

## THERAPEUTICAL ITINERARIES OF PEOPLE WITH CHRONIC RENAL DISEASE AND THEIR FAMILIES

Rafaely de Cassia Nogueira Sanches\*  
Fernanda Sabini Faix Figueiredo\*\*  
Anderson da Silva Rêgo\*\*\*  
Maria das Neves Decesaro\*\*\*\*  
Maria Aparecida Salci\*\*\*\*\*  
Cremilde Aparecida Trindade Radovanovic\*\*\*\*\*

### ABSTRACT

The therapeutic itinerary is a strategy that allows the health professional to know the trajectory searching for care of sick people and their families, contributing to an understanding of the contexts that influence behavior and choices regarding the process of becoming ill, treatment and ways of taking self care. Thus the objective of to understand the therapeutic trajectory of people with chronic renal failure and their families. It is qualitative multiple case study, carried out with three people with hemodialysis treatment and their families. The data collection was through open interview and the data compiled by content analysis, thematic modality. In order to construct the therapeutic itinerary, the results were organized into three categories: family; professional; and cultural subsystem. The family appeared as the first and main source to seek care. Afterwards, family members go along with the sick member in search of professional care, keeping the knowledge and beliefs acquired culturally. The construction of the itinerary was effective because it provides important information for the planning of a humanized and effective care to the real health needs of the sick people and their families.

**Keywords:** Daily activities. Chronic disease. Humanization of Assistance.

### INTRODUCTION

Chronic kidney disease (CKD) is characterized by kidney damage with progressive and irreversible loss of renal function and, consequently, loss of ability to maintain metabolic and hydroelectrolytic balance<sup>(1,2)</sup>. It currently affects around 10% of the world's population and means a growing public health problem throughout the world. It should be noted that CKD is, in most cases, an asymptomatic and silent disease, which makes early diagnosis difficult<sup>(2,3)</sup>.

Once installed it is necessary to establish conservative treatment for life, or even kidney transplantation. This condition presents itself as a great challenge for the family, as it leads the subjects to dependence on specific and continuous care, modifying their daily dynamics and routine. As the main pillar of support for the sick person, the family goes beyond offering

care, seeking care from the health services along with their sick members from the beginning of symptoms<sup>(4,5)</sup>.

With regard to health services, it is expected that the treatment process of the person with CKD will be continuous, capable of ensuring a positive impact on survival, with a decrease in comorbidities<sup>(5)</sup>. However, there is a large gap between levels of attention and proximity to the sick person and their specificities. The care assistance, briefly, neglects socio-cultural, environmental and family contexts, which directly influence the behavior of the subjects, easily observed from the reflection on daily life<sup>(1,4)</sup>.

It is necessary to understand that the path of seeking care for people and their families occurs in the daily life and goes beyond the limits of health services, reaching cultural levels and relations with the community<sup>(6,7)</sup>. This daily search for care is named Therapeutic Itinerary (TI). The Latin term "itinerariu" is related to the

\*1Nurse. Doctorate student in the Graduate Nursing Program at State University of Maringá, Paraná, Brazil. E-mail: rafaely.uem@gmail.com.

\*\*urse. Master student in the Graduate Nursing Program at State University of Maringá, Paraná, Brazil. E-mail: sabinifaix@hotmail.com

\*\*\*Nurse. Master student in the Graduate Nursing Program at State University of Maringá, Paraná, Brazil. E-mail: anderson0788@hotmail.com

\*\*\*\*Nurse. Doctor in nursing. Professor at the Undergraduate and Post-graduate Nursing Program at State University of Maringá, Paraná, Brazil. E-mail: mndecesaro@uem.br

\*\*\*\*\*Nurse. Doctor in Philosophy. Professor at the Undergraduate Nursing Program at State University of Maringá, Paraná, Brazil. E-mail: masalci@uem.br

\*\*\*\*\*Nurse. Doctor in Health Science. Professor at the Undergraduate and Post-graduate Nursing Program at State University of Maringá, Paraná, Brazil. E-mail: kikanovic2010@hotmail.com

roads, to the paths, but also can be understood as the indication or path plan to follow. It highlights the close and intense relationships of family members and society with the sick person during their journey in search of care, as well as demonstrating the significant participation of people at more specific moments<sup>(8,9)</sup>.

In this sense, knowing the factors present in the therapeutic itineraries of people seeking care contributes significantly to the understanding of the contexts that influence behavior towards illness and the search for care<sup>(10)</sup>. This broader view of the CKD process leads to more comprehensive, holistic, humanized, and effective health care. Thus, based on the daily life experience of the person with chronic disease, the objective of this research was to apprehend the therapeutic trajectory of people with chronic kidney disease and their families.

## METHODOLOGY

It is an exploratory-descriptive study, with a qualitative approach of the multiple-case study, which is a deep and exhaustive study of one or a few objects. This delineation contributes to the understanding of complex phenomena, at individual, social and political levels, preserving the significant characteristics of real-life events<sup>(11)</sup>.

The participants' approach was in a dialysis clinic, located in the northwestern part of the state of Paraná, Brazil, linked to the Unified Health System (SUS). As inclusion criteria, the following were established: a person with a CKD, aged between 20 and 49 years, on hemodialysis treatment, living with a family member, able to speak and accepted home visits. Seven possible subjects were included according with the established inclusion criteria, to whom were explained the objectives and how the participation would be. Of these, two did not agree to participate in the study, one declined after the first interview and one was not found at the time of the clinic visit, leaving three people who participated in this study.

The study scenario was the residence, and the visits to the people with CKD counted on the participation of the family members who played the role of main care giver. During the interviews, a close, generous and corresponding

relationship was sought<sup>(11)</sup>. For that, it was necessary the process of interaction and bonding between interviewer and interviewee<sup>(11)</sup>.

For data collection, it was used open interviews, carried out from July to September 2014, with a total of 12 home visits, four for each family, with an average duration of 40 minutes. The following trigger question was asked: "Tell me about your pursuit for care from the beginning of symptoms up to today?" In order to complement the data, the field diary was adopted in which after the interviews were finished, the researcher made notes about elements that were significant for the interpretation of the statements, such as relations with the place, body and facial expressions of the participants<sup>(11)</sup>. The interviews were recorded after the consent of the participants and then entirely transcribed, and after analysis, incinerated.

The composition of the obtained data from the interviews resulted in 190 Word® document pages and the organization was based on content analysis, thematic modality<sup>(11)</sup>. After transcription and analysis of the interviews, one last visit was done in which the transcripts and the inferences of the researchers were presented for the approval of the participants (feedback).

The thematic categories were pre-determined according to the categorization of subsystems that construct TI<sup>(12)</sup> and thus named: Popular subsystem: The family as the main cornerstone of support for the sick person; Professional subsystem: In search of sensitive care in health care; Cultural subsystem: The superior power that strengthens and breathes life.

The study was approved by the Standing Committee on Ethics in Research with Human Beings of the State University of Maringá (Opinion 727.511/2014, CAA: 30689914.3.0000.0104). All participants signed the Free and Informed Consent Form in two forms.

To ensure families anonymity, they were identified with names of planets that make up the Solar System, starting from the analogy that each family has its own movements and characteristics as well as each of the millions of planets that make up the universe. For the members of the families the name of the natural satellites of each chosen planet was used.

## RESULTS AND DISCUSSION

### Describing planet families

For a better visualization of the characteristics of the three participating families, a descriptive table was constructed.

**Chart 1.** Description of families

Uranus Family	Saturn Family	Neptune Family
Composed by the couple Titania, 47, housewife, evangelical, with CKD, Arterial Hypertension and Type 2 <i>Mellitus</i> Diabetes and her husband Oberon, 53, worker, alcoholic and with hypertension. They reside with two of their three daughters: Ring eight years old and Umbriel 15 years old, Miranda, 23 years old is married for four years and has a two-year old daughter. Titania underwent hemodialysis four months ago, showed a lot of emotional sensitivity during the interviews and had not yet accepted the diagnosis of CKD. She is considered by the daughters as the central pillar of family harmony.	Composed by an elderly couple and son, being the father Hipérion, 93 years old, retired, with diagnosis of hypertension and incapacities due to three Cerebral Vascular Accidents; The mother Mimas, 83 years old, retired, Catholic, with diagnosis of Mellitus diabetes, arterial hypertension and cardiopathy; and Titan, 49, divorced, catholic, retired, smoker, with CKD on hemodialysis for four years. Titan has two children with whom he has had a distant relationship since the divorce eight years ago, when he returned to live with his parents. The family showed signs of bond and companionship.	Composed by a couple and a son, Triton, 29 years old, evangelical, with arterial hypertension, cardiopathy, liver disease, CKD and with decreased visual acuity due to the Macular Hole. He has been on hemodialysis for nine years. The wife, Nereida, 28, a seamstress, and her five-year-old son Proteus. Triton has shown a rather shaken emotional state and has reported attempting suicide three times in the past two years. Socially isolated and the only social environment that attends outside the hemodialysis clinic, is the church that is near his house.

#### Popular subsystem - The family as the main cornerstone of support for the sick person

By knowing the paths taken by the participants of the research and their families, similar changes in behavior among their members were observed, mainly related to the family's role, which was presented as a primary one in the reception and support from the beginning of the illness of its members.

When I need them, they will always talk to the doctor, to find out how the exams are, check the right follow up. They gave and give all the support I need (Titania, Uranus Family).

I would go to the hospital to stay with him when he was hospitalized. When he got home I would take care of him, cook, always worried. And I had him and his father had to take care of... The other son would come to sleep over here at night to keep him company (Mimas, Saturn Family).

It was always like this, I have to be at his disposal. He gets worse, I ask demission and I take care of him. He gets a little better, I go back to work to support them [the family]. We get going by (Nereida, Neptune Family).

Participating families showed a commitment to

offer care, sharing their feelings, making themselves available for follow-up from the first medical visits, as well as after CKD diagnosis. The family has appeared in the narratives as the first and main source of care since the beginning of the illness of its members. In addition to this monitoring, they act as the main unit to strengthen their sick members.

In this perspective, it is observed that the family is the inexhaustible source of support for the family member, being responsible for the beginning of the therapeutic itinerary. It is in it that the patient puts his sadness and his initial anxieties about the illness, and not different from the expectations, they correspond as pillars that sustain the situations that were deposited to them<sup>(10)</sup>. This support is considered of extreme importance for adherence to treatment, as well as adaptation to the psycho-sociological aspects that involve the process of becoming ill<sup>(5,13)</sup>.

It was also observed that the presence of small children is a motivating factor for adherence to treatment and its continuity. In the Uranus family, Mimas said that one of the strongest reasons for her to accept the disease, especially when she learned of her diagnosis, was Anel, her eight-year-old daughter. For the

Neptune family, news of Nereida's pregnancy for Triton filled him with strength being primordial for his recovery and discharge from the Intensive Care Unit:

It was a great joy for me to know that I would be a father. It seems to have given me more strength to live (Triton, Neptune Family).

I spoke softly at the his ear. And then a tear fell from his eye. Three days later, he left the coma. He even managed to eat. So it was such a strength ... (Nereida, Neptune Family).

Even the treatment being bad, being harmful, I think of my girls. I still have an eight year old girl, she is young, she depends on me ... [cries, pauses]. I hang on, crying, but I'm hoping to heal myself to finish raising my daughters, I need to guarantee the future of the youngster (Titania, Uranus Family).

The importance and spot of the family in the process of illness for the participants of the study is observed. In this sense, it is evident that the family occupies a significant role for human existence. For, as a collective group, it provides a space of care, strengthening, listening, feeling and support among each other<sup>(13)</sup>.

Health professionals working in dialysis clinics need to provide greater support to family caregivers in the face of various possible complications in the home environment<sup>(14)</sup>. Based on the information obtained about each family, the professional can use their knowledge to ensure care that relates biological, social and spiritual factors, promoting a higher quality, more effective care, sensitive to the real health needs of people and so, more humanized<sup>(14,15)</sup>.

### **Professional subsystem: Searching for a sensitive, close and welcoming care**

In the narratives of the three participating families, it was possible to observe that the health service was activated as soon as the first symptoms appeared. However, they report a low effectiveness in care practice for the early diagnosis of the disease:

I was urinating blood. I went to look for a doctor, and I would just get a little medication. A while after, the anemia attacked got to me, I couldn't even walk any more (Titan, Saturn Family).

I went to the health clinic to see why I was feeling very swollen and could not urinate properly. But it was prescribed a medication for a urinary tract infection only, and my kidney was going, it went until

it couldn't go anymore. It was fast, but maybe it could have been avoided right? (Triton, Neptune Family).

One never imagines having a disease like this, I went to the doctor, the gynecologist, I was monitoring the blood pressure. I had several times too high blood pressure. I was swollen. [...] In the meeting of hiperdia I would get the medication, [...] my feet, legs,, knees all swollen. But they said it was because of my blood pressure (Titania, Uranus Family).

It is evidenced that all the participants had a late diagnosis, since the disease was diagnosed after the renal function was completely compromised. This situation makes it clear that the assistance, promotion and prevention actions, attributes of primary health care (APS), were inefficient for these subjects, considering that the evolution of this disease depends on the quality of care offered early, avoiding the occurrence of kidney disease<sup>(5)</sup>.

It is observed that even though residing in three distinct regions of the city, the care offered was fragmented, focused only on the occasional symptoms reported by the patients. Even Titania, who was monitoring the hypertension in the Basic Health Unit (UBS), had a late diagnosis. A study<sup>(10)</sup> that approached the TI of people with CKD also showed that treatment was inadequate in the underlying diseases, delaying early diagnosis.

Despite the evolution of public health policies in Brazil, the work of health professionals is mostly vertical, focused on individual life cycles and fragmented therapeutic plans. It is believed that, for health care to be effective in the early diagnosis of CKD, more comprehensive approaches are needed, considering the family as well as the political, social, economic, environmental and cultural factors of the people in the elaboration of therapeutic practices<sup>(16,17)</sup>.

In this continuity, the three participants started replacement therapy at the Dialysis Clinic after confirming the diagnosis of CKD. Regarding the treatment in the clinic, the patients referred with great affection about the care they receive from the nursing and medical team during the hemodialysis sessions. However, they emphasized the need for greater psychological support from the institution, as well as closer and more complete follow-up in coping with comorbidities and adversities in daily life.

Wow, I really like everyone on the team. They are all very good to me [...] I miss the support of a psychologist, because the one who goes there almost never comes to talk to me (Titan, Saturn Family).

Very difficult, this beginning (crying) I need a psychologist, but there is one for a lot of people, heso we talk little[...] We get a little disappointed, I have doubts, fear. And then I do not know what it's going to be like, how to deal with the catheter, the symptoms after the dialysis, I feel like this, kind of unprotected... (Titania, Uranus Family).

The doctors, the nurses, are all good. There is always one or the other that is more timid [...] What is difficult is that the clinic does not interact with the basic health unit. They can not interfere in the matter of marking things out of the post. One is one, another is another (Nereida, Neptune Family).

Nereida reports on the disarticulation of clinic services with UBS, where Triton has been in the line waiting for more than a year for ophthalmologic evaluation, due to morbidity acquired after the onset of hemodialysis. The Saturn family and Uranus emphasize the need for the psychologist's support in the face of emotional and psychological difficulties associated with chronic illness, especially in the early stages of treatment.

The discovery of CKD is a fragile situation for ill people. This happens because the diagnosis and treatment promotes a series of modifications in the daily life, requiring a reorganization and complete (re)modeling of social-family relations. The professionals, therefore, offering a care closer to the reality of the subjects, will be acting directly to strengthen the family in the confrontation of the new demands resulting from the chronic disease, consequently, promoting a better adherence to the treatment<sup>(14)</sup>.

However, it is emphasized that there are many barriers to be overcome in health services so that care is integrated and truly effective. Among them, we highlight the discontinuity and fragmentation of care and services, as well as the need to advance in specific structural issues, such as the strengthening of APS and interprofessional health care for people with CKD<sup>(16)</sup>.

It should be pointed out, however, that the fragmented and hospital-centered practice of care is a reflection of professional training focused on compliance with rules, programs,

protocols and general guidelines of modern traditional education. This conduct neglects the sensitivity, reception and construction of processes more committed to people suffering from illness, their care and cures<sup>(16)</sup>.

Therefore it is indispensable to consider the importance of academic training, since this reflects directly in the modo operantis, that is, in the way the professional will behave facing the adversities of daily work. It is necessary to transform traditional education into a training that prepares the new professional capable of forming a link and promoting a critical and reflective health care, about the process of sickness of people and their health needs<sup>(18)</sup>.

### **Cultural subsystem - the superior strength that comforts and welcomes**

The search for healing made the three families find within their spirituality, the hope of receiving a kidney, or of the regenerating kidney. The Neptune family was baptized into an evangelical church, and Triton's main goal is not only healing, but also relating to other people. In the Uranus family, early in the illness of Titania, the pastor of the evangelical church near his home made several visits for prayer, which motivated him to continue to participate effectively in the church.

When I got bad, very swollen, the pastor came almost every day here at my home to pray for my cure. That made me feel like participating,, their concern about us and even then, they do not want anything in return (Titania, Uranus Family).

I give everything into the hands of God. I was always evangelical, my husband became too because of the disease. We decided to get baptized, and there, since it is close to home, it is the only place that goes besides going to the hemodialysis clinic (Nereida, Neptune Family).

The path taken from health to illness corresponds to a reorganization and reorientation of the person's behavior, in the same way that the perspective in which the subject perceives his world and relates to other people. The search for care also runs through alternative paths within and beyond spirituality.

In this study, we observed that the search for a superior force occurred after illness, and was characterized, mainly, by the presence and

participation of the religious during the treatment process, through prayers. It is also worth noting that these people play an important role in getting closer to the patient and their families, offering intense care to the sick body, as well as providing psychological and emotional support in coping with the disease process<sup>(9,19)</sup>.

Other possibilities for cultural support were also described by the Uranus family. Titan sought the cure in the Umbanda terreiro and made use of several types of tea recommended by the healers, that could cure his kidney, as it is in the speech:

I went in the terreiro to talk to the black father. At the time of illness we seek everything we can to heal ourselves. But now, I participate more because of friends, the conversations, even more because they are the same as the game of chess. Then meet at one place, meet at manother (Titan, Family Saturn).

In all human tribes, there are some people who perform activities such as midwives, prayers, "garrafeiros", "raizeiros", among others, which are mostly sought for advice, health examination and treatment of diseases. They use the popular empirical knowledge to recommend the use of the most diverse therapeutic methods<sup>(9,20)</sup>.

Titan found in the healer, contrary to what he found in the attendance of health professionals, someone who has a similar life experience, who spoke the same language and could understand him, besides maintaining a close and sensitive relationship during his illness process.

The observation of the disease by this cultural group is not only seen biologically and symptomatically, but necessarily involves

important aspects in human living, such as social, cultural and psychological relations<sup>(19,20)</sup>. It is through these popular sages that popular medicine ceases to be fragmented and becomes a more complex system which articulates with empirical knowledge about life, disease and death<sup>(9,10)</sup>.

## FINAL CONSIDERATIONS

This study presents limitations regarding the qualitative method, since this way of searching can not be generalized. However, the results are relevant to the understanding of the path taken by people with CKD and their family in search of therapeutic care. It was pointed out that the experience of sickness is a very rich and sophisticated field of social experimentation and that it is not enough only reducing the assistance to the biological field.

The first place of search for care pointed out by the participants of this study was the family, which starts to seek professional care together with the member who is ill. In view of the professional diagnosis, the participating families maintained the determination in their knowledge and beliefs, thus evidencing, that the subjects make parallel use of culturally acquired practices, complementing the medical therapeutics with the popular one.

That way, tracing the TI of people in their processes of illness, treatment and healing, makes possible the knowledge of the multiple dimensions that make up the human beings, which influences choices and behaviors in the face of adversities arising from the chronic condition in daily life.

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## ITINERÁRIOS TERAPÊUTICOS DE PESSOAS COM DOENÇA RENAL CRÔNICA E SUAS FAMÍLIAS

### RESUMO

O itinerário terapêutico é uma estratégia que permite ao profissional de saúde conhecer como se dá o caminho de busca por cuidados de pessoas adoecidas e suas famílias, contribuindo para compreensão dos contextos que influenciam o comportamento e escolhas frente ao processo de adoecer, tratamento e modos de se cuidar. Assim, o objetivo do estudo foi apreender a trajetória terapêutica de pessoas com insuficiência renal crônica e seus familiares. Trata-se de uma pesquisa qualitativa do tipo estudo de casos múltiplos, realizado junto a três pessoas adoecidas em tratamento hemodialítico e suas famílias. A coleta se deu por entrevista aberta e os dados compilados por análise de conteúdo, modalidade temática. Para construir o itinerário terapêutico, os resultados foram organizados em três categorias: subsistema familiar, profissional e cultural. A família apareceu como o primeiro e principal local de busca por cuidados. Posteriormente, familiares passam a caminhar juntamente com o membro adoecido em busca de cuidados profissionais, mantendo os conhecimentos e crenças adquiridas culturalmente. A construção do itinerário mostrou-se eficaz, pois oferece importantes informações para o planejamento de um cuidado humanizado e efetivo às reais necessidades de saúde das pessoas adoecidas e suas famílias.

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**Palavras-chave:** Atividades cotidianas. Doença Crônica. Humanização da Assistência.

## ITINERARIOS TERAPÉUTICOS DE PERSONAS CON ENFERMEDAD RENAL CRÓNICA Y SUS FAMILIAS

### RESUMEN

El itinerario terapéutico es una estrategia que permite al profesional sanitario saber cómo es la ruta de búsqueda para el cuidado de los enfermos y sus familias, lo que contribuye a la comprensión de los contextos que influyen en la elección de comportamientos frente al proceso de enfermar, tratamiento y formas de cuidar. Este estudio tuvo como objetivo emprender el itinerario terapéutico de las personas con insuficiencia renal crónica y sus familias. Es estudio cualitativo de casos múltiples de tipo investigación llevada a cabo con tres personas enfermas en tratamiento de hemodiálisis y sus familias. La colección se llevó a cabo por medio de entrevistas abiertas y los datos compilados por el análisis de contenido, modalidad temática. Para construir el itinerario terapéutico, los resultados fueron organizados en tres categorías: subsistema de la familia, profesional y cultural. La familia apareció como el primer y principal lugar de la búsqueda de atención. Más tarde, miembros de la familia comienzan a caminar junto con el miembro enfermo buscando atención profesional, manteniendo el conocimiento y las creencias adquiridas culturalmente. La construcción de la ruta fue efectiva, ya que proporciona información importante para la planificación de una atención humana y eficaz a las necesidades reales de salud de las personas enfermas y sus familias.

**Palabras clave:** Actividades de la vida diaria. Enfermedad crónica. Humanización de la Atención.

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**Corresponding author:** Rafaely de Cassia Nogueira Sanches. Rua São Pedro, 1430. Maringá, PR. Cep. 87030211. Email: [rafaely.uem@gmail.com](mailto:rafaely.uem@gmail.com)

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