female and 44.4% (4) male.

All children were diagnosed with chronic renal failure before the age of 8; these only 11.1% (1) was diagnosed in the first month of life, for having renal malformation. For other cases, all the accompanying reported that disease started with the repetitive urinary tracts with posterior diagnosis of a glomerulonephritis (GN), which is a disease that occurs after infection in various structures within the kidney, and the treatment with antibiotics and anti-inflammatories and corticosteroids was not enough to resolution of the problem.

Regarding the type of dialysis 77.8% (7) performed automated peritoneal dialysis and 22.2% (2) performed manual peritoneal dialysis.

The family income of 77.8% (7) was accompanied by his father, represented by 11.1% (1) of the sample.

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amounts ranging from R$ 500 to 1000.00, then 22.2% (2) living with income of R$ 1500 to 1800.00.

This data were obtained from the guiding questions. The first: How was the family's reaction upon knowing of the child's chronic renal failure? Being identified two central ideas: I - The discovery was shocking, II - A lot of difficulty and sadness. The second question: Tell me about your experience when living with the child with chronic renal disease? Also were identified two central ideas: I - A new experience, II - There are cases of this disease in the family. The third question: What has changed in the family routine for you can do the accompanying of peritoneal dialysis in child? There was a Central Idea: I - Everything has changed the routine and in our lives. Each one CI is accompanied by the Collective Subject Discourse.

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<thead>
<tr>
<th>Central Idea</th>
<th>Collective Subject Discourse</th>
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<tr>
<td>The Discovery was shocking</td>
<td>[...] to hear was a shock for the whole family, it seemed to discover that the world was falling apart [...] a shock, because it is too strong a word for the whole family [...] very upset, because nobody ever had this problem, no cases in the family, was a big shock.</td>
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<td>A lot of difficulty and sadness</td>
<td>[...] very difficult, very difficult indeed [...] to find the HU with him and was sent back here, it was very difficult [...] never expected it to happen to me, was very difficult because I was alone when I knew, because my husband was traveling to work was very difficult for [...] very sad, we did not expect it for it because it only made the pediatrician said it was testing and urinary tract infection, spent ten days in the antibiotic until came in and said that one day she would have to do a transplant, because the only kidney that functioned as the other was atrophied came to paralyze [...] were very sad, very upset [...] the reaction was very sad we were desperate running down the street with him in his arms, it seemed the world was crashing down on our heads.</td>
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<td>A new experience</td>
<td>[...] is a new experience, never imagined that could happen to my daughter [...] is a new experience, I'm still getting used to all this [...] had to stop doing many things, do not walk cycling, can not run, can not swim in the pool or beach and it was very boring she did not study hard time hindered his studies, had to be coming twice a week to make the treatment, so it was not to study [...] so she had to put the catheter and was doing at home, the doctor taught my children how to do her dialysis at home, then after a while, it appeared an infection, because dialysis does not was working. I took her back to St. Vincent, where it was discovered that the catheter it was out of place then was referred to here, where it was reattached another catheter and initiated dialysis manual [...] I am very careful with it, the catheter with it, with cleaning, falls, attention to diet him.</td>
</tr>
<tr>
<td>There are cases of this disease in the family</td>
<td>[...] Normal, do not think bad [...] is normal [...] for me it was a very difficult experience, since I already have cases of this disease in the family [...] Live Well, treat it very, very careful attention.</td>
</tr>
<tr>
<td>Everything has changed the routine and in our lives</td>
<td>changed everything in my life, I stopped working to care for him, he came twice a week to the hospital for dialysis, and in the days he is at home going to school [...] had to change many things, because I had to leave my husband and my children who live in the countryside to come here to look after him, as I have no one here in João Pessoa, I support the house that is part of the hospital and go home only on weekends [...] he eats well, his meals are made separately, is no salt, do not eat fried food, I was working and had to quit my job, I am currently separated from his mother and she did not want to come with him, then I have to come with him twice a week, goes to school only when there is in the hospital [...] has changed, the places that can not attend is largely because of her immunity is low, can not be in place that has accumulated and the diets that we have to be without salt, so I worked, I can not, because she always have to follow [...] his father had to come away to the interior to follow his treatment with me, because I am five months pregnant and for me it is very difficult [...] I worked, took care of the house, have another teenager, changed my routine a little bit because we had to come twice a week to perform dialysis , until a time that the catheter removed as urea lowered it, but unfortunately increased again and had to put the catheter back, so now I come every two weeks [...] I worked, stopped working, I am left with it, take care of her as a child.</td>
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Figure 1. Central Idea and the Collective Subject Discourse composed of relatives of patients with Chronic Renal Disease attended in Child Reference Hospital, in response to the question: how was the family's reaction upon learning of the child's chronic renal failure? João Pessoa/Paraíba - Brazil, 2010. Source: Field study.

Figure 2. Central Idea and the Collective Subject Discourse composed of relatives of patients with Chronic Renal Disease attended in Child Reference Hospital, in response to the question: Tell me about your experience when living with the child with chronic renal disease? João Pessoa/Paraíba - Brazil, 2010. Source: Field study.

Figure 3. Central Idea and the Collective Subject Discourse composed of relatives of patients with Chronic Renal Disease attended at the Child Reference Hospital in response to the question: What has changed in the family routine for you can do the accompanying of peritoneal dialysis in child? João Pessoa/Paraíba - Brazil, 2010. Source: Field research.
DISCUSSION

The most of the accompanying of children was done by mothers, helping them in repair or maintenance of well-being. When the father is the companioning, the intentions are the same as mothers have, but socially, or for reasons of financial maintenance of the family among other factors, such as the standard input of only one attendant at the hospital, makes mothers take greater responsibility for doing the accompanying - which requires the reorganization of family dynamics to take up for the hospitalization process.

Relating to the discovery of the disease in children, all of them were diagnosed with Chronic Renal Failure (CRF) until 8 years of age, however, as discussed above, the incidence of CRF in children is poorly documented and the causes are multifactorial. It can occur at any age and is more common in male children, although in this study, at the time of the survey, 55.5% (5) were girls and 44.4% (4) were boys. Among children on dialysis treatment, only one case was of renal malformation.

The indication for dialysis occurs when conservative treatment is unable to maintain the quality of life of patients. In such cases, peritoneal dialysis is a therapeutic alternative that preserves the residual function of the kidneys, controls pressure and hematological levels and provides hemodynamic stability; it is the ideal modality for children with CRF, supposing that parents or other person responsible for the child wish to perform the procedure at home when possible. The use of peritoneal dialysis eliminates the need for vascular access (very difficult to maintain in this age group), reduces the need for dietary restrictions and liquid and permit that parents maintain the ultimate responsibility for the child.

It was asked about family income, the item in which was demonstratred by the responsible the worry and the difficulties faced by families. Although the treatment is financed by the Brazilian National Health System - Sistema Único de Saúde (SUS) and that children are entitled to receive a financial benefit from the government, it demonstrates that the low income group families hinders access to adequate food, medicine drugs, satisfactory habitation conditions and even more difficult the displacement to treatment place. For often, it lacks money for transportation, which due the frequency of treatment, it becomes very expensive. It also was seen that the benefit received by the child that should be spent on it, become a part of the family income.

For discussion of the family's experience in living with chronic renal disease in children, the subjective questions are presented in Figures 1, 2 and 3 with the central ideas and their Collective Subject Discourse - Discurso do Sujeito Coletivo (DSC), articulated to the theoretical references adopted in this investigation.

The family at the news that his son is a patient with chronic renal disease, undergoes an unexpected situation, and has difficulty to accept the disease. Before diagnosis, the child was healthy, active, with their social, family and normal school activities, with a whole life expectancy and build a promising future. Nevertheless, suddenly, the future becomes uncertain, since the discovery of the disease triggers profound impact on the family can lead to feelings until now not experienced.

Despite technological advances and increased survival time of patients with chronic disease, usually this does not lessen the impact on the lives of these patients; this factor is evidenced by the large number of researches on the quality of life related to the topic.

The shock of the discovery is very strong, despite the family is seeking to know why the child might not be good, never expected that the diagnosis show it is a serious and incurable disease. This is one of the moments in which the family feels that is losing control of the situation experienced: it does not know what is the disease, does not know the consequences, does not know what the treatment or if there is no treatment; also has no idea of implications of the disease in everyday of family and the child. So the family is in emotional overload, experiencing unimaginable suffering that sometimes leaves it immobilized and unable to help the child. One study emphasizes that the most difficult stage for the family, is one in which the lack of control of the situation is highly experienced or even total.

In the DSC it identifies the shock and despair of the family, because it believes it is unlikely that one of its members, especially a child, would have a diagnostic health-compromising. The feelings at the time of discovery of the disease include disbelief, despair, anger and guilt. The feeling of guilt expressed by parents originates from they think were not competent enough to create a child without problems. It is difficult for the family to accept the disease, because in addition to causing lack of control of the
current situation will cause even the lack of family control over the child's future. The family is just beginning its process of accepting and living with the disease, failing to have broad and realistic vision of what it means and will mean the child's chronic disease, its consequences and treatments. 11

Caring for children with chronic disease requires specific skills, knowledge about the disease, signs, symptoms and other characteristics peculiar to each type of disease. When does the child’s hospitalization, the family needs to receive clear information from health professionals and have your doubts clarified about the care in order to make it autonomous and secure as much as possible before the child's disease.

Knowing the condition of the child, the family will be instrumentalized for the care and supply the demands arising from the chronic condition in childhood. It is necessary for parents to understand through concise and consistent information, the state of child health, the chosen treatment, diagnosis, specific care and its role as a participant in the care process so that they can better assist the child. 13

The trajectory of chronic disease in children is reported by family members, not as an episode, but as an adventure full of detail and uncertainty. They include details on the journey from the beginning of the disease and seek explanations or causal relations for its occurrence. 8

In Central Idea I of Figure 2, the DSC describes changes in family and child lives in search of the child's treatment. It was observed that this new experience (disease) changed the habits of both: the child and the family. The child sometimes fails to participate with other children in activities that are peculiar to the age and could it trigger a feeling of frustration and affect the psychological part. Moreover, there is still aggravating factor of the removal of school activities, adversely affecting learning, may also contribute to the emergence of behavioral disturbances.

The family in turn also has changed its routine, and it is asked to learning about techniques unknown until now (dialysis), to help in child's treatment. The family by putting itself at its disposal, showing love and patience, is of fundamental relevance for the care, contributing to the well-being of the child.

It was obtained in the study that families move in various directions in search of health resources available, seek what they think is the best treatment, the best procedure or the best therapy. Always with many doubts, at times, they accept them in others or choose to deny. However, in many cases, families do not have many options and submit to a single service, in which one can have access. 14

As a strategy to deal with the disease and treatment, many families seek to maintain the integrity and value their family member, emphasize the inclusion of attention of sick relative in the daily decisions and tasks, in order to help him/her deal with the disease and do him/her feel useful and important. Beyond it, some family members use the method of negation as a shield, in order to protect and psychological well-being of their loved relatives and themselves. 14

The Central Idea of DSC II of Figure 2, contrary to expectations, and reports founds in the literature, expresses the good acceptance of the family to treatment the child, in the cases they had previous experience with other family members. Although, the living in the family ambit with people in similar situations to the child to facilitate understanding of the disease process by the family, it can also generate a sense of appreciation, because it feels able to contribute to improving the health status of child, although they also know that the trajectory is long and often painful.

Living with chronic renal disease of the child, makes the family to develop strategies to cope with the adversities imposed by this chronic condition. In addition, many feelings and values are being added to the process of falling ill, causing the family learns to deal with them. 14

The adaptation to the peculiarities of renal disease comprises an extremely complex process, with many implications and impacts of various orders, it is essential to appreciate the quality of that survival. 15

The existence of chronic disease affects the entire family and creates difficult times, with advances and setbacks in relations between its members. The care of children with chronic disease consumes energy, time, cut the family's privacy and may cause social and emotional isolation. 16 In particular a chronic disease requires daily care and frequent visits to health services, which generally implies have a caregiver with the child constantly, occurring radical changes in family routines, as shown in Figure 3, the Central Idea I. They describe the changes in family life from the onset of disease. These are changes that range from behavioral
changes, feelings of its members in family routines, social life, and scholar life of the child, the change in eating habits, even in the change related to the city where they lived, as she seeks the best resources and conditions for the child. The job of parents is also affected, with the need to shut down the job in order to care for the child and especially change the way of seeing life.

Chronic conditions in childhood, beyond to affect family relationships, it becomes a family disease. The need for permanent care and hospitalizations, reaches parents, children, brothers. Parents worry about the sick child and want to help him/her to overcome and live with the disease.\(^7\) Due to chronic disease in childhood generate new demands on family members, it is important to encourage the sharing of feelings between them to cope with problems in a healthy way.\(^8\)

Resources are required, through professional support, social network, financial and psychological attending, to be offered favorable conditions for the proper care of the child and emotional stability for the family. Study with families of children with chronic renal failure found that the identification and characterization of types of support received by the family allow better use of these supports strengthening the coping mechanisms.

**FINAL CONSIDERATIONS**

The family and the child with chronic renal failure live unique experiences, previously untried and it requires a social network that provides the necessary support to attending the demands of child care. The family life is being affected by the disease of the child and the relationship between its members can also change.

Knowledge of the child’s problem is essential for these families so that they understand about the disease and the treatment forms and needing care, thus allowing that they are able to reduce the negative feelings from this problem, seeking the best way of coping and trying to have some control over this situation for life.

This present study has enabled to expand the knowledge about the family’s experience in living with chronic renal disease showing up the difficulties faced, especially when the disease was diagnosed. The confirmation of diagnosis requires the establishment of a new routine for the family system. However, the confrontation of this problem is complex and will depend on how families can mobilize internal and external resources to keep the situation under control.

The trajectory of the child in this new phase of its life is reported by their families not as a certainty that their children will return to their homes cured, as they would like, but with uncertainty after each treatment made, leaving them sad; but with mind full of hope that one day his/her child have a kidney transplant, often put on as a goal of the treatments available.

The chronic disease, as the name describes can not be cured. In an especially way, the chronic renal disease in children influences the whole process of normal growth and development of the child. Therefore, child and family cares should be based on the promotion of best possible quality of life throughout treatment.

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