



Uncertainties of mothers of children in conservative renal treatment

Incertezas de mães de crianças em tratamento conservador renal *Incertidumbres de madres de niños en tratamiento conservador renal*

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ABSTRACT

Objective: To understand the uncertainties of mothers of children undergoing conservative renal treatment due to the child's illness. **Method:** A qualitative study was carried out with 11 mothers of children undergoing conservative renal treatment at a pediatric nephrology service in the southern region of Brazil. For the data collection, a semi-structured interview and conventional content analysis were performed. **Results:** Two categories of statements emerged: "Uncertainties regarding the disease and adaptation methods" and "Experiencing unpredictability". The uncertainties were due to the ambiguity of the symptoms and reasons for the development of the disease, lack of information, clarity and unpredictability in relation to the future. **Conclusion and implications for practice:** Faced with uncertainties, mothers seek to maintain emotional balance, but need support from the healthcare team and nursing team, in primary health care, in order to promote assurance by giving clear information on how this process occurs, reducing anxiety regarding the unpredictability of the disease in the future.

Keywords: Life Change Events; Child; Nursing; Uncertainty; Renal Insufficiency, Chronic.

RESUMO

Objetivo: Conhecer as incertezas de mães de crianças em tratamento conservador renal decorrentes do processo de adoecimento do filho. **Método:** Estudo qualitativo, realizado com 11 mães de crianças em tratamento conservador renal em um serviço de nefrologia pediátrica da região Sul do Brasil. Para a coleta dos dados realizou-se entrevista semiestruturada e Análise de Conteúdo convencional. **Resultados:** Emergiram duas categorias de depoimentos: "Incertezas na doença e formas de adaptação" e "Vivendo a imprevisibilidade". As incertezas foram decorrentes da ambiguidade dos sintomas e motivos do desenvolvimento da enfermidade, falta de informação, clareza e imprevisibilidade em relação ao futuro. **Conclusão e implicações para a prática:** Diante de incertezas, as mães buscam a manutenção do equilíbrio emocional, porém necessitam de amparo da equipe de saúde e a Enfermagem, na atenção primária à saúde, para promover a segurança, com informações claras sobre como se dará esse processo, diminuindo os anseios em relação à imprevisibilidade da doença no futuro.

Palavras-chave: Acontecimentos que mudam a vida; Criança; Enfermagem; Incerteza; Insuficiência renal crônica.

RESUMEN

Objetivo: Conocer las incertidumbres de madres de niños en tratamiento conservador renal debido al proceso de enfermedad del hijo. **Método:** Estudio cualitativo, realizado con 11 madres en un servicio de nefrología pediátrica de la región Sur de Brasil. Se realizó una entrevista semiestructurada y Análisis de Contenido convencional. **Resultados:** Emergieron dos categorías de testimonios: "Incertidumbres en la enfermedad y formas de adaptación" y "Viviendo la imprevisibilidad". Las incertidumbres fueron consecuencia de la ambigüedad de los síntomas y motivos del desarrollo de la enfermedad, falta de información, aclaraciones e imprevisibilidades en relación al futuro. **Conclusión e implicaciones para la práctica:** Las madres buscan el mantenimiento del equilibrio emocional, pero necesitan de amparo del equipo de salud y de la Enfermería, en la atención primaria a la salud, para promover la seguridad, con informaciones esclarecidas sobre cómo se dará este proceso, disminuyendo la ansiedad en relación a la imprevisibilidad de la enfermedad.

Palabras clave: Acontecimientos que Cambian la Vida; Niño; Enfermería; Incertidumbre; Insuficiencia Renal Crónica.

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INTRODUCTION

Throughout the journey of the chronic condition of a child, mothers, as primary caregivers, may present many doubts, which refer to the concept of uncertainty surrounding the disease. This refers to the individual's inability to evaluate and/or predict the outcome of the disease due to lack of clarification,¹ causing mothers to experience various uncertainties regarding the child's life.

Chronic Kidney Disease (CKD) in childhood requires that the mothers of these children adapt to the routine of caring for the child's health and to manage the changes brought about in the everyday life of the other family members. Among the forms of treatment for childhood CKD, the conservative renal treatment is highlighted, which is characterized by the need for changes in the everyday life of the family, which include changes in eating habits, medication administration, physical activity and periodic health evaluations in in healthcare services in order to monitor the evolution of the disease. It is considered an exhaustive and stressful experience, since there are many doubts, mainly, arising from the indetermination of the reasons that led to the occurrence of the disease and also in relation to the prognosis.²

Studies indicate that nursing is centered on the concept of uncertainty, nurses can influence individuals and families, because they maintain frequent contact with them and can provide assurance by giving information that promotes understanding of the experience.^{3,4}

The experience of uncertainty due to the disease was identified and discussed in studies with parents of children with other chronic conditions, descriptions of different realities with high levels of uncertainty in relation to the disease were evidenced, which is directly related to the demand on caregivers.⁵ It was also revealed that the ambiguity, defined as the lack of clarity regarding the symptoms for the diagnosis of the child's disease, experienced by the mother of the child, was related to the maternal symptom of posttraumatic stress. Researches consider that the feeling of uncertainty can be avoided when the mother has support in evaluating the diagnosis and prognosis of the child's illness, trust in health professionals and a higher educational level.⁴⁻⁸

In a literature review, studies that addressed uncertainty due to the disease were classified as quantitative and used the uncertainty scale for parents/children in the Uncertainty in Illness Theory developed by Mishel.⁴⁻¹² Qualitative studies addressed the parents' uncertainty regarding the disease.¹³⁻¹⁶ However, insufficient qualitative and quantitative investigations with mothers of children with Chronic Kidney Disease were identified.

Nurse Merle Helaine Mishel's Uncertainty in Illness Theory is composed of four concepts: 1) **ambiguity** of symptoms: due to the difficulty in determining the diagnosis; 2) **lack of clarity/complexity** regarding the guidelines on childcare; 3) **lack of information** about the diagnosis of the disease and 4) **unpredictability** related to the inability to foresee the disease.^{4-10,12,17}

These concepts were chosen because they are believed to contribute to the uncertainty of the mothers of children in conservative renal treatment as these concepts address the uncertainties of those who experience a condition in which the prognosis of the child's disease is uncertain. Thus, the following research question was elaborated: What are the uncertainties of the mother of the child in conservative renal treatment due to the child's illness? This objective of this study was to understand the uncertainties of the mother of the child in conservative renal treatment, due to the child's illness.

METHOD

A qualitative study with theoretical support in Uncertainty in Illness Theory developed by Mishel.¹⁷ The concepts of this theory were chosen because it is considered propitious for the understanding of the uncertainties of the mother of the child in renal conservative treatment.

Data were collected from April to August 2015, through semi-structured interviews, which were recorded on an audio file and transcribed in full. The questions asked were: "Tell me about your experience of caring for a child with kidney disease from the beginning," and "How did it feel to receive the diagnosis of your child's disease?"

Eleven mothers of children undergoing conservative renal treatment in a pediatric nephrology department of the Faculty of Medicine of a Federal University in the South of Brazil participated in this study, which included the following inclusion criteria: be the primary family caregiver of the child in conservative renal treatment; be more than 18 years of age, reside in the southern part of the state of Rio Grande do Sul. In this study, it is important to highlight that all family caregivers were mothers.

The initial contact from the researcher (Nurse, Pediatric Nursing specialist, MSc student with no connection to the service) with the participants occurred at the Pediatric Nephrology Service of the Pediatric Outpatient Department on the day of the child's consultation with the nephrologist. Afterwards, contact was made by telephone with the mothers whose children did not have a scheduled appointment. It was verified, that in spite of being registered, these children had been followed up by other health institutions from the state of Rio Grande do Sul for some months or years. Thus, the snowball technique was used, in which the first interviewees suggested other participants. After the first six interviewees were interviewed, a further five mothers were contacted and the collection was completed after the objectives had been reached and when there was an absence of new data in the participants' reports. Data collection was performed in a place chosen by the participants, mostly in their households, and had an average duration of 60 minutes.

After each interview, the data were transcribed, organized, and analyzed using conventional data analysis, as it is a commonly used method for describing, analyzing, and reporting data themes and patterns. In the conventional approach of Content Analysis the information is obtained directly from

the study participants without the imposition of preconceived categories or theoretical perspectives, that is to say, the categories of codification are derived directly from the textual data, meaning that the codes were extracted after the exhaustive reading of the interviews and from them, it was possible to compose the categories.¹⁸

The study respected the ethical principles of research involving human beings, according to National Health Council Resolution 466 of December 12, 2012.¹⁹ The Informed Consent Form was delivered and read to the participants on the day of the interview, and two copies were signed by the mother and the researcher, assuring the freedom of spontaneous participation and the right of withdrawal at any moment during the research. The study was approved by the Ethics Committee, opinion number 985,770 and Certificate of Presentation for Ethical Assessment (CAAE) number 41609214.8.0000.5316. In order to preserve the anonymity of the participants, the initial "E", followed by the Arabic number, according to the order of interviews, was adopted for the purpose of participant identification.

RESULTS

The 11 mothers who were interviewed were between 27 - 43 years of age. Most of them live in urban areas, were married, Catholic and had completed elementary education and did not perform paid professional work. Among the children in renal conservative treatment, there was a predominance of white females, between two months and 11 years of age, with an initial diagnosis of urinary tract malformations and glomerulopathies. In expressing their experiences, the mothers reported uncertainty regarding the child's illness and the data analysis: this allowed us to construct two categories called "Uncertainties surrounding the disease and ways of adaptation" and "Experiencing unpredictability", as presented below.

"Uncertainties regarding the disease and adaptation methods"

The mothers of the children receiving conservative renal treatment showed their uncertainties due to the experience of their child's CKD in their statements. Such uncertainties are related to ambiguity, the symptoms of CKD presented by the child, lack of information related to the reason for the onset of the disease, unpredictability of the diagnosis and prognosis of the disease. In addition, the complexity of the disease and/or lack of clarity related to orientations and guidelines directed to the care of the child; as well as maternal unawareness about kidney disease. Regarding the doubts about the disease, the mothers reported:

[...] it is difficult, because sometimes you have so many doubts. What you can do or not. I keep thinking ... until now I could not understand why the kidneys (name of the child) fell (they reduced the rate of glomerular filtration) in this way [...]. (E-4).

[...] it was a terrible experience, because you do not know what you are going to do. Then every day the disease evolves more, she doesn't urinate, doesn't eat, it only gets more and more swollen. Now this lump appeared, after arriving from the hospital, we do not know what to do ... I returned home without knowing anything, because there are two test results there (at the health service) that I haven't received yet. It's complicated [...]. (E-10).

Maternal misunderstanding about the child's pathology may be a trigger for uncertainties. The feeling of ambiguity is related, especially when the interviewee reports concern, with signs that the clinical condition of their child is worsening and the attempt to contain its advancement by searching for specialized care.

[...] I think her urine is still smelling very strong and it's very yellow, so I'm going to move her appointment forward to find out if this is normal, whether it's a kidney thing or if it's in my head. [...] because she only has one (kidney) [...]. (E-1).

The statement describes the events that show the unpredictability, i.e., the maternal concern with the future and the disease, and when they feel insecure, they seek the necessary support in healthcare services to clear up their doubts.

The uncertainties are also related to communication problems, which can affect the quality of care offered in healthcare services. The statement below is an example of the poor communication between health professionals and mothers.

[...] Ah, I know very little, because the doctors there do not talk much with us [...]. I know we're going to have to have follow-up with a psychologist (after the child's kidney transplant), but until now we have not been referred for anything [...]. (E-6). [...] and so, a lot of things happen in a way that if we had more information, I know a little, but the little I know now, if I knew at first I think it would have helped more, it would have made it easier for both of us (mother and father). I think if the mother has more access to the information, she knows how the process works, I mean, how this whole thing works. I think it helps to improve things a lot, at least for us to have the care that we have to have. [...]. (E-9).

The statement suggests doubts that are caused due to the possible lack of information regarding the continuity of the follow-up care in the healthcare service.

The following statements are regarding the adaptation methods used by mothers in the care of children with CKD in conservative treatment which include the maintenance of emotional balance and spirituality. They say that maintaining serenity when faced with the difficulties experienced on a daily basis is a way to maintain their mental health.

[...] we will sort it out, as they (the problems) happen without stress, because if you think about it in the long run, then you start to go crazy, then you start wanting to have another child, a possible kidney transplant donor), then you start wanting other things to try to solve the problem that has not happened yet (E-4).

Faced with the feeling of uselessness and incapacity regarding the outcome of the chronic condition experienced in the treatment of the child's kidney disease, such feelings can be redeemed with the comfort found in spirituality, according to the following statement:

[...] it may seem irrelevant, but faith is fundamental at this time. Fundamental! When the doctor tells you so ... I gave all the medicines that were possible, everything! If you do not have faith in God, if you do not hold on to God, you go crazy. (E-8).

"Experiencing unpredictability"

The uncertainties of the mothers are related to the prognosis of the chronic condition experienced by the child. This category addresses the unpredictability that involves the maternal inability to foresee how the disease will be in the future, concerns regarding the need for care and the possibility of the child's clinical condition worsening.

The statements show the maternal concern for the care of the child in the future, reaffirming that the doubts regarding the pathology contribute to the increase in unpredictability.

[...] I always have many doubts because of this disease, because it is a disease, that over the years new problems can arise, [...] I do not know what the future will be like, [...] what it will be like to take care of her [...]. (E-7). [...] if I leave the house, I'm already worried about her at home, because at any moment she could get worse [...]. (E-10).

This experience may be obscure for the mother because it is an imprecise process, which can be attenuated with the exchange of experience with other people having similar experiences. Another emerging point is the maternal desire for their child to return to their healthy status prior to the kidney disease, and mothers also have a feeling of compassion for the condition faced by their children.

[...] I would like her to go back to eating everything normal later. If it's not possible, it's not possible, but if she could one day, [...] we feel sorry for her [...]. (E-11).

In addition, doubts regarding the prognosis of the child's illness show that some mothers are aware of the diagnosis, yet they coexist with the unpredictability of the child's future.

[...] one of the two: either these cysts will atrophy and will not work, because that kidney really does not work ... or (the child) will grow and the kidney will get small along with the cysts [...]. (E-4). [...] and will a transplant help her? [...]. (E-5).

Such an unpredictable condition prompts some mothers to construct and justify hypotheses, favoring the reflections on the present form of treatment and also treatment in the future.

Another participant mentioned that the experience of conservative renal treatment is comforting, however, reveals the apprehension regarding the possibility of the daughter needing the kidney transplant, since a different family member had already had a transplant, despite this experience she showed an expectation that the transplant could be the "cure" for their daughter's disease.

[...] you know that there is no end yet (treatment of the disease), because it is chronic! Only with a transplant, you know that you will have a lot more things, for now it is lessened, but in a while she will have the transplant, we know that the transplant is not easy (after the interview the participant reported to the researcher about the experience she had of family member receiving a kidney transplant) [...]. (E-2).

The news of the need for the child to undergo a kidney transplant and the possibility of not obtaining a compatible donor causes the feeling of uncertainty in the mother who, due to lack of knowledge of the process, refers to the sensation of fear.

[...] she (the doctor) said that maybe, sometime soon she will have to have a kidney transplant. I hope it's not necessary, you know? Because bah! Getting on the waiting list, even more so with a child, I'm afraid of that [...]. (E-3).

Furthermore, regarding unpredictability, the forms of treatment are thought by the mothers of the children who look for alternatives of resolution for unreal situations.

[...] because this is one of the great causes of kidney transplantation (talking about kidney failure), that's why I came (from the city where the treatment is performed), I came thinking (laughs) about having another baby already. But the doctor called me saying no, that the hypothesis was rejected (of the transplant), but even so, I'm afraid, you know? (E-4).

DISCUSSION

The results showed that the mothers of children undergoing conservative renal treatment experience uncertainties due

to ambiguities, complexities, lack of information regarding the diagnosis and the unpredictability of the child's disease in the future.

The ambiguity of the symptoms hinders the accuracy of the diagnosis, and the diagnosis of chronic kidney disease can be a trigger for uncertainties. Studies indicate that receiving the diagnosis caused a feeling of uncertainty in mothers of children with chronic conditions^{4-8,11,13-15,17} and, they may even associate the time elapsed until the confirmation of the diagnosis with the chronicity of the disease.²⁰

This result was evidenced in the statements of the participants and corroborated with the uncertainties of mothers of children with different diagnoses. In the context of rheumatic disease, the uncertainty of the parents regarding the disease was related to the depressive symptoms in the child.⁵ For the parents of children with Down Syndrome, the level of uncertainty, hope, and adaptation to the new condition were significantly correlated.¹¹

When corroborating with the presented results, they indicate that the uncertainty surrounding the disease can be a complex experience for the mother of the child in conservative renal treatment, which are related to the ambiguity of the symptoms, the lack of information and the unpredictability.

The ambiguity of the symptoms, as found in studies with mothers of children with different chronic conditions, stems from the inability to discern the meaning of the events related to the disease and when the results are perceived as unpredictable.^{8,17,20} Research shows that the low level of education may contribute to triggering uncertainty regarding the disease, as they require specific information and resources according to the child's condition,⁸ such a reality can negatively influence and impair the quality of the child's care, as high levels of uncertainty during the course of the disease reduces the quality of life of the mothers.^{8,20}

In this study, the mothers showed the lack of information in their statements, which proves in order to understand this process, maternal empowerment with clear and objective guidelines is necessary as well as strengthening the health service support network. It is important to emphasize that parents often receive information from health professionals, however they do not understand this information, reiterating the need to provide feedback when guiding the family of a child with a chronic condition.

Regarding the uncertainties caused by the ambiguous signs of the worsening illness, lack of information, and lack of clear care guidelines, are factors which may contribute to making disease-related events complex and uncertain. In the experience of cancer patients it was found that receiving ambiguous answers from physicians and other health professionals triggered doubt.⁹ For mothers of children with autism, the long waiting time to confirm diagnosis increased the level of uncertainty.⁸ This feeling was consistent for parents of children with cancer from the moment of diagnosis regardless of waiting time period.¹⁶ These results corroborate those found in this study.

Among the factors that reduce levels of uncertainty are the availability of clear information, the availability of a social support network, the clarity and specificity of the professionals' information, and confidence in health professionals,⁸ which may favor coping.⁹ In many cases, care guidelines do not always take into account the sociocultural and emotional factors of the family of the child with a chronic condition,⁷ which makes coping difficult.

This fact can be minimized by establishing a dialogue which is capable of reducing maternal distress. The establishment of communication between professionals and mothers needs to be developed with attention and commitment, taking into account clear and objective maternal guidelines that promote safety for both. In doing so the professional can obtain feedback throughout the dialogue in relation to what was discussed, guaranteeing the soundness of the intervention.

Thus, the feeling of uncertainty can be mitigated by the availability of professional attention and the promotion of recognition of the family resources available to face future events, which may reduce the unpredictability related to the illness. Thus, maternal uncertainty and perceived social support are indicators of coping.¹² The mobilization of resources for adaptation is related to the ability or availability of resources to deal with new events and can be addressed in family-centered interventions.⁸

The availability of clear and objective information can contribute to maternal coping, understanding the events and trust in health professionals and are ways to reduce the uncertainty in mothers. Thus, education, social support and trust in professionals are resources for understanding the events related to the disease and suggests that uncertainty regarding the disease can be prevented.¹

Another point that caused uncertainty was the unpredictability of the child's life. In another study, the unpredictability of the future due to the disease also caused uncertainties in the mother and children, which directly influenced family dynamics and treatment decisions.²¹ For families who experience the possibility of kidney transplantation, mothers may seek alternatives when faced with the insecurity that involves the kidney transplant process (impossibility of compatible donor and fear of the unknown), nevertheless, they presented the expectation of cure with this procedure.

Provide clear information and feedback to the child's family regarding the understanding of the dialogue established with family-centered planning. As, the more empowered, the less uncertainties, and the better the adjustment to the clinical situation. Therefore, nurses can respond to concerns through education strategies and therapeutic communication in order to alleviate the stressor of uncertainty.¹⁴

Among the restrictions imposed in the conservative renal treatment, diet is one of the most difficult, as it is related to cultural habits and requires involvement and understanding, diet adjustment by other members of the family for the effectiveness of care, as reported in the results, the mother has the desire that the daughter can start to eat "normal".

Despite the experience of uncertainties, each mother in her singularity, uses the resources available in the construction of the adaptation process. According to the uncertainty theory, such a cognitive state is perceived when a situation considered as uncertain, drives the movement of the available resources for adaptation.¹ The intensity of involvement can make them assume the role of advocates of the children and learn to manage the network in order to meet their needs. This movement can initially focus on the present and "live one day at a time".¹⁶

In the tension generated by the experience of the CKD, the maternal imaginary can create and recreate innumerable situations much more exhausting than the actual experienced reality. However, this disturbance can be generated by factors such as the diagnosis of an unknown pathology and/or changes in the routine, which require skills for family stability, and for some mothers, this balance is found in spirituality.

Therefore, hope for an improvement in the child's health prognosis can reduce uncertainty,⁷ perceived uncertainty and hope may be important targets for improving psychological well-being.¹¹ Since parents articulate positive coping strategies (faith, belief in God, prayer and other religious rituals), as a positive factor in the reduction of the feeling of uncertainty and a way to deal with such experience in a better way and reduce its negative effects.²²

By emphasizing faith as support, it is a form of support that regardless of the measure used in adapting the disease, is an attempt to maintain the emotional balance when faced with the adversities and uncertainties generated by such experiences.

For the mother of the child in conservative renal treatment spirituality is a foundation which has an impact on the comprehension regarding the severity of the symptoms and the unfavorable prognosis of CKD, but mainly on the prospects of coping with the illness, as it can provide a sense of certainty and safety.

Nurses can take a more active role in identifying parents' sources and level of uncertainty, encouraging them to adopt optimistic postures and leverage perceptual change, envisioning opportunities for positive coping, and can demonstrate positive psychological changes, including greater adaptability.⁴

The expectation generated by the need for renal transplantation and the unpredictability of obtaining a compatible donor motivates the mother to seek alternative measures that may even involve the possibility of having another child and taking the risk that that child could have the same pathology, with the expectation of "saving" the life of the child who needs the renal graft, because it is an option that allows some certainty regarding compatibility and reduction of the risk of rejection.

Thus, the mothers of the children need support from the healthcare team. Nursing, in primary health care, can act as a promoter of certainty, by giving clear information on how this process takes place, and diminishing anxiety regarding the unpredictability of the disease in the future.

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

This study helped to understand the uncertainties of the mother of the child in conservative renal treatment, due to the illness of the child. It confirms that some mothers experience ambiguity regarding the diagnosis, lack of knowledge about the necessary health care of the child and the lack of clarity in the information obtained in the health services where they sought specialized care. In addition, they coexist with the unpredictability in relation to the future of the disease, which may be related to the incomprehension of the disease and, consequently, act as a trigger for uncertainties. Even so, mothers sought alternatives for coping and adaptation in order to maintain emotional balance.

Therefore, it is considered that Nursing, in the care of the child in conservative renal treatment, can prevent factors that trigger maternal uncertainty. These can be addressed as strengthening the bond and providing increased trust between the family and the professionals, with the availability of clear information and the recognition of the network of social support accessible to the family in order to improve the quality of life and the perception of the mothers regarding the disease, taking the disease out of focus and fostering healthy coping.

The limitations of this study are related to the number of participants and their characteristics, given that the results given cannot be generalized by addressing the experiences. Thus, the need for other studies which assess maternal and family caregiver uncertainties is highlighted, dimensions such as support network, family structure, requested and received interventions, which helps in the experience and increase the family empowerment for the care of the child with chronic kidney disease.

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