



Child in conservative renal treatment: maternal interactions with the social support network

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ABSTRACT. This study aimed to know the interaction of the mother of the child in renal conservative treatment with the social support network. Qualitative delineation, whose theoretical reference was Symbolic Interactionism. For data collection, we used semi-structured interview, genogram and ecomap. Eleven mothers of children undergoing conservative renal treatment participated. The data were analyzed with conventional content analysis. It was possible to construct two categories: Being supported by the formal social support network; Being supported by the informal social support network. The analysis showed that the main source of maternal support was related to the family. In addition, the mothers stressed the importance of the support of professionals, health services and non-governmental organization. It is concluded that Nursing can improve the targeting of care actions aimed at the family of the child in renal conservative treatment, expanding the social support network.

Keywords: social support; child; caregivers; pediatric nursing; renal insufficiency, chronic.

Criança em tratamento conservador renal: interações maternas com a rede de apoio social

RESUMO. Este estudo objetivou conhecer a interação da mãe da criança em tratamento conservador renal com a rede de apoio social. Delineamento qualitativo, cujo referencial teórico foi o Interacionismo Simbólico. Para a coleta dos dados, utilizaram-se entrevista semiestruturada, genograma e ecomapa. Participaram 11 mães de crianças em tratamento conservador renal. Os dados foram analisados com a análise de conteúdo convencional. Foi possível a construção de duas categorias: Sendo amparada pela rede de apoio social formal; Sendo amparada pela rede de apoio social informal. A análise permitiu identificar que a principal fonte de apoio materno esteve relacionada à família. Além disso, as mães destacaram a importância do apoio de profissionais, dos serviços de saúde e da organização não governamental. Conclui-se que a Enfermagem pode melhorar o direcionamento de ações de cuidado destinadas à família da criança em tratamento conservador renal, ampliando a rede de apoio social.

Palavras-chave: apoio social; criança; cuidadores; enfermagem pediátrica; insuficiência renal crônica.

Introduction

Chronic Kidney Disease (CKD) has become a worrying health problem due to its high morbidity and mortality rates. When diagnosed in children or adolescents, it has negative consequences on quality of life, as well as changes in family dynamics and daily routine, due to the therapeutic process, clinical control and constant hospitalization (Abreu & Santos, 2014).

When dealing with the presence of a chronic disease such as CKD, especially in childhood, it becomes a topic of interest to reflect on the need for adaptation and coping of the family in the face of the limitations that appear on the family system. In this context, the demand for care offered to the child implies a network of social support supported by

health services, family and community, in order to assist the main caretakers in decision making so that they are autonomous subjects and aware of their attitudes (Barbosa, Reis, Lomba, Alves, & Braga, 2016).

In Brazil, by the predominance of nuclear families, the couples are organized according to traditional references. The mother takes responsibility for the role of primary caregiver with full availability. Already the father adopts the secondary role of provision, with significant absence in relation to child care (Martins, Abreu, & Figueiredo, 2014).

Thus, knowing the relationships that the mother possesses, not only quantitatively, but also in what way they happen, cooperates so that health professionals institute interventions to promote the

health of caregivers, thus improving care for dependent patients and, even, the family dynamics. Moreover, the absence of opportunities to leave or to participate in extra-community activities may lead the mother to seek shelter in the family, which makes it important to have other forms of ties, such as friends or neighbors, providing greater support (Yamashita, Gaspar, Amendola, Alvarenga, & Campos, 2014). As sociocultural influence on maternal empowerment occurs individually for the social, it is strongly influenced by the social support network (Neves, Cabral, & Silveira, 2013).

In this sense, the mother, as the main caregiver, assumes a demand for essential care to improve the child's quality of life, which leads to the existence of emotional and physical overload to provide the necessary care for the child's health (Neves, Silveira, Arrué, Pieszak, Zamberlan, & Santos, 2015; Pinto, Torquato, Collet, Reichert, Souza Neto, & Saraiva, 2016). In this way, living with the family and other people can mean a mutual interaction, from affective exchanges that lead to development in the diversity of roles, the alteration and balance of power, the conjunction of looks, physical contact, respect, among other elements (Polita & Tacla, 2014).

Studies on the social support network of the family caregiver / mothers / families (Neves et al., 2013; Franco & Velhinho, 2013; Silva, Lima, Albuquerque, Santos, Silva, & Medeiros, 2013; Polita & Tacla, 2014; Yamashita et al., 2014; Cabral & Moraes, 2015; Dezoti, Alexandre, Freire, Mercês, & Mazza, 2015) have included children with a clinical diagnosis of cerebral palsy (Polita & Tacla, 2014; Dezoti et al., 2015) and children with special needs (Neves et al., 2013; Cabral & Moraes, 2015). However, no publications related to the social support network were found when the family, especially the mother, is faced with the need for conservative renal treatment for the child with CKD. Thus, this study had as a guiding question: 'What is the interaction of the mother of the child in conservative renal treatment with the social support network?'. And the objective of knowing the interaction of the mother of the child in conservative renal treatment with the social support network.

Methodology

This is a descriptive study, with a qualitative approach, carried out in the light of Symbolic Interactionism, since it is a theoretical reference that seeks to know how people interact and thus understand their behavior in face of the situations experienced (Sandstrom, Martin, & Fine, 2016).

Data collection was performed between April and August 2015, with 11 mothers of children in renal conservative treatment coming from a public outpatient clinic of pediatric nephrology located in the south of the State of Rio Grande do Sul, Brazil. Inclusion criteria were: to be characterized as the primary family caregiver of the child and to be 18 years old or older. The exclusion criteria were: not to communicate verbally and not to speak Portuguese.

The initial contact with the participants occurred in the public outpatient clinic of pediatric nephrology on the day of the child's consultation with the nephrologist. Subsequently, by telephone, with the children who did not have a scheduled appointment, it was verified that, although registered in the service, they were in follow-up in other places of the same state for some months or years. In this way, the technique of snowball was used, in which the first interviewees indicated others. From the indication of the first, contact was made with five more mothers and the collection was finalized upon reaching the target. Thus, there were 11 participants. The interviews, with an average time of 60 minutes, were carried out in a place defined by the participants, most of them in their homes.

As a data collection instrument, a semi-structured interview was used and, after the interviews, the genogram and ecomap was constructed to identify the social support network of the mothers of children undergoing conservative renal treatment. For the construction of the genogram and ecomap, the software 'Dia', a free software for the creation and editing of vector graphics, flowcharts and diagrams, was used. The genogram allows us to know the family configuration, specifically emphasizing the occurrence of kidney disease in the family, since its main function is to organize the data regarding the family and its relational processes (Wright & Leahey, 2012).

For the analysis of data, conventional content analysis was used, which occurred concomitantly to the interviews, because it is a commonly used method to describe, analyze and report on themes and patterns of data without the imposition of preconceived categories or theoretical perspectives. In this form of analysis, after completing the interview, the researcher performs the steps of transcription, reading the transcribed interview and codifying the data for later categorization of the information contained in the interview, which derives directly from the textual data (Hsieh & Shannon, 2005).

The study respected the ethical principles of research involving human beings, according to Resolution 466/2012 (Brasil, 2012). The Informed Consent Form was delivered and read to the participant on the day of the interview, signed in two copies by the participants and by the researcher, ensuring the freedom of spontaneous participation and the right of withdrawal at any time during the research. The study was approved by the Ethics Committee under opinion no. 985.770 and CAAE no. 41609214.8.0000.5316. In order to preserve the participants' anonymity, the initial 'E' was used for identification, followed by the Arabic number, according to the order of interviews.

Results

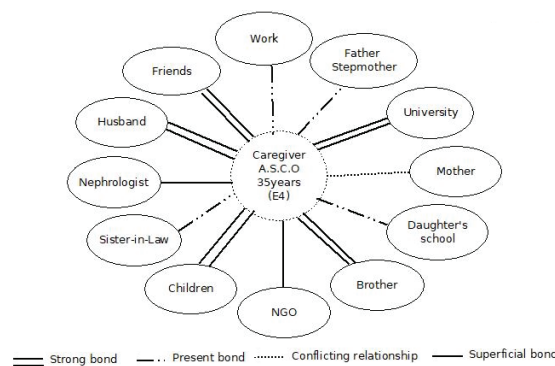
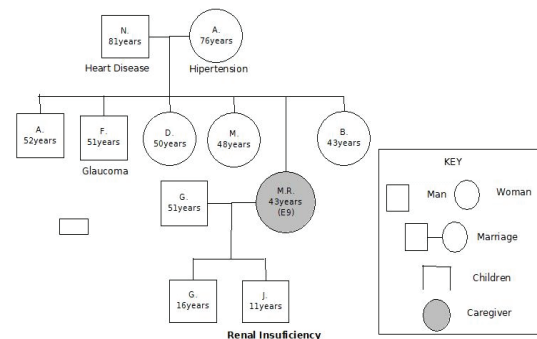
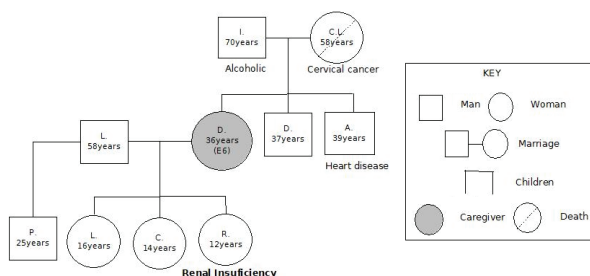
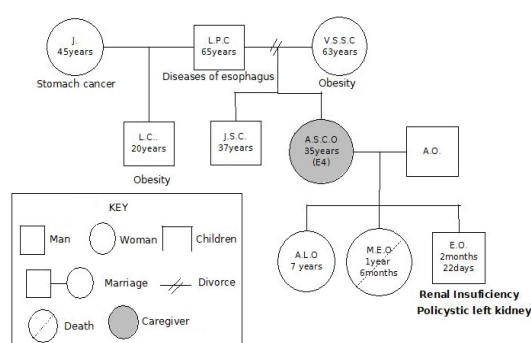
The results allowed to know the interactions of the mothers of the children in conservative renal treatment with the social support network. Thus, it was observed that this is formed by a formal and

informal social support network, being presented in the categories 'Being supported by the formal social support network' and 'Being supported by the informal social support network', which will be described after presentation of the genograms and ecomapas (Figure 1), which were chosen for representing the formal and informal social network.

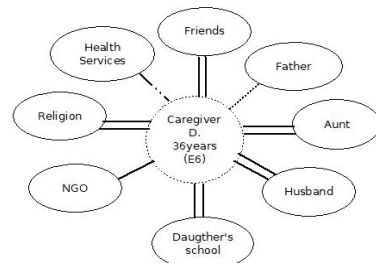
Being supported by the formal social support network

The formal social support network was formed by health professionals, health services, non-governmental organization (NGO) and school. Such forms of support were related to receiving information and guidance that provided an optimistic view of the future.

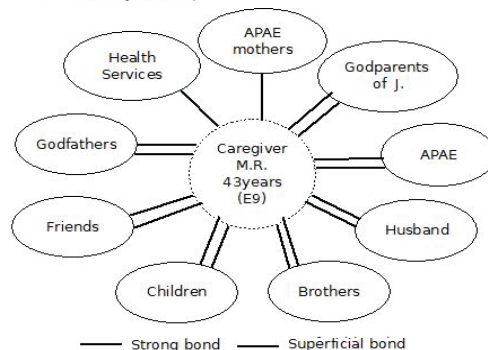
In the support network formed by the health professionals, it was observed that the interaction was beneficial for the mothers of the children in renal conservative treatment. Above all, the established medical relationship.



== Strong bond ... Present bond Conflicting relationship --- Superficial bond



..... Conflicting relationship ... Present bond == Strong bond --- Superficial bond



== Strong bond --- Superficial bond

Figure 1. Genograms and ecomapas of mothers of children in renal conservative treatment, 2015.

I started to take her [daughter] there to the [nephropediatrics] doctor, who, by the way, is very good for her, and thanks to God, even when they are leaving, her teeth do not have anything (E-1).

Medicine helped me a lot and even more there in [the city where she performed the treatment] she [doctor] did everything to help her [child] (E-2).

It is something that is difficult only the family to help. You need a group of doctors. [...] Needing the [nephropediatricist's name], I can call her, talk (E-5).

This doctor is very good! So he was interested in the case because no one was interested (E-6).

The [name of the nephropediatrician] is very good, it also helps me a lot [...]. I'm kind of wrong, I'll call her [nephropediatrician]. So when [she] is in a bit of trouble, I'll call her and tell her [nephropediatrician], I'll explain. The [name of the pediatric nephrologist] is my second mother, as the other [popular saying] says (E-11).

The testimonies show that the link between mothers and health professionals, especially physicians, was significant. This situation leads to a compromise with the health care of the child in renal conservative treatment.

Besides the support network being formed by the health professionals, the mothers mentioned the importance of the relationship with the health services. So much so that one participant approached the link with the specialized service of pediatric nephrology, since this service provides significant assistance for the care of the child when comparing with that of other places.

The federal staff (pediatric public ambulatory) is well liked, they help a lot because, in other places, the service is terrible, it's horrible (E-5).

In this category, a mother addressed the support received from a person represented by a Non-Governmental Organization (NGO) and the recognition of this institution in the care network, emphasizing its importance in helping children with CKD and their families.

It's just that I learned this week from a transplanting gentleman and even an NGO [for the care of people with CKD] that although she [kid], earning that kidney, her life will not be as it was before. She will not be able to catch the sun, take a bath on the beach, it will never be normal again. She's going to have to keep taking medicine and being a psychologist, and so am I because I'm going to take medication at the beginning, too. People who, if I came here at home, after she goes to get the kidney, with the flu, not even think about entering the house. Dust, not even think. Her life will never be the same again. I thought it would be. It is sad for a mother to know that although she is receiving an

organ, it will not be the same thing [...]. It was to have a big space, a huge big NGO to help these people (referring to something that would help the families of children with CKD) (E-6).

The interest in seeking guidance on existing treatments for CKD, receiving information about renal transplantation, which could be thought of in the future for the child who is in renal conservative treatment.

Being supported by the informal social support network

In this category, the network of informal social support, formed by the family (husband, children, sister-in-law, mother-in-law, uncles and brothers) and spirituality will be approached, which is related to faith, providing an optimistic vision regarding the future. The family has been described as a source of social, emotional and financial support and is considered positive for the mothers of children undergoing conservative renal care, which makes family support safe.

With my mother and my sister, with my family [...]. They'll help me if I need to. They go with me also [to the consultation] [...]. Both the psychological support, help me a lot, are always there (E-2).

My mother took care of her [daughter] ever since she was little, she slept with my mother! So, my mother knows everything (E-3).

The whole family goes [in the nephropediatrics appointment]. Back home, where one goes, everybody's gone. No one is intimidated. The [name of the oldest daughter] is missing the class, everyone goes to [the city where the treatment is performed], we are going to take a walk in the mall. We're going to relax too (E-4).

Only with my husband, you have no one to tell. My daughter is far away (E-5).

With my husband, he's the only one (E-6).

Especially with my family, father and mother, they are the ones that help me the most (E-7).

I tell his father [the child's father] and his brother [brother of the child] helps me a lot, he's my oldest son. [...] My son, if I need to leave, in the function of having to leave and not need to take him [child], he stays, he exchanges, he gives food, he stays with him for me, (E-9).

My mother-in-law helps me, my sister-in-law helps me, everyone always comes back. [...] They [sister-in-law and mother-in-law] help with clothes, these things like that. My sister-in-law, since she [child] was born, helps me. Because to eat always gives, we always have, for her medicines have everything [...]. Everyone helps themselves (E-10).

My sister-in-law there, I have to count on her, anything, if I have to lower [myself hospitalized], I have to ask her [sister-in-law], but she's not like us anymore. Of course, I was going to explain to her [sister-in-law] how things are like that (E-11).

In view of these statements, the importance of the support received by the family, which was not only nuclear but extensive, was observed for the mothers of children undergoing conservative renal treatment. Family unity, for the sake of care, conveys a meaning that there is a positive interaction between the people involved.

Still, in this category, the informal support of the family was seen as negative by some mothers of the children in conservative renal treatment. There were references of deprivation, overload with care and lack of support for maintenance of treatment, leading to insecure family support.

He [the child's father] helps, he comes, but it's not that thing, I can not almost always tell him. Not even to spend a weekend with him [child], he [father] does not stay. You deprive yourself of many things (E-2).

I think if he [father of the child] had more presence in her [child] care, I think it might be a bit different. And I do not have much help from her father [father of the child] too, which makes a difference (E-7).

It's difficult, that's the way it is, it's a ride we need to go to the doctor all the time. No one can ever, everyone has to work (E-8).

The situation observed, based on the testimonies of these three mothers, shows the difficulties faced for the provision of health care for the child in renal conservative treatment. Two mothers, E-2 and E-7, have in common the lack of support from the child's parent, while E-8 has difficulties to travel to the health services because they live far from these places and there are no means of transport available for its locomotion.

Another important source of informal social support addressed by mothers was spirituality, since one emphasized the learning provided by the experience of having a child with CKD in conservative treatment for mutual help, referring to the spiritual growth of the child and mother provided experience of the disease.

So we have to be calm. I think what is for you is stored, regardless of whether you want it or not. So, what has to happen will happen. I believe this a lot [...] because Spiritism is that. We have a cycle to pass and a time to pass. And if it's his time [kid] to be with me, we'll be together. And I'm here to help him [child] (E-4).

For E-4, it is important to have a philosophy of life that supports the maintenance of mental health

in order to face the CKD process and the need for treatment for the child. The fact experienced by the mother makes her believe in the existence of a certain destiny for her life and the life of her child.

Discussion

In the formal social support network, the mothers of the children in conservative renal treatment considered the health professionals as members of their family by the established trust. This means that professionals can present empathic characteristics and offer humanized care that caregivers perceive in relationships conceived as support, trust and safety (Baltor, Matos, Wernet, Ferreira, & Dupas, 2013). In this sense, in the formal social support network, Nursing needs to establish care strategies to know the home environment and its caregivers (Silva et al., 2013; Polita & Tacla, 2014). In order to do so, the use of the genogram and the ecomap is suggested as a favorable therapeutic tool for the approximation of professionals and families (Nascimento, Dantas, Andrade, & Mello, 2014).

In the light of Symbolic Interactionism, the experience lived by the mother with the professional showed the meaning expressed in words of brotherly sense, when associating the physician with the maternal figure. This is due to the social interaction, fruit of the reflection, interpretation and action of the individuals (Sandstrom et al., 2016). Thus, the interaction established by the professional and the mother promoted confidence regarding the care of the child in renal conservative treatment.

Another significant form of support, cited by the mothers, was the health services, since the maternal experience of going through an exhausting itinerary for the treatment of children with CKD allows comparisons and conclusions about the meaning of the support received in the health service. The symbolic elements, offered in this place, contribute to strengthen the relationship between services and patients (Mello, Moreira, & Batista, 2016). And the meaning attributed by the mothers of the children in conservative treatment to the health service was empathy, which may enhance the adherence to care and guidelines that seek in the service.

Regarding the satisfaction with health care, the interviewee E-5 points out that, in the outpatient clinic where the care of her child occurs, she is well attended, when comparing with the other services. According to the principles of the Brazilian health system, it is the right of every person to receive humanized and respectful attention, being a duty to receive in all health services, with equality and

humanization. In addition, when a mother experiences the illness of her child, attitudes of readiness for health care may mean receiving support to face this difficult moment.

NGOs form part of the formal social support network, which have the role of collaborating with the state in the process of promoting the empowerment of society (Santos, 2016). The support offered by an NGO showed the relevance of this institution in maternal empowerment, through guidelines on the need for continuity of care with the health of the child and the mother, after renal transplantation.

From the point of view of Symbolic Interactionism, the mother, when receiving guidance on the care needed after the transplant, realizes the meaning of the NGO's activity and, in this way, recognizes the importance of this institution for herself and others in a similar condition.

The informal social support network of mothers of children on conservative renal treatment is formed by members of the nuclear and extended family. This interaction is perceived as positive, since there is collaboration in the child's health care, alleviating maternal overload. It can be considered as a form of complementation to the formal support network. However, it goes beyond the regulation of the State, because each family nucleus seeks, in available support, a certain form of organization to attend to the needs of care, being a form of collective support to overcome the demands not contemplated in the formal social support network (Rezende, Assis, & Barca, 2014).

In this same aspect, emotional support provided by family members is an important element and demonstrates that factors that are not directly related to the disease can intervene in their state of equilibrium (Silva et al., 2013). According to Symbolic Interactionism, the consciousness of humanized care is formed in the social interaction in which relations of mutual exchange between members occur (Sandstrom et al., 2016).

It was identified that in the maternal perception, the negative performance of the family in the informal social support network, referring mainly to the absence of parental support, may be related to the parents' neglect of the child's health care or, affective, educational and financial abandonment. According to the literature, the culture that mothers are the main responsible for the care of their children (Franco & Velhinho, 2013; Dezoti et al., 2015; Pinto et al., 2016) is rooted in society, such as in the DRC.

The way in which parents manage their relationship with their mothers and their children in

renal conservative treatment shows that they have difficulties adjusting and thus assume different levels of commitment in their family role. In the interactionist perspective, the father can perceive himself as society sees him, deprived of responsibilities with the care of the child's health. In this way the person internalizes this general view of the self and behaves coherently with such a vision and, through the process of mental reflection, mentally plans and repeats symbolic behavior, preparing for subsequent interaction with others (Sandstrom et al., 2016).

In general, the father is responsible for the financial maintenance of the family, participating in a limited way in decisions and actions on care, which usually occur when requested by the mother (Pinto et al., 2016). However, Nursing can contribute to the involvement of the father, making him perceive himself part of the health care network of the child in renal conservative treatment. For through interactions with other people one can attribute new meanings to things and situations, reshaping and transforming society (Sandstrom et al., 2016).

As found in this study, there is a need for support from other people, such as family, neighbors and / or friends, since the intense need and constant dedication to the child's health care can affect the quality of life of the child. (Neves et al., 2013), which may be related to the sporadic performance of other members in child care (Dezoti et al., 2015).

Among the ways to stimulate maternal autonomy, there is a need for support programs that can identify potentialities and support fragilities (Rezen et al., 2014). In this logic, the family-centered model of care foresees the implementation of policies that promote financial support and emotional support to meet the demands of care (Barbosa, Balieiro, & Pettengill, 2012).

Spirituality was considered a significant form of informal social support for the mothers of children in renal conservative treatment, since it helps to promote better management of the child's health condition and established treatment, reducing the negative effects of this experience (Heydari, Shahidi, & Mohammadpour, 2015). Thus, spirituality becomes a conscious practice that, in the light of Symbolic Interactionism, is related to the conscious confrontation of the mother to the adaptation to the new reality (Carter & Fuller, 2015).

According to Symbolic Interactionism, maternal experience can be altered, since human beings are the result of social construction (Sandstrom et al., 2016). In this sense, Nursing can work to promote the strengthening of the support network and family empowerment. Thus, the existence, recognition and

valuation of the support network is fundamental, as it has an indispensable role in reducing maternal overload in child care in renal conservative treatment, improving the quality of life of the caregiver and, consequently, quality of child care.

Final considerations

The results showed the interaction of the mother of the child in renal conservative treatment with the social support network and, thus, identify the various actors that participate in the formal and informal social support network, with emphasis on the social support from the family, health professionals, health services, NGOs and spirituality. Such results can allow Nursing to understand how families have found balance in relationships established with their social support network and contribute to the redefinition of family roles, encouraging the father to greater participation in decisions and actions of child care in conservative treatment renal.

It is emphasized that, although the interaction has an individual meaning, it is regulated by social constructions. And Nursing can use the genogram and the ecomap as tools to evaluate the social support network, in order to establish a link and, consequently, to improve family care and improve strategies for maternal coping.

It is highlighted, as frailties of the research, the approach centered on the caregiver of the child in renal conservative treatment, in this case, the mothers, not extending to the other family members. Thus, it is suggested to carry out other studies on the theme involving the family.

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