

CHILDREN WITH CHRONIC RENAL FAILURE ON CONSERVATIVE TREATMENT: ADAPTATION PROCESS OF THE CAREGIVER-MOTHER¹

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ABSTRACT

To know the woman's adaptation process when becoming caregiver-mother of a child with chronic renal failure on conservative renal treatment. This is a qualitative study developed from a specific form and semi-structured interviews with family caregivers of children with chronic renal failure undergoing conservative treatment in nephrology centers. Data were analyzed by content analysis. 11 caregiver-mothers have participated. Most of them were married, Catholic, not engaged in any paid professional activity but received financial assistance for the child's health, lived in urban areas and had finished elementary school. The adaptation process allowed constructing the category "Reorganizing the daily routine", which addresses the changes and forms of adjustment. The adaptation process of women becoming caregiver-mothers of children on conservative renal treatment can provide better understanding to the nursing staff of the reality experienced and contribute to reorganize and promote balance in the family's daily routine.

Keywords: Caregivers. Child. Nursing. Chronic Renal Failure.

INTRODUCTION

Kidney disease is considered to be a silent condition, since children generally do not have symptoms until severe dysfunction is manifested⁽¹⁾. When established, it compromises the development and modifies the child's daily life due to the restrictions it causes⁽²⁾, such as growth deficits, low self-esteem, behavioral and learning problems⁽¹⁾, especially when it is diagnosed in childhood.

Consequently, since childhood is the stage of life in which individuals depend on a person to perform care and prevent health problems⁽³⁾, the family caregiver, often represented by the mother, is the person who cares for the child's health most of the time⁽⁴⁾, making it essential for them to be present throughout the child's development, especially when it comes to the care required to maintain the child's health.

Since the need for health care of the child with kidney disease is constant, such activity is considered as exhausting for the caregiver due to the need to

reorganize their lives. They need to dedicate a lot of time to child health care, such as medical follow-up, adaptation to dietary restrictions, administration of drugs and the range of invasive procedures to which the child is subjected⁽⁵⁾.

Studies characterizing family caregivers, regardless of pathology, are mostly quantitative, and describing these caregivers as being female, mothers or daughters who do not exercise paid work⁽⁶⁾. The picture is similar when it comes to family caregivers of children in chronic conditions^(4,6-10).

Regarding the studies focused on the family caregiver of the child with renal disease, these are scarce and do not address the initial phase related to conservative renal treatment, as well as the process of adaptation of the child's caregiver, which justify the accomplishment of this study, since the studies already performed emphasize only the advanced stages of chronic kidney disease and the infant mortality due to renal failure⁽¹¹⁾, which indicates the lack of information that represents the panorama of this disease in

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Brazil^(1,7,9,10,11). From this perspective, this research aimed to know the process of adaptation of the mother-caregiver of the child in conservative renal treatment.

METHODOLOGY

This is a qualitative, descriptive and exploratory study, whose elaboration sought to comply with the checklist of COREQ (Consolidated Criteria for Qualitative Research Report) recommendations⁽¹²⁾. The inclusion criteria of the participants in this study were: being the main family caregiver of the child with renal disease undergoing conservative treatment and performing care for the child most of the day; being 18 years of age or older; being able to understand and speak the Portuguese language.

Initial contact with the mothers-caregivers occurred in the nephrology department of the pediatrics ambulatory of the Faculty of Medicine of a university of Southern Brazil on the day of appointment scheduled with the nephrologist. Later, we contacted by telephone the caregivers of the children enrolled in the service, but who had no appointments scheduled, and it we found that these children were being followed up at other public and private institutions in the State of Rio Grande do Sul, Brazil. As the total sample in the service under study was six participants, we decided to contact these six participants, who had already been interviewed, so that they could refer other caregivers living in the region. Thus, five other caregivers were indicated, thus totaling 11 participants. It should be noted that all people invited agreed to participate.

As an instrument for the data collection, a pre-structured form was used to characterize the participants and a semi-structured interview was conducted with each participant, which was recorded and had an average duration of one hour. Also, notes were made in a field diary after the interview. Data collection was conducted by the first author of this study (master, experienced in interview with families and with no previous relation with the participants). The data were obtained from April to August 2015 at a place set by the participant. Most interviews were held in participants' homes and in the presence of only the mother-caregiver and the researcher. Before starting to collect the data, the Free and Informed Consent Form was read, delivered and signed in two copies, by the mother-caregiver and the researcher, and a copy was left with each one. At that moment, the purpose of the study was explained, and the

freedom of spontaneous participation and the right of withdrawal at any moment of the research were assured.

After transcription, we used the content analysis⁽¹³⁾, consisting of a system of previous categories in which the initial readings gave rise to a distribution of contents and record units aimed to know the process of adaptation of the woman that have become the mother-caregiver of a child undergoing conservative renal treatment. The statements answering to the objective of this study were highlighted and grouped, thus allowing the construction of the category "Reorganizing the daily routine".

The development of this study respected the ethical principles of research involving human beings, according to Resolution No. 466/2012⁽¹⁴⁾. It was approved by the Research Ethics Committee of the Faculty of Nursing of the Federal University of Pelotas (opinion No. 985,770). In order to ensure anonymity, participants were identified by the letter "R" for respondent, followed by the Arabic number corresponding to the chronological order in which the interviews were conducted.

RESULTS AND DISCUSSION

Eleven mother-caregivers participated in this study, which allowed knowing the adaptation process of women who had become mother-caregivers of children undergoing conservative renal treatment. Participants were aged between 27 and 43 years. Nine of them lived in the urban area, were Catholic and had complete elementary education. As for marital status, they were married and belonged to a nuclear-type family. Regarding the experience with kidney disease in the family, five participants stated that they had a previous experience.

They did not perform paid professional activities, but received financial assistance for the child's health care. Family income varied from one to two minimum wages per month and the main provider was the husband of the mother-caregiver. Regarding the treatment of the child's kidney disease, most claimed being using the public system and only one mother-caregiver has used the private system for the health care of the child.

The age of the mothers under study is similar to that found in studies conducted in Brazil with family caregivers of children with CKD, which have indicated that these are usually young^(5,9).

The fact that three mother-caregivers live in rural areas is a worrying factor because the place of residence may be a compromising factor in the management of the health care of a child undergoing conservative renal treatment, considering that rural-based caregivers may experience difficulties in access to the health service, and it is therefore a barrier to care. Thus, it is necessary to provide more attention and support to the family caregivers of children with renal disease living in rural areas⁽⁹⁾.

In this study, most caregivers declared themselves Catholic. This fact is proven by the Brazilian Institute of Geography and Statistics (IBGE), which states that this is the predominant religion in the South of Brazil, with a percentage of 70%⁽¹⁵⁾. A study of mothers of children with chronic conditions found that all participants believed in God to provide them with strength and support to deal with the suffering generated by the chronic condition⁽¹⁶⁾.

There was low level of schooling in the population under analysis in this study, as they only had complete elementary education. No primary studies were found in Brazil addressing the schooling of mother-caregivers of children with CKD; only an integrative review was found⁽⁶⁾. However, studies in the United States found that family caregivers of children with chronic kidney diseases had higher education⁽¹⁷⁾, indicating that the socioeconomic level may have an influence on the level of schooling and, therefore, the low level of schooling may contribute to increased hospitalizations and decreased adherence to the health care of the child, since many caregivers do not understand the health information provided⁽¹⁸⁾.

The predominant family constitution of mother-caregivers in this study was the simple nuclear family; two families were single-parented and one was a reconstituted nuclear family. The simple nuclear family consists of a couple and their children; the simple single-parented may be female or male and is organized around a person who has no partner living in the same household, and they may live or not with their children; and the reconstituted nuclear family is constituted by a couple in which one or both spouses had already had another previous marriage, and they may have children or not. Studies carried out with family caregivers of children with chronic diseases concluded that families were mostly mixed, followed by nuclear families⁽¹⁹⁾ or, still, formed by husband, partners and other members, and that the changes in the structure are related to the child's disease status⁽²⁾.

The profile of Brazilian families, according to

IBGE, shows that the common family arrangement continues to be that of couples with children, in 55% of families. Of the total of 27.4 million couples with children, one-sixth (16.3%) lives with stepchildren, in addition to children, or only with stepchildren^(12,21).

It is common for women to abandon their professional activities after assuming the role of mother-caregiver, as found in this study, which found that they had their professional and/or social activities interrupted. According to the literature, similar results were found in Brazil in studies with family caregivers of children with chronic conditions^(5,6).

The monthly family income of the participants was one to two minimum wages per month (value in reais, from R\$ 788.00 to R\$ 1,576.00), and the husband was the main provider. In this context, it should be noted that the family income of the child's caregiver may interfere in the quality of life of the family, since the chronic illness generates expenses with the treatment, besides promoting changes in the lifestyle^(5-6,18).

Most of the mother-caregivers was receiving financial assistance for the child's health care (LOAS - Organic Law of Social Assistance). However, studies carried out with family caregivers of children with chronic conditions indicated that the minority of caregivers receive State welfare/financial assistance for health care⁽¹⁸⁾. This fact shows the importance of women knowing their rights in the financial sphere, since the earning of financial assistance for health care has an important contribution in the family budget of the mother-caregiver.

The Unified Health System (SUS) was the choice of access to the health service of most mother-caregivers for the care of their children undergoing conservative renal treatment, and only one mother-caregiver reported using private service because her child is dependent on the healthcare plan available in the company where she works. Thus, socioeconomic and demographic characteristics can influence the access to the service used. However, it is believed that the quality of care depends on the satisfaction of the user, which is the direct beneficiary of the service and on the managers involved in health care⁽²²⁾.

The adaptation process of becoming the mother-caregiver of a child with renal disease undergoing conservative renal treatment is undeniably full of changes arising from the routine changes imposed by the treatment. Such process is described in the following category, which presents a report of the dedication of the mother-caregivers and evidences the need to support families so that they can be effective.

Reorganizing the daily routine

The adaptation process of a woman becoming a mother-caregiver of a child in conservative renal treatment requires the reorganization of her life and she needs to rethink her priorities and seek to adapt initially to the changes of the daily routine. Such changes involve differentiated feeding, administration of drugs, invasive procedures such as bladder catheterization, and frequent medical follow-up, as reported below.

[...] your priority is your child, then, there are the other things, and finally you. You can be sure of this (R-5).

It changed everything, because he is totally dependent, dependent on me (R-9).

It's full time at home with her. (R-7).

She takes several [medications], sodium bicarbonate, calcium carbonate, B complex, erythropoietin, calcitriol (R-2).

We have to do the probing [indwelling bladder catheter] and take her to a doctor often (R-7).

This process also involves the lack of support from the father of the child of four participants. These fathers end up not having a significant affective bond with the child, since they do not participate in the education and/or the routine of care, which can contribute to the overload of the mother.

I do not have help from her father too; it makes a great difference (R-7).

The mother-caregiver in this process has to deal with the abandonment of social activities, which means the loss of autonomy to perform daily activities, such as work and study, for needing to dedicate to the care of the child at home full time, only having as income the financial assistance provided by the social security system. However, they still wish to resume studies for personal and professional growth and to seek better living conditions for the child.

Stop working, I used to work; I lost my job because she has been hospitalized for a long time (R-7).

For me, working is very difficult! Now, I'm in this [informal] job, but I do not know if I'm staying. I cannot have a formal employment, because she earns financial assistance for health care. I want to finish high school. I have to have some study to give her a better life (R-2).

Financial difficulty is an important factor triggered by the increase of expenses, abandonment of professional activities, with consequent reduction of income, and still difficulties of access to health care. In

this circumstance, increased expenses are related to the child's feeding, which has to be differentiated, and to the cost of drug treatment. In addition, difficult access to the health service for rural residents can compromise the budget and the achievement of treatment goals, since despite receiving public health care, it does not fully meet these people's needs.

Money for the medicines, often for food, because we have to have it; it cannot miss. So the problem is the money (R-6).

You have to pay the bills, you have to solve the problems, but at the same time, you need to stay in the hospital with your daughter (R-8).

Financial difficulties because we are poor. For many times, I have been with my sick daughter by bus, and she would say: "Mom, I cannot walk. I cannot walk." And I would say: "Daughter, just a few more steps" (R-8).

Managing this condition may be less traumatic when the woman, when becoming a mother-caregiver of the child in conservative renal treatment had experienced the kidney disease in the family previously, because this experience provides a singular look.

Polycystic kidneys, her father and his entire family have it. And my father [child's grandfather] has even had a transplant. I know how it is (R-3).

My mother [child's grandmother] died on hemodialysis (R-8).

The women's adaptation may occur more naturally depending on the experiences and support provided by the social support network, which may contribute to management and adaptation. In this context, nursing professionals in primary health care need to identify the stressors and promote initial support to the family, thus preventing the overload of the mother-caregiver of the child.

After knowing the adaptation process of the woman becoming the mother-caregiver of a child in conservative renal treatment, the results refer to the reflection that, due to a cultural issue, the society has cultivated the belief that it is up to the woman to take care of the family. In this sense, the mother is the one who takes care of the children's health, especially when they get sick and such obligation is considered innate to the women. Studies conducted in Brazil, Canada, the United States and Portugal have shown that family caregivers of children with chronic conditions are predominantly female and are usually the mothers of the children^(2,5-6).

Despite the change of roles, with the insertion of

women in the labor market, it is common in Brazilian families for mothers to teach their daughters to be caregivers in the face of concern about the continuity of care. Thus, the female gender remains "obligatorily" in family care, which has been passed from generation to generation, and this must be appreciated and understood by nursing professionals when planning the interventions according to the needs of each child with CKD and also of their relatives⁽⁷⁾.

Mother-caregivers are subject to the overload generated by the care routine, which can be a triggering factor for illnesses, since they do not value themselves and consequently do not care for themselves. In addition, these women often do not have a social support network that promotes physical, emotional and behavioral benefits for the maintenance of social and professional activities, thus requiring their exclusive dedication to the child's health care^(2,5-6).

It should be emphasized that initially the social support network can be formed by health professionals, since they contribute with correct knowledge and information to the process of adaptation to care and to reduce fear and conflicts in the family, thus contributing to the acceptance of the chronic condition^(3,5,6,8). In this sense, nursing professionals can contribute by acting as a bridge in the formation of the family support network and promoting the participation of the multidisciplinary team. Family support in the different areas is vital for the physical and mental health of the caregiver, which will directly influence the quality of care provided to the child^(3,6,7).

All families experience the moment of the family life cycle classified as "Families with young children" and four families. Besides this classification, they are in the life cycle "Families with adolescents". A study found that the majority of mother-caregivers had on average two children with a mean age of six years^(5,19).

The previous experience of renal disease in other family members is reported by five mother-caregivers of the child undergoing conservative renal treatment. This experience can modify the management of care, since the caregiver is empowered with practical knowledge from the previous experience, which can facilitate the care with the child's health. Studies with relatives of children with chronic diseases have reported that 10% of families had had a history of chronic patients⁽¹⁹⁾. On the other hand, CKD is triggered in childhood, in most cases, by genetic factors. Thus, the multidisciplinary team can contribute with the counseling, preventing its occurrence⁽²³⁾.

These results evidence the need for support and appreciation of the mother-caregivers of children undergoing conservative renal treatment so that these mothers can be empowered, which needs to be ethically assumed by nursing professionals when dealing with families.

FINAL CONSIDERATIONS

Knowing the adaptation process of the woman becoming the mother-caregiver of a child in conservative renal treatment allowed identifying aspects that influence the reorganization of daily life and, as a result, the need to interrupt their social life to dedicate themselves to the care of children with chronic kidney disease.

In addition, the receipt of the financial assistance for health care has an important contribution in the family budget of the mother-caregiver because with the interruption of the formal work of the mother-caregiver, this aid contributes to pay the expenses related to the treatment, since, although families have used the public service, there are often extra expenses with food, medication and tests, among others, for which the family has not been prepared.

In this sense, nursing professionals can contribute to the reorganization of family roles by addressing the family's adaptation throughout the experience of a chronic kidney disease, in order to promote the balance of the family with the support of mother-caregivers. This may reduce the stress generated by the lack of information regarding family management and reorganization, and provide care for the child with renal disease under conservative renal treatment, valuing the particularities, the socioeconomic and cultural context of the family.

The limitations of this study are related to the number of participants and to the restricted literature addressing the coping of the family caregiver of a child undergoing a conservative renal treatment, which did not compromise the understanding of the studied phenomenon. Still, due to the scarcity of studies in this subject, further studies with mother-caregivers of children in conservative renal treatment are encouraged.

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CRIANÇA EM TRATAMENTO CONSERVADOR RENAL: PROCESSO DE ADAPTAÇÃO DA MÃE CUIDADORA

RESUMO

Este estudo objetivou conhecer o processo de adaptação da mulher ao tornar-se mãe/cuidadora de uma criança em tratamento conservador renal. Trata-se de um estudo qualitativo, desenvolvido a partir do formulário específico e entrevista semiestruturada com cuidadores familiares da criança em tratamento conservador renal em acompanhamento em serviços de nefrologia. Os dados foram analisados com a técnica de Análise de Conteúdo. Participaram 11 mães cuidadoras. A maioria das participantes vive em áreas urbanas, é casada, católica, possui ensino fundamental completo, não desempenhava atividades profissionais remuneradas, mas recebia auxílio-saúde da criança, e o processo de adaptação permitiu a construção da categoria "Reorganizando o cotidiano", na qual são abordadas as mudanças e formas de ajustamento. O processo de adaptação da mulher, ao tornar-se mãe/cuidadora da criança em tratamento conservador renal, pode proporcionar, aos profissionais de Enfermagem, melhor compreensão da subjetividade vivenciada e contribuir para a reorganização e a promoção do equilíbrio no cotidiano da unidade familiar.

Palavras-chave: Cuidadores. Criança. Enfermagem. Insuficiência Renal Crônica.

NIÑO EN TRATAMIENTO CONSERVADOR RENAL: PROCESO DE ADAPTACIÓN DE LA MADRE CUIDADORA

RESUMEN

Este estudio tuvo el objetivo de conocer el proceso de adaptación de la mujer al volverse madre/cuidadora de un niño en tratamiento conservador renal. Se trata de un estudio cualitativo, desarrollado a partir del formulario específico y de la entrevista semiestruturada con cuidadores familiares del niño en tratamiento conservador renal acompañado por los servicios de nefrología. Los datos fueron analizados con la técnica de Análisis de Contenido. Participaron 11 madres cuidadoras. La mayoría de las participantes vive en áreas urbanas, es casada, católica, posee enseñanza primaria completa, no ejercía actividades profesionales remuneradas, pero recibía auxilio-salud al niño, y el proceso de adaptación permitió la construcción de la categoría "Reorganizando el cotidiano", en el cual son tratados los cambios y las formas de ajuste. El proceso de adaptación de la mujer, al volverse madre/cuidadora del niño en tratamiento conservador renal, puede proporcionar, a los profesionales de Enfermería, mejor comprensión de la subjetividad vivida y contribuir para la reorganización y la promoción del equilibrio en el cotidiano de la unidad familiar.

Palabras clave: Cuidadores. Niño. Enfermería. Insuficiencia Renal Crónica.

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