

<http://dx.doi.org/10.1590/0104-07072017001110016>

CHILDREN IN CONSERVATIVE RENAL TREATMENT: EXPERIENCES OF FAMILY CAREGIVERS

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ABSTRACT

Objective: to understand the experience of the family caregiver of the child in conservative renal treatment.

Method: a qualitative study. Participants consisted of 11 family caregivers of children in conservative renal treatment in the South of Brazil, during the period of April to August of 2015. For the collection of the information, semi-structured interviews were carried out, whose data were recorded. For the analysis of the information, transcription of the interviews was used, codification, and organization of the categories according to the scholars.

Results: the data allowed the construction of five categories: discovering the disease, dealing with the disease, realization of the child's health; living life for the child; and realizing the existence of support.

Conclusion: the experience of family caregivers is related to affective, social, professional and economic changes.

DESCRIPTORS: Caregivers. Child. Nursing. Family. Chronic renal failure.

CRIANÇA EM TRATAMENTO CONSERVADOR RENAL: EXPERIÊNCIAS DAS CUIDADORAS FAMILIARES

RESUMO

Objetivo: conhecer a experiência da cuidadora familiar da criança em tratamento conservador renal.

Método: estudo qualitativo. Participaram 11 cuidadoras familiares de crianças em tratamento conservador renal no sul do Brasil, no período de abril a agosto de 2015. Para a coleta das informações foram realizadas entrevistas semiestruturadas, cujos dados foram gravados. Para análise das informações, utilizou-se transcrição das entrevistas, codificação, organização das categorias e discussão à luz de estudos da temática.

Resultados: os dados permitiram a construção de cinco categorias: descobrindo a doença, lidando com a doença, percebendo a saúde da criança, vivendo a vida pela criança, e percebendo o apoio.

Conclusão: a experiência ocorrida na vida das cuidadoras familiares está ligada à mudanças de ordem afetiva, sociais, profissionais e econômicas.

DESCRIPTORIOS: Cuidadores. Criança. Enfermagem. Família. Insuficiência renal crônica.

NIÑO EN TRATAMIENTO CONSERVADOR RENAL: EXPERIENCIAS DE LAS CUIDADORAS FAMILIARES

RESUMEN

Objetivo: conocer la experiencia de la cuidadora familiar del niño en tratamiento conservador renal.

Método: investigación cualitativa. Participaron 11 cuidadoras familiares de niños en tratamiento conservador renal del Sur de Brasil, en el periodo de abril a agosto de 2015. Para la recolección de datos fueron realizadas entrevistas semiestructuradas las cuales fueron grabadas. Para el análisis se utilizó la transcripción, la codificación, organización de categoría y la discusión a la luz de estudiosos en el tema.

Resultados: los datos permitieron la construcción de cinco categorías: descubriendo la enfermedad; lidiando con la enfermedad, percibiendo la salud del niño, viviendo la vida por el niño y; percibiendo el apoyo.

Conclusión: la experiencia ocurrida en la vida de las cuidadoras familiares está ligada a cambios de orden afectivo, sociales, profesionales y económicos.

DESCRIPTORES: Cuidadores. Niño. Enfermería. Familia. Insuficiencia renal crónica.

INTRODUCTION

Chronic Kidney Disease (CKD) in childhood is defined by both the presence of injury and the loss of renal function, differentiated in stages (1 to 5), with diagnostic criteria being the assessment of glomerular filtration and alterations in complementary medical exams.¹ The number of children with CKD has increased in the world, however, the majority of the information in relation to incidence corresponds to the final stages, with information on the early stages still limited.²

It is believed that the development of CKD in children is mainly related to physical and social factors. The first, associated with low birth weight and the second, by the disadvantaged socioeconomic level in childhood being considered fundamental.³ As a therapeutic method in the initial phase of the disease, conservative renal or pre-dialysis treatment aims to delay renal damage and consists in dietary changes that aim to promote an adequate nutritional status and influence lifestyle, control of metabolic disorders and uremic symptomatology.⁴

In this context, there are family caregivers of children with CKD, for whom their experience in the initial phase of the disease has not been given voice, or rather, who experience changes which are significant in the life of the family caregivers of the children in conservative renal treatment. It is believed that the family experience is similar to that of caregivers of children with other chronic illnesses, who report that the experience of becoming ill consists of several stages, such as fear of death, lack of family support, financial hardship until the adaptation to the new condition.⁵

Due to it being a challenging experience, it can provoke emotional tensions that will impact on the quality of life of the parents who develop different ways of managing the child's health.⁶ Carers are not only child care providers, but child care specialists

due to their own experiences. Thus, it is important to give a voice to them, so that professionals can develop care strategies capable of achieving better results in the medium and long term; preventing ailments which affect the quality of life of both the child in the renal conservative treatment and of their caregivers.

Thus, the objective of this article is to understand the experience of the family caregiver of the child in conservative renal treatment.

METHOD

A qualitative study was carried out between April and August 2015 with 11 family caregivers of children in conservative renal treatment in a pediatric nephrology public service located in the south of the State of Rio Grande do Sul (Brazil). Inclusion criteria consisted of the family caregiver being 18 years of age or older and be characterized as the main family caregiver of the child.

Initial contact with the family caregivers occurred in the nephrology service of the Pediatric Outpatient Department on the day of the child's consultation with the nephrologist. Afterwards, the contact was done by telephone with the caregivers, which the children had no scheduled appointment, and it was verified that despite being registered in the service, these children had been attended in other services of the State of Rio Grande do Sul in the past few months or years. Thus, the snowball technique was used, in which the first five interviewees recommended others, it was decided to contact the participants who had already been interviewed, so that they could recommend the other caregivers (residents in the region). From the recommendations, contact was made with five other caregivers and the collection was finalized. The interviews which lasted an average of 60 minutes were performed in a place defined by the participants, with most of them happening in their homes.

As a tool for data collection, some general guidelines for the Wong Family Interview⁷ and open interview with stimulus phrases were used, such as: "can you tell me your experience of caring for the child with kidney disease?" And as the participants responded, stimulus phrases were used to broaden the discussion on the issue, e.g. "tell me more about it!" The interviews were recorded on an audio file and transcribed into a Word file for the coding of the data, which facilitated the formation of categories. The data were organized and analyzed with thematic analysis, concomitant to the interviews, due to it being a commonly used method to describe, analyze and report on data themes and patterns,⁸ thus allowing for the development of new definitions on abstract aspects of the caregiver's social experience.

The study respected the ethical principles of research involving human beings, according to Resolution N. 466/2012. The Informed Consent Form was delivered and read to the participant on the day of the interview, two copies were signed by the family caregiver and the researcher, assuring the

freedom of spontaneous participation and the right of withdrawal at any moment of the research. The study was approved by the Ethics Committee, opinion N. 985,770 and CAAE: 41609214.8.0000.5316. In order to preserve the anonymity of the participants and for identification purposes, the initial "E" was used to represent the interviewee which was followed by the Arabic number, according to the order of interviews.

RESULTS AND DISCUSSION

It was found that all family caregivers were female who were mothers of the children, aged between 27 and 43 years, the majority were married, and the Catholic religion predominated. As for the level of education, the majority had incomplete elementary education, only one had a postgraduate degree.

The categorization of interviews allowed the development of five defined categories and shoran in figure 1.

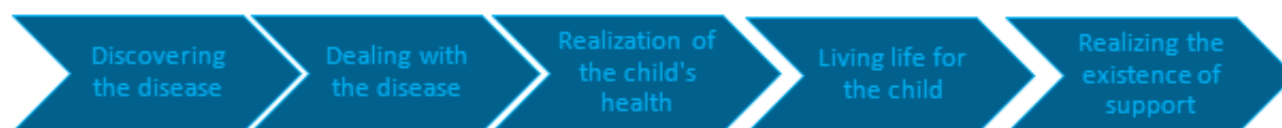


Figure 1- Thematic categories of the study - experience of the family caregiver of the child in conservative renal treatment

Discovering the disease

In this category the experience of the family caregiver was related to the discovery of the disease, when they became aware of something unknown and unexpected during pregnancy, in the neonatal period or in an acute urgent and / or emergency situation during childhood. The feelings were defined as shock and fear, characterized by the period of uncertainty, waiting and tension because important decisions needed to be made.

In the results, it is seen that the feelings caused by the diagnosis of the child's illness was like an encounter with the unexpected. However, when confrontation became necessary at the same time that they felt as if they were without support, they also had to have the strength to take care of the child.

[...] when I found out it was a shock! We did not expect it, there was hope that it wasn't going to be so serious. I was really devastated. The world fell from under me! Because we never want a child to have this problem [...] (E-6). [...] I got scared a little at first, it

was a scare (E-7). Because she never had anything. It was all of a sudden (E-10).

These statements demonstrate how much the experience of the discovery of the disease affects the family caregiver of the child with CKD in conservative treatment. The testimonies corroborate with Australian and Brazilian authors, who affirm that the diagnosis caused fear when they were faced with the disease.⁹⁻¹⁰

When the diagnosis of the child's disease occurs during pregnancy or in the neonatal period, mothers may present feelings of guilt regarding the malformation, generating stress in a period of physiological and psychosocial changes, in which the mother's imagination lies in the perception of a "perfect" child, according to the following reports: [...] it was very tense, because I discovered it when I was six months pregnant. They said that she would not survive, that I had to stop the pregnancy, of course, I was very shocked, very shaken, but I was able to deal with the situation from the first time they told me. Now there are mothers who are still treated [...] (E-2). I discovered that

[daughter] had a kidney problem during the pregnancy, I had an ultrasound and the doctor found that there was something wrong [...], I almost died when I heard the news (E-3). [...] I came home, I had a urinary infection for a month and twenty-one days, then I discovered that she did not have a kidney [...], so we started blaming ourselves and everything else (E-1). [...] and I always think why me? (E-6). [...] when I discovered it was the kidney, it was a relief (E-4).

It was noted that most of the caregivers were diagnosed with the child's diagnosis of CKD during pregnancy due to a congenital malformation of the urinary tract, which can cause the mother to feel guilty and carry the guilt for the rest of her life.

Congenital malformations of the urinary tract account for about half of the cases of CKD in children and are probably caused by defects in a single gene.¹¹ They are prevalent in developed countries, while acquired causes often occur in developing countries. Children with congenital disorders experience slower progression of CKD, and despite the improvement in survival rate, it is 30 times lower than that of healthy pairs, resulting in death mainly from cardiovascular causes and infection and not from CKD.²

On the other hand, the suspected malformation during gestation causes the mother to imagine several serious pathologies and the confirmation of the renal malformation is an attenuating factor which softens the impact of the diagnosis, since they expected confirmation of other malformations.

Thus, a study showed that living with a child with a congenital malformation can motivate the need for differentiated emotional care for the mother, who is lacking social network support and guidance in the adaptation of their idealized child to the real child.¹² Similar results related to family dynamics (the home, employment, financial and leisure environment) was interrupted with the diagnosis of the child's kidney disease, since the family caregiver is most often the mother and needs to be present with the child in addition to managing care at home.¹³

In this context, the experience of discovering CKD with confirmation of diagnosis needs to be observed by the nursing profession as an opportunity to approach the family in primary health care and to invest in the promotion of the adaptation to the care that will be necessary to ensure the equilibrium of the family unit.

Dealing with the disease

This category includes the experiences of the family caregivers regarding changes in the internal

structure of families and the adjustments brought about by the health care needs of the child. The change in the family structure was caused by divorce due to the diagnosis of chronic child illness. The adaptations and adjustments were represented by the inclusion of new eating habits, with the need to introduce, diversify and replace food, medication administration routine, bladder catheter care, follow-up at the health service for disease control and financial organization.

Chronic illness can affect the dynamics of marital relationships as divorces are cited as a result of the child's illness. In these cases, the diagnoses occurred in the neonatal period, and the child's illness may represent a stressor for those involved.

[...] shortly after she was born, he [husband / father of the child] ran away, he was married to me. Married on paper. But, from time to time he appeared [...] (E-5). [...] it's very complicated, because when the separation came, everything became more difficult. When we were together everything was easier. I was alone for everything [...] (E-2).

According to the literature, the change in the family dynamics caused by divorces can be motivated by the absence of the caregiver, who besides being a mother, is a wife. As the mother needs to dedicate herself to the care of her child, the couple is unable to adjust to the adaptation of the child's health care and, consequently, results in separation and with the father's denial and their distancing away from the child. However, couples can learn to improve the emotional quality of their relationship, express their feelings to each other to expand their emotional experiences and meet each other's needs for safety and comfort, despite the limitations and challenges presented by the child's CKD.¹⁴

Other health care for the child causes changes in the family dynamics, for example, requiring adaptations to the new dietary guidelines.

What she can [eat] is fruit, which I try to give to her because she is just beginning to eat and I give her water (E-1). [...] it costs me nothing to make a meal, because she does not eat reheated food at noon, I make something completely without fat and without salt, and talk to her and say that she is wonderful and make her feel good [...] (E-5). She cannot eat too much salt, she has to drink more water (E-8). [...] learn to live with disease, [...] it's time to eat and you're going to eat salt and she can't. The greatest difficulty [...], is when we have a barbecue and she looks at me like this, [...] (E-10). [...] I take care of her first, I do everything right, I make all the food without salt, everything as I was told, so that she can be healthy [...] (E-11).

The need for adjustments to the dietary restrictions prescribed for each child at the beginning of treatment consequently causes the imposition of changes in the eating habits of the other members. To ensure that this care is implemented, all members are forced to rethink their lifestyle, however, environmental, socio-cultural and economic factors may interfere with the introduction of healthy habits as can be seen in the *gaúcho's* habit of consuming roast beef (Barbecue).

Such a situation can generate conflict among family members, since it can be difficult to accept the child and their diet, and eventually this can be intensified in the others family members. These issues imply changes in habits and are directly related to the cultural aspects of the family, which interferes with the adaptation process.¹⁵

As for adjustments to deal with the disease, the experience of the caregivers includes the routine of children's health care, such as constant medical follow-up that can be a stressful factor for the caregiver who manages the routine of medical consultations, exams and schedules and also of the house. The financial organization of the caregiver of the child with CKD is affected by the various demands, increased expenses, loss of source of income, the need to dedicate care to the child's health and abandonment of their professional activity.

[...] you have to be at the doctor all the time. She'll always have to go to the doctor (E-8). [...] she is very careful ... we take great care with the flu ... because it is good to avoid taking too many antibiotics. She can't even take much medicine. So we have to take care of all of this (E-3). [...] the greatest difficulty is money, because the pharmacy often doesn't have the medicine, so I have to buy it [...] food, because these things we have to have, we can't do without. So the problem is money [...] (E-6). [...] I need to buy medicine, need to buy food. You need to pay the bills, you need to solve the problems, but at the same time you need to stay in the hospital with your daughter, at the same time you have to take care of her [E-8]. [...] we are separated, he said he would give financial support, but he never gave it [...]. And SUS being a bankrupt machine does not help, it does not help anyone [...] (E-5).

Caregivers of children with CKD face the financial commitment to meet the nutritional needs and continuity of the child's treatment. Although the monitoring is performed by the Brazilian Unified Health System (SUS, *Sistema Único de Saúde*), they still need to meet the needs of drug therapy that is not always available through the public network.

In this sense, the greatest difficulties faced by parents of children with CKD are financial dif-

iculties because they cannot sustain the routine of employment, child health care and medical expenses, which contributes the most to financial instability.¹⁶

In addition, the child's family caregiver needs to learn to perform unknown invasive procedures and try to adapt. A situation like the following; *[...] when they told me that I was going to have to catheterize her, I was a bit scared (E-7). [...] this whole process, you have to catheterize her. sometimes you have to change it, always taking good care of the hygiene, diapers, then you change the diaper, it is a difficult process [...] (E-9).*

Anxiety can be triggered when the caregiver needs to perform invasive techniques that they are not used to, they need support to withstand the stress of the care routine of the child in conservative renal treatment.

In this context, parents may present feelings of anguish and impotence when performing invasive procedures, believing that the child is constantly being tortured during the procedure.¹³

Still, adaptation requires that the family caregiver includes all family members, so that the healthy ones don't feel neglected as described below: *[...] because taking care of the child is essential, so I soften the bad news for the sister [healthy sister of the child with CKD] (E-4).*

This way of dealing demonstrates the caregiver's attempt to provide protection to the healthy sister by avoiding affecting the integrity of the family relationship as well as the impact of the illness on others. Thus, parents may choose not to communicate the truth about their sibling's illness to their healthy children, believing in their protection and reducing their anxiety.¹⁷ Providing alternative care for the siblings of the sick child, after needing to re-establish relationships with the siblings who felt excluded, abandoned and neglected because they did not receive the same attention.^{13,18} In this context, communication is an important factor among family members, since children can perceive this difficult moment and not understand what is happening, and even feel guilty about the circumstance the family is facing.¹⁹

Thus, nursing in primary health care can contribute to the prevention of aggravations caused by communication, creating healthy methods of coping with the chronic condition together with the family, contributing to the improvement in the quality of life of all members by preparing them for the new health condition.

Realization of the child's health

This category consists of the perception of the family caregivers in relation to the current state and the future projection of the child's health. The caregivers were insecure about the prognosis that in some cases was still undefined. This insecurity included the quality of life, dependence and / or autonomy of the child to perform daily activities, such as dressing, feeding, playing, attending school and socializing, even manifesting in the prejudice regarding the chronic condition.

For the time being, everything is OK, because there is nothing too bad, hopefully it stays that way ... if something goes wrong, if it gets messed up [kidney] then it's is going to be difficult (E-1). Her kidneys are still [...], I do not know if they're actually stopped or if they're just lazy. If you let them stop, [...]. For us, she is very well now (E-11). [...] as it is chronic, only with transplantation, but she is always playing with everyone, she is very active (E-2).

Caregivers describe their perceptions of the child's health, which despite the need for adjustments is considered good and they have a satisfactory quality of life, which is an important element for children undergoing conservative renal treatment.

Corroborating the results of studies with children in different modalities of renal replacement therapy, it was concluded that the quality of life of children undergoing conservative treatment is greater when compared to other therapeutic modalities.²⁰ For the caregivers, the future is characterized by uncertainties and doubts, due to there being insecurity and fear of "tomorrow", in the face of chronic disease prognosis.

She is five years old and has been through so much since her birth! And when will it stop? (E-3). Waiting to see if the cysts will atrophy and the kidney will grow normally or if the kidney will get stunted and small (E-4). What makes me a bit frustrated is that I do not know what's going to happen in the future, me without work, how am I going to take care of her? (E-7). [...] it will never be normal. It is difficult for the child to understand what is happening [...] (E-6).

The uncertainty of disease prognosis and anxiety about the chronic situation demonstrates that caregivers need preparation for disease management and for the emotional aspects involved. The need to prepare the family caregiver for the adjustment of the role and emotions that they can experience, since the parents need to be aware of the new condition, as CKD is for life, regardless of the type of adopted treatment.²¹

On the other hand, for some caregivers, despite the difficulties experienced, they stimulate the child's coexistence with other children. [...] *you can take her to one place, or take her to the other [...]. And you have to make them stay with the other children [...]. Having that exchange with other children is very difficult. Because she is small, the other children talk to her in a little voice and then she asks, but why are they talking like that? [She] asks some questions, and there are things in her head. And you don't know how to answer her (E-5).*

In an attempt to promote healthy coexistence with other children, the family caregiver and the child end up with incomprehension of the children's peers, which can affect their development, since they perceive the disapproval of their condition in their attitudes.

Children with CKD face the challenges and constraints related to short stature.²² The change in daily routine restricts the performance of various activities, depriving the family of leisure which causes social isolation.¹⁷

The perception of the child's health with CKD by the family caregiver depends on the way society and, consequently, the family accepts and manages the situation. For some the children's health is considered good, for others the negative experiences from judgments by society regarding physical appearance interfere with the healthy development of the child. In this sense, the nursing profession can contribute to healthy forms of coexistence, through guidelines in primary health care.

Living life for the child

This category refers to the abandonment of the professional and social activities that the family caregiver previously exercised in order to totally dedicate themselves to the care of the child, either because they did not trust in the care of third parties or because of unavailability [...] *I lost a job because she was sick for so long. My life is to take care of her. I'm seeing a psychiatrist now, because of this, because your life stops, you have no choice [...]* (E-8). *So I had to leave the job [...]. I dropped everything. My life was revolved around her, I did not do anything: I did not cook, I did not wash clothes, I did not do any housework, I only lived with her on my lap. I can't even take a shower by myself because she has to be there with me (E-1). For me, working is very difficult. I cannot do anything else. Do you understand? I can't work, I have to stop my life to take care of her [...]. It's very complicated!* (E-2). [...] *I cannot leave, I cannot work. Now she needs the most care (E-10).*

Caregivers present an intense routine of care

directed at the child's health. This fact makes caring for oneself impossible, which, consequently, compromises the quality of life of these caregivers whose lives are only focused on the needs of the child.

Similar results related to the commitment to the quality of life were obtained in studies performed with mothers of children with CKD in Australia^{9,13} and in Brazil,¹⁸ due to care overload affecting the primary caregiver who, in most cases, is the mother, and needs to be present with the child in addition to managing the care at home.

Caregivers also refer to a lack of confidence regarding the care of the child when it is provided by other people, highlighting the fear that the school is unable to provide support for the continuity of care, as well as the relatives who do not have the capacity to deal with the children in their absence.

[...] for example, the catheter, it has to done in a suitable place, there is no way, because I have to do this cauterization. Then there is no way to leave her in a creche or kindergarten [...] (E-7). We send them to school because we need them to go, but we always wonder if they will take care of them like we do. (E-2). I don't trust [the father] to leave [the child] with him [...], he won't know what he can and cannot do (E-6).

The testimonies express the anxieties of the caregivers, who have a support network, but in some cases are not allowed to use them because they believe only in their own ability to perform care accurately and safely. In this sense, nursing in primary health care can contribute to the approximation and increase of trust between the family caregiver and the support network, guiding the delivery of care, and reducing maternal care overload. It is also important to emphasize the need for nurses to be included in schools and day care centers, as well as to work in health education in order to care for the children living with chronic conditions or with special needs.

Realizing the existence of support

In this category, family caregivers referred to the presence or absence of sources of support in the health care of children with CKD. These sources were family (husband, children, grandparents, uncles and brothers), institutional (school, nephrology service, health system) and spiritual. The family has been described as a source of social, emotional and financial support. The support from the institutions was related to receiving information and guidelines; and spirituality related to faith which provides an optimistic view of the future.

Caregivers recognize family support as being the main pillar of care for the child's health.

She [the eldest daughter] is my foundation (E-4). I count on my mother and my sister, my family, everyone [...] helps me a lot, they are always there. When I'm not there, my mother takes care, she knows everything! And I have confidence in her (E-3). I count on his father and brother [of the child], and they help me a lot [...] (E-9).

It is observed that the family is still the unit that provides the greatest source of support to the caregiver of the child with CKD, since the closeness of the members can provide security for the family caregiver. A similar result was obtained with parents of children with CKD, in whom emotional support was found mainly in the family.¹⁵

In another testimony, the support received in the health service was remembered as something remarkable by the caregiver. *So, the SUS, the nurses, I am grateful to them and I will always be grateful (E-2). [...] I discovered that not even people who have money, who had consultations with the best doctors managed to overcome this disease and my daughter was treated in SUS and survived (E-8). They [doctors] helped me a lot, and the [nephrologist's name] is very good, she helps me a lot too, she's my second mother (E-11).*

This statement demonstrates that the link between the caregiver of the child with CKD and the health service is significant. The strengthening of the professional / caregiver relationship promotes closeness, which is relevant for both, as it favors treatment and the caregiver perceives him/herself as an element of care. However, primary health care still needs to improve the approach to the model of attention for chronic conditions favoring the integrality and continuity of care for children in chronic conditions.¹⁹

The absence of a source of support was reported by a caregiver, who feels she has no one to count on in the family or in the health services, which can lead to feeling overwhelmed with child care. *[...] I have no support and the health service is bad, nobody helps anyone [...]* (E-5).

In the absence of full support, the caregiver of the child with CKD may feel overwhelmed by the care, as they don't have the support to deal with the new demands. Studies have evidenced the need for the family caregiver to have a social support network due to the new demands, given the difficulties faced in dealing with the child's illness during all stages of the illness.^{13,20}

The social support network becomes important so that parents can learn and provide support

to their peers facing a similar situation, allowing efficient communication, leading to the coping of the problems in a healthy way.²⁰ Although the burden experienced by family caregivers is a heavy and stressful routine for most family caregivers, they are aware of the presence of the support network, but they do not use it, because they do not allow or do not feel that they can take care of the child and count on the network for self-care.

In this sense, nursing can strengthen the relationship, increasing the confidence of family caregivers to obtain quality of life for themselves and for other members.²⁴

CONCLUSION

This study provided an opportunity to understand the experience of family caregivers of children in conservative renal treatment, being understood as an experience that generates affective, social, professional and economic changes. Regarding affective changes, there may be an association with the divorces experienced by family caregivers and the abandonment of the children by the fathers, compromising the adjustment of the child's health care. Concerning social aspects, they refer to the impossibility of carrying out leisure activities and the conviviality with family members and friends and attending daycare centers, since in many cases they need to carry out care that does not allow such activities or do not have a support network for the care, causing a fastidious overload on the caregiver. The change of professional order was related to the commitment of the family caregiver to the child's health care, which prevents them from carrying out other paid activities. As for the economic aspects, they were due to professional and / or affective changes, since some caregivers were financially dependent on their spouses and after diagnosis of the child's kidney disease, they began to count on the help of family, friends and assistance.

Understanding the experiences of the family caregiver directs primary health care nursing to contribute to the improvement of the quality of life of the family and children, since this study provided a voice to the participants, demonstrating the complexity of this experience, which requires a lot of from themselves and from all family members. The aspects related to the need for guidance for the family caregivers of children with renal disease can be overcome through support in the adaptation so that the adjustments with the new demands occur naturally. However, this will only be possible with family empowerment, or rather, family participa-

tion in decisions involving the health of children with kidney disease. This involvement values it as a being, since professional knowledge is only one part of care.

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