

Therapeutic itinerary of patients with chronic renal failure under dialytic treatment

Araújo, Rafaella Cristina de Souza; Silva, Richardson Augusto Rosendo da; Bezerra, Moiziara Xavier; Onofre, Mileny Souza; Araújo, Ana Elisa Vilar de; Silva, Kamila Maiane Pessoa da

Veröffentlichungsversion / Published Version
Zeitschriftenartikel / journal article

Empfohlene Zitierung / Suggested Citation:

Araújo, R. C. d. S., Silva, R. A. R. d., Bezerra, M. X., Onofre, M. S., Araújo, A. E. V. d., & Silva, K. M. P. d. (2014). Therapeutic itinerary of patients with chronic renal failure under dialytic treatment. *Revista de Pesquisa: Cuidado é Fundamental Online*, 6(2), 525-538. <https://doi.org/10.9789/2175-5361.2014.v6i2.525-538>

Nutzungsbedingungen:

Dieser Text wird unter einer CC BY-NC Lizenz (Namensnennung-Nicht-kommerziell) zur Verfügung gestellt. Nähere Auskünfte zu den CC-Lizenzen finden Sie hier:
<https://creativecommons.org/licenses/by-nc/4.0/deed.de>

Terms of use:

This document is made available under a CC BY-NC Licence (Attribution-NonCommercial). For more information see:
<https://creativecommons.org/licenses/by-nc/4.0>

Federal University of Rio de Janeiro State



Journal of Research Fundamental Care Online

ISSN 2175-5361
DOI: 10.9789/2175-5361

RESEARCH

Itinerário terapêutico de pacientes renais crônicos em tratamento dialítico

Therapeutic itinerary of patients with chronic renal failure under dialytic treatment

Itinerario terapéutico de pacientes renales crónicos en tratamiento dialítico

Rafaella Cristina de Souza Araújo¹, Richardson Augusto Rosendo da Silva², Moiziara Xavier Bezerra³, Mileny Souza Onofre⁴, Ana Elisa Vilar de Araújo⁵, Kamila Maiane Pessoa da Silva⁶

ABSTRACT

Objective: To know the therapeutic itinerary of patients with chronic renal failure (CRF) under dialytic treatment. **Method:** This is a descriptive and exploratory study, with qualitative nature, performed in 40 patients with chronic renal failure who underwent dialysis in a clinic located in the municipality of Natal-RN. The data collection was held through semi-structured interviews. **Results:** The study showed that the therapeutic itinerary of the interviewed patients was marked by the discovery of the renal disease, search for health care, dialytic treatment and future prospects. **Conclusion:** it was notorious that the majority of the interviewed were belatedly referred to the specialist, when the renal function is already largely affected, which often requires a dialytic treatment or even the accomplishment of urgent admissions. The transplantation was characterized as hope for a better quality of life and release from the dialytic therapy. **Descriptors:** Chronic renal failure, dialysis, healthcare, access to health services.

RESUMO

Objetivo: Conhecer o itinerário terapêutico de pacientes portadores de insuficiência renal crônica (IRC) em diálise. **Método:** Estudo do tipo descritivo-exploratório, de natureza qualitativa, realizado com 40 pacientes portadores de insuficiência renal crônica que realizavam diálise em uma clínica localizada no município de Natal-RN. A coleta de dados foi realizada através de entrevista semiestruturada. **Resultados:** O estudo evidenciou que o itinerário terapêutico dos pacientes entrevistados foi marcado pela descoberta da doença renal, a busca pela assistência à saúde, o tratamento dialítico e perspectivas futuras. **Conclusão:** Ficou notório que a maioria dos entrevistados foi encaminhada tardiamente para o especialista, quando a função renal já está bastante comprometida, necessitando muitas vezes de um tratamento dialítico ou mesmo da realização de internações de urgência. O transplante caracterizou-se como a esperança de uma melhor qualidade de vida e da libertação da terapia dialítica. **Descritores:** Insuficiência renal crônica, diálise, assistência à saúde, acesso aos serviços de saúde.

RESUMEN

Objetivo: Conocer el itinerario terapéutico de los pacientes con insuficiencia renal crónica (IRC) en diálisis. **Método:** Estudio cualitativo de tipo exploratorio descriptivo, realizado en 40 pacientes con insuficiencia renal crónica sometidos a diálisis en una clínica situada en Natal -RN. La recolección de datos se realizó a través de entrevistas semi-estructuradas. **Resultados:** El estudio mostró que el itinerario terapéutico de los pacientes entrevistados estuvo marcado por el descubrimiento de la enfermedad renal, la búsqueda de la atención de salud, la diálisis y las perspectivas futuras. **Conclusión:** Es notable que la mayoría de los entrevistados fueron encaminados tardiamente para el especialista, con la función renal ya bastante comprometida, necesitando muchas veces de un tratamiento de diálisis o aun realizar internaciones de emergencia. El trasplante se caracteriza como la esperanza de una mejor calidad de vida y la liberación de la diálisis. **Descriptor:** Enfermedad renal crónica, diálisis, salud, asistencia a la salud, acceso a servicios de salud.

¹ Nurse Graduated at the Federal University of Rio Grande do Norte/UFRN. E-mail: rafaellamusic@hotmail.com ² Nurse. PHD in Health Sciences. Adjunct Professor III from the Graduation and Post-Graduation Course in Nursing (Academic Master and Doctorate) from Department of Nursing from the Federal University of Rio Grande do Norte (UFRN). Member of the Research Group Care and Epidemiological Practices in Health and Nursing/UFRN. Email: rirosendo@yahoo.com.br ³ Nurse Graduated at the Federal University of Rio Grande do Norte/UFRN. E-mail: moiziara@yahoo.com.br ⁴ Nurse Graduated at the Federal University of Rio Grande do Norte/UFRN. E-mail: milenyinh@hotmail.com ⁵ Nurse Graduated at the Federal University of Rio Grande do Norte/UFRN. E-mail: ana_elisa_vilar@yahoo.com.br ⁶ Nurse Graduated at the Federal University of Rio Grande do Norte/UFRN. E-mail: kamilamaiane@hotmail.com.

INTRODUCTION

Among the most prevalent chronic diseases, one should include the chronic renal failure (CRF), which is characterized as a progressive and irreversible deterioration of the renal function, and it makes the kidney unable to maintain internal homeostasis of the body, thereby interfering in metabolic and hidroelectrolyte imbalances. CRF might be caused by systemic diseases such as diabetes mellitus, hypertension, chronic glomerulonephritis, urinary tract obstruction, hereditary injuries, among others.¹

Epidemiological data demonstrate that the prevalence of CRF is estimated at 5% in Brazil and 6% in world population. Between the years 2000 and 2004, 90.356 patients started dialysis in Brazil, 7% of them underwent renal transplantation and 42% passed away.² In January 2009, the estimated number of patients on dialysis was 77.589, with more than half of the Southeast Region of Brazil. At that year, 27.612 patients started their treatment. Of the prevalent patients, 89,6% were submitted to hemodialysis, 10,4% peritoneal dialysis, 39,2% were on the waiting list for renal transplantation, 27% were diabetic and 35% hypertensive.³

The available treatments for CRF are continuous outpatient peritoneal dialysis, automated peritoneal dialysis, intermittent peritoneal dialysis, hemodialysis and renal transplantation. Currently, technological and therapeutic advances in dialysis are contributing to a greater survival rate of patients with chronic renal diseases, since these treatments alleviate symptoms of disease, preserve life and partially replace the renal function, however they do not promote disease healing.⁴

Despite the great scientific advances before the dialysis therapies, the patients with CRF have limitations in their daily lives, since they experience multiple losses, which generates conflicts, feelings of guilt, frustrations and depression, both in the individual in situation of chronic illness and in its family members.⁵

One should also realize that the health services that meet such individuals are not prepared to offer a comprehensive and humanized care that enable them to achieve a life with quality. In light of the foregoing, it is necessary that these services recognize the reality and behavior of their patients, thereby seeking to ensure the quality of care to be provided and the adequacy of procedures to be performed, with the purpose of promoting direct benefits to users.⁶

Under this perspective, the National Policy for People with Renal Disease, established by the Ordinance nº 1168/GM, on June 15th, 2004, defines a series of measures to be developed in all levels of care, from the scope of primary care until the outpatient and hospital actions of high complexity, by having the inversion of the care model to patients with CRF as one of the main strategies, from the medium and high complexity until the primary care.⁷

Such inversion is necessary due to a deficiency of health care actions aimed at health promotion and prevention in primary care, thereby causing the entrance of patients by the port of urgency and emergency for the accomplishment of Renal Replacement Therapy.⁸ This problem delays the diagnosis and treatment of disease, since the evolution of CRF has much more to do with the quality of offered earlier attendance than with the occurrence of renal functional failure.⁹

The Article 3rd of the National Policy for People with Renal Disease sets out that it is the responsibility of primary care to perform actions of individual or collective nature, focused on health promotion and prevention of damages, as well as the clinical interventions for controlling arterial hypertension, diabetes mellitus and renal diseases that might be performed in this level. It is a task of the medium complexity to conduct diagnostic care and specialized therapeutic guaranteed from the process of reference and counter-reference of people with renal diseases, diabetes mellitus and arterial hypertension. It is up to the high complexity to guarantee access and ensure the quality of the dialytic process and guarantee equity in the insertion into the waiting list for renal transplantation. Such assistance will be given by means of reference centers for nephrology and of nephrology services.⁷

This paper sought to know the therapeutic itinerary of people with chronic renal failure (CRF) in the Brazilian Unified Health System (known as SUS), from the primary care until the service of high complexity. In order to develop such trajectory, it was necessary to incorporate new resources that were focused on the individual and that could consider its interaction with its context and life history. Under this perspective, the development of therapeutic itineraries, term originated from the fields of sociology and anthropology, is characterized as a tool, as it provides an investigation of choices experienced by the subjects with regard to their therapeutic process and the multiplicity of pathways present in the process.¹⁰

Accordingly, it is denoted that social relationships or, more precisely, social networks, define how the illness is experienced, comprehended and expressed by individuals. In order to understand the “process by which the individuals or social groups choose, assess and adhere (or not) certain forms of treatment”^{11:125}, it is informed how the proposed treatments are experimented, assessed, modified, abandoned or accepted, thereby revealing the importance of user participation in the production process of its care.¹¹⁻²

Thus, the understanding of how social groups and people adhere or not to a certain treatment is essential to guide the new health practices.¹³ Nonetheless, it is necessary to criticize the offer focused on fragmentation, which does not allow recognizing the user as a subject of desires, necessities, rights, possibilities and as a partner in the development of therapeutic projects.¹⁴

In light of this proposal, the work was aimed at knowing the therapeutic itinerary of patients with chronic renal failure undergoing dialytic treatment, by raising information about the lived experiences, the choices adopted for treatment, the therapeutic adherence, as well as the service networks sought for the accomplishment of the dialytic therapeutic. The interest in discoursing on this topic arose from the necessity of knowing the reality and behavior of such patients with regard to the experiences of each subject in

relation to the choices that guide their health practices, as well as the assistance provided for them by means of the demanded services.

METHOD

The present work is a descriptive-exploratory study and has qualitative nature. The study location was one dialysis clinic, located in Natal-RN, which provides medical care for patients with acute and chronic renal failure, by performing hemodialysis, peritoneal dialysis and outpatient monitoring. The data collection was conducted in two months, beginning in October 2012 and ending in November of that same year.

The study participants were 40 patients with CRF, who used the aforementioned dialysis service in the institution. The data collection was finished from the moment in which there was occurrence of repetitive answers, with failure to produce new information, i.e., it reached the saturation point.¹⁵ The used criteria for inclusion were: having a confirmed medical diagnosis of chronic renal failure, being a person undergoing dialytic therapy; being a person aged over 18 years and signing the Free and Informed Consent Form (FICF). The used criteria for exclusion were: patients with clinical damages and diagnosed with cancer; refusal to sign the Free and Informed Consent Form.

In order to obtain the data, we made use of semi-structured interviews with open questions. The data were collected in proper form, through a semi-structured interview script, with identification data, everyday data, data about the history of the current illness, data about the trajectory in health services and, lastly, data about prospects for the future.

The interviews took place during the dialysis session and were recorded by means of MP4 player, saved into CD-ROM and, subsequently, transcribed. The data were analyzed according to the methodology of content analysis of Bardin.¹⁶ Through the aforementioned method, after successive readings of interviews, four categories were established, and they were called: the discovery of the renal disease, the search for health care, dialytic treatment and future prospects.

In accordance with the provisions of Resolution nº 196/96, which deals with research involving human beings, this study took place after approval of the Research Ethics Committee from the Federal University of Rio Grande do Norte (UFRN), according to the Opinion: 119.181, Certificate of Presentation for Ethical Consideration (CAAE, as per its acronym in Portuguese) nº 03022412.4.0000.5295. In addition, there was the approval of the subjects participating in the research by means of the signature of the Free and Informed Consent Form. In order to maintain the anonymity of the interviewees, they were identified by codes - from E1 to E40.

RESULTS AND DISCUSSION

Initially, it is necessary to expose a short characterization of the surveyed subjects: 50% were female and 50% were male; 61% were aged over 50 years; 53% were married and 21% were single; 28% have uncompleted elementary school, 38% have completed high school and 18% have completed some higher education course; 80% were Catholic; 53% had CRF for more than 5 years; 65% were retired or received benefit and 13% were working; 36% had a family income between one and two minimum wages.

The discovery of the renal disease

In general, the discovery of the renal disease occurs when the individual realizes that something is not right in its body, i.e., when the first signs and symptoms start to emerge - headache, nausea, anorexia, fatigue, weakness, change in mental status, change in diuresis, pale skin color, uremic breath-, which are seen by patients as uncomfortable and painful situations, often preventing the development of customary everyday tasks.¹⁷ The speeches of interviewees can prove this reality:

The first symptoms were tiredness, when I arrived in the health station I was feeling a kind of swelling, shortness of breath, high blood pressure, blurred view. When I sought the doctor, he referred me, and then I came to the hospital, where the staff did examinations and found that my kidneys were stopped. (E20)

At home, I was already having high pressure crises. And I just wanted to sleep, sleep, had no desire to go out, to go to any place, and neither wanted to eat, all the sort of food seemed bad for me. Then, my mother took me to the hospital for performing some examinations, a general check-up; this was how they discovered the disease [...]. (E24)

It is worth highlighting that the discovery of renal disease is closely related to the emergence of these signs and symptoms, which often lead to a delayed diagnosis, as it is discovered in a stage that complications are already present.¹⁸ It is also characterized as a silent condition, since the carrier often only begins to realize that has a kidney change when uremic symptoms start to appear, with a loss of renal function around 50%.¹⁹ Such fact might be seen in the following speech, in which the patient reports no distrust in the presence of renal problem:

It seems that is general to all people, because, as their urea increases, it causes nausea and lack of appetite. Then, it changes the skin color, since the person acquires a yellowish aspect. Then, slight itches start to appear, and the person never suspects that it is an illness. Then, those who have the rapid attack to achieve diuresis, as was my case, I had diuresis during six years...There was no more urine, I was only eliminating liquid, but

it was in a great amount. When the person is under that condition, she does not suspect [...]. (E35)

The symptoms highlighted in the previous statement are typical of uremia, and it is notorious that this patient had a late diagnosis, since he discovered the disease when the renal function was already largely affected, thereby putting in evidence the surprise in relation to the diagnosis, since he did not suspect of the presence of renal problem, due to having no changes in diuresis in the early stage.

Through the analysis of the interviews, it was realized that the main feelings emphasized by patients related to the discovery of the renal disease were: fear, sadness, surprise, depression, despair and feeling of panic.

I think it is not my case, for all renal cases, the person becomes desperate. I was desperate, I did not get in shock, because I am a person who has ... I always found difficulties in my life, that is why I'm better prepared to face difficulty, but the person gets desperate [...]. (E35)

[...] In the beginning, it was very sad, because it is like... Then I cried a lot, I was thinking: Oh! I cannot do anything, so I will not be able to do the things I like. (E13)

Thus, the discovery of the renal disease might initially be seen as a difficulty, by putting the individual in a situation of intense suffering, with several concerns before the possible restrictions imposed by the illness, especially during the performance of everyday activities, as demonstrated in the speech E13.

The search for health care

Concerning the search for health care, after analysis of the interviews, it was found that the majority of individuals did not perform monitoring in primary care, and those who performed such monitoring was not enough to solve their situation. The inadequate treatment of underlying diseases, as well as the lack of early diagnosis illustrates the cutouts of the speeches below:

Not, I really only looked for the health stations located in the place I lived. The last time was the one in which I came to the hospital ... I came to the hospital, it was when I found out, did you know? It was the last time I came to the hospital. But I only looked for the health stations. In case of high pressure, I took medication and came back to home and so on. Then, the last time I came here was when they admitted me, during three days, in order to discover the cause of pressure, what it was. Then, they found. (E34)

I looked for the health station, there in my area, so the doctor referred me to the hospital, because she did not understand the matter. Then, she refereed me and I went to the hospital, upon arriving there I was hastily admitted, I was even submitted to examinations, everything in case of emergency. (E20)

Through the reports, it was also observed that in most cases patients are belatedly referred to an expert, that is to say, at a stage in which the renal function is already very affected, often requiring a dialytic treatment. The speech below expresses this reality:

Then, when I sought a nephrologist (office), where I had never been in my life, she performed those examinations, those test of nephrology, of ultrasonography and, due to her experience, she found and got surprised because I never asked for an examination of creatinine, which can directly show the illness. In the first exam she asked, it showed a bond, 22% loss, I think you understand! From this, I came here [referring to the dialysis clinic]. (E21)

This belated discovery associated with late referral to a specialist often entails the necessity for hospitalizations and urgent dialysis, as shown by the cutouts of the following speeches:

I was with a stomachache. First, I had a pain in the stomach, so the doctor thought it was gastritis, but it was not, it was a kidney problem. Then, when we did the blood examination, it was found that the problem was in my kidneys. Then, I was hospitalized; I spent a month and fifteen days hospitalized. Then, after I went out and I came here [referring to the dialysis clinic]. (E30)

[...] I even thought I had cancer. Such term arrived. Thus, I went to the doctor [...]. A very strong anemia appeared, but he did not tell me what it was. Then, after a while they were suspecting that it was a problem in liver or kidney. Then, that was when I was admitted, since I was really seeing my life at risk [...]. (E33)

Dialytic treatment

The beginning of the dialytic treatment often leads to the development of contradictory feelings of revolt and acceptance, because both guarantees life as make the dependent on technology; by configuring itself both as a constraining factor in its quality of life, as it promotes changes in its daily routine, and as a optimizing factor, as it promotes improvements in health conditions.²⁰ Such contradictory feelings are expressed in the speeches below:

At first, it was kind of complicated, but afterwards it was surmounted. Feeling of fear, I even lost two brothers, so I thought I was going to die too. Subsequently, I started to realize that the situation was not quite what I imagined. (E18)

Oh! If I could no longer undergo dialysis! It's simple and easy, but I cannot, I have to accept, right! If we cannot accept what we have, we have to accept. Anyway, I accept. If I could also, I wouldn't come, wouldn't also come, but I cannot. (E36)

Thus, we realize that this partnership human being/machine provokes the explosion of various feelings, such as anger, since the individual becomes dependent on the machine, and gratitude, since the machine keeps him alive. Often, the human being shows contempt, by remaining during a good part of the four hours in which it is connected to the machine

asleep or with closed eyes.²¹The following speech reports this reality, thereby elucidating the routine and the feelings towards the permanence during the connection to the machine:

Here, Monday, Wednesday and Friday, we remain watching TV, right? [...] Here is three, four hours and half. It is like this: or watching TV, or eating, or sleeping, or feeling migraine every once in a while, the headache. But it's normal for patients. (E23)

According to some authors, after a long period of treatment, the majority of patients assess the accomplishment of the dialytic therapeutic as the possibility of obtaining a better quality of life, with improved clinical picture, by facing dialysis as a necessary procedure^{20,22}, that is to say, with a meaning of survival and possibility of maintaining life and well-being of these patients.²³ The speeches below are in line with such statement:

This is good, right! Because if we are not here, we don't have health, ok! Poor health, we have to come here. I don't think this is bad, I think it's good. At the very beginning, I didn't like it, but now I'm getting used to it. It has been 10 years already since I'm here. Then, I'm used to it. (E30)

This is normal, I consider normal, I accept the treatment, I see that this is the opportunity I have for my well-being, for mine, so, quality of life, I depend on the machine, so I accepted it very well. (E38)

It is worth mentioning that many patients reported improvement of symptoms of CRF from the accomplishment of dialysis. This question can be observed in the speech below:

[...] I've been very dependent, with abdominal pain, I come here and then I go out, I feel nothing. Thus, for me, it's pretty good. When I'm connected to the machine, after 10 minutes I arrive here, I already feel the effect in the body. Some people don't like it, but I have a very good friendship relationship with the hemodialysis machine. For me, it's excellent. (E32)

The assiduity during treatment was also expressed, in which the patient E31 reports being aware of the necessity for dialysis, as well as the risks and consequences that might suffer by missing the sections:

[...] I, throughout these six years, realized that it was practically uninterrupted. There was never any interruption, and I understand that the information I have that is one cannot stop it. It is not possible to fail in the days, because you have to do it [...]. (E31)

Despite the comprehension of the importance of the hemodialysis, there is a certain difficulty in adapting, mainly because of limitations imposed by the disease and the dialytic treatment.²³

[...] I was very afraid, very afraid to undergo this treatment. But I had to accept, right! I didn't want to accept, but it was the way. (E34)

[...] And, thank God, we had to get used to it and live with it [referring to hemodialysis]. (E25)

Through speeches, we also realized that, when building their therapeutic trajectory, the patients were often influenced by health professionals, as well as by their family members. The speeches below express this reality:

[...] the doctors are the ones who really decide, we don't decide anything in a situation like this [...]. (E40)

[...] Here, I do the following: I do what the doctor decides [...]. It doesn't help to hear my family say "you should do this or that", because family doesn't know; the doctor is the one who really knows. (E28)

It was the family, the family is the one who commands; who leads me, helps me, it's my family. I, at this point, I don't control myself, they're the boss, did you know? (E15)

Future prospects

Another possibility that arises towards the renal patient is the transplantation, which is seen by some people with chronic renal failure as a way of liberation from the dialytic treatment. Such finding highlights the hope that, through the transplantation, changes will occur, with rescue of its life prior to the illness, thereby providing greater freedom and easing the daily routine.²⁴ Many interviewees voiced their feelings and hopes with regard to the possibilities and meanings of transplantation:

[...] nowadays, this disease doesn't have a treatment, transplantation is the only solution. This is the way I see it, right? This care we do is only a palliative, doesn't solve, the solution is a new kidney, which works 100%. (E39)

Transplantation means better life, quality of life. (E38)

Undergoing transplantation and being a person free from this machine. Mainly, the person wants go out and is not able to do so, because the person is tied, this machine holds her. Then, I want...Firstly, thank God, undergo my transplantation, in order to get out of here. (E12)

The hope for healing of chronic illness also permeates the speeches. People rely on God and on faith to face and overcome the difficulties of the dialytic condition and treatment.

[...] But I feel that, after I started undergoing hemodialysis, I became more confident in my part, in order to improve my renal part. I'm full of hope that I can...How would I say? I hope to be cured yet. (E22)

If I could I would get out of here, ok! But without transplantation, I wanted to leave this place healed by God [...]. (E34)

Some authors indicate that chronic renal failure is a silent condition, which is often belatedly diagnosed.⁵ Many patients start renal replacement therapy in emergency situations, without any previous preparation, thereby reflecting the situation of a person who considered herself healthy and starts to require constant and continuous care of a machine, of a health service and of a multidisciplinary team.²⁵ Such fact was evidenced by the survey, through which patients reported feelings of surprise in the face of the diagnosis, with the discovery often associated with hospital admissions, thereby leading to the necessity for dialytic therapy.

Upon being aware of the diagnosis, the renal patient experiences a disruption of its lifestyle, which causes a physical, psychological and social suffering, in addition to leaving it confined to its own residence and the hospital admissions, thereby inserting this individual into a context of social exclusion. Thus, the pathway of chronic renal patients is

marked by losses, which are not limited only to the renal problem, but also interfere in daily life activities, in affective relationships, besides promoting deprivations of freedom and independence.⁵

As for the reactions of patients in the face of the diagnosis of CRF, the research has emphasized feelings of fear, sadness, surprise, depression, despair and panic. The findings are in line with recent studies that demonstrated the predominance of negative feelings (58%), with highlight to: concern, surprise, crying, sadness, fear, denial, revolt, nervousness, outrage, despair, suicide attempt and suffering.²⁶ Such feelings should be assessed and considered of great relevance by the nursing staff, mainly for development of care plans.²⁰

With respect to the search for health care, one can realize that the therapeutic itinerary of interviewees was permeated by difficulties, and the decisions often negotiated by the patient itself with chronic condition, as well as by the health professionals, might interfere in this process.

The study highlighted that there is fragility in health care actions of primary care, as well as a late referral of the patient towards the nephrologist. This initial failure in monitoring the patient with renal disease causes the necessity for hospitalization, since the renal problem is often discovered and diagnosed from such hospitalizations.

According to the Ordinance nº 1168/GM, on June 15th, 2004, which establishes the National Policy for People with Renal Disease, it is the responsibility of primary care:

[...] Perform actions of individual or collective nature, targeted to health promotion and disease prevention, as well as the clinical actions for the controlling arterial hypertension, diabetes mellitus and kidney diseases that might be performed at this level. Such actions will take place in the network of basic health services (Basic Health Units and Family Health Teams).^{7:2}

Thus, it is the responsibility of primary care: promoting prevention strategies, as well as holding early diagnosis and strict control of individuals who present risk factors for progression of renal failure.²⁷ Such proposal leads to decreased expenditures, since it is cheaper to invest in prevention, given the high cost of the dialytic therapy.²⁸

Despite the provisions of the aforementioned ordinance, the principles of the SUS, completeness and resoluteness, are still challenges in the scope of health services; given that many patients have difficulties when searching for assistance, since the offered professional practices are not always resolute or appropriately referred.²¹

This fragility of the health care offered by professionals, as well as the fragility of knowledge of the population before the prevention, often leads to a late diagnosis, when the renal function is already largely affected.²⁰ Such belated referral to specialized services both entails high costs for the health system and promotes high social cost, since it favors changes in individual and family routine of the subject.²⁹

Studies show that a suitable clinical management in CRF implies immediate diagnosis, early referral to a specialist, implementation of measures to slow disease progression, identification and correction of comorbidities, as well as education and preparation for SRT (substitutive renal therapy).⁹ The monitoring by a nephrologist before entering the dialysis provides a series of measures for the benefit of the patient, among

them: psychological support, appropriate choice of the substitutive treatment of the renal function, as well as the appropriate vascular access.³⁰

With respect to the beginning of the dialytic treatment, some authors verified the onset of contradictory feelings of revolt and acceptance, since the therapy both guarantees life as well as make the individual dependent on the machine.²⁰ The time spent on the dialytic therapy leads to a decrease in social activities of the patient, thereby provoking conflicts, frustrations and depression.⁵

Studies show that, after a long period of treatment, the patients start to demonstrate feelings of dependence, since they feel physical necessities of attending the sessions and seeing the dialytic treatment as a way to ensure survival. Accordingly, the feelings of rejection will give rise to positive feelings.²² This statement was evidenced in this research through the speech E32, and the treatment seen as synonymous with survival and well-being, thereby providing improvements of the symptoms of CRF.

Authors claim that the adaptation to treatment is pretty individual, thereby involving psychological and social questions, and the time that the individual had to prepare himself before starting the dialytic treatment, as well as the lack of knowledge and information about treatment, might interfere in this process.²³ Thus, it is essential that health professionals provide patients with information about their disease so that they develop self-responsibility towards their health, by taking care and control of the treatment scheme, thereby becoming able to coexist with the hemodialysis and the chronic disease.³¹

In a recent study on the adherence of patients with CRF to hemodialytic treatment, conducted with 47 patients, it was found that the difficulties to adhere to the hemodialytic treatment are mainly related to transportation, frequency and time allocated for the treatment sessions, pain or discomfort caused by puncture of the arteriovenous fistula, distance, financial factors, care actions with the arteriovenous fistula, restriction of recreation and the fact of waking up early. Among the main factors promoting treatment adherence, one should highlight: the fear of death, faith in God and hope for transplantation, conformation and family.²⁶

Another very important point is the assiduity of patients in relation to the dialysis sessions, in which it is essential the transmission of guidelines so that the patients do not neglect the treatment, as well as comply with the prescribed medications and diets.⁵ From the speech of the individual E31, one can observe that the patient is aware of the importance of treatment, as well as of the risks that he might suffer if fails to attend the dialysis sessions.

Regarding the future prospects, speeches E39, E38, E12 demonstrated that the renal transplantation is characterized as a hope for a better quality of life and freedom from the hemodialytic treatment. Studies also emphasized that the transplantation has been a form capable of transforming the lives of patients, by enabling them to win back the freedom that they have lost, thereby making the daily routine easier.^{18,21,24}

Authors also highlight that faith in God promotes hope in relation to the promotion of relief and healing of the chronic illness, by favoring adaptation of patients to their health conditions and becoming a form of aid to combat the disease, since God is the hope of healing.^{26,32}

By resuming the therapeutic itinerary, we can realize that this route has various ways, in which not all care-related suggestions are accepted, because the therapeutic trajectory is constructed by the individual, and is often influenced by the biomedical, familiar, popular or religious model, in which there is no rule about the way to be followed, but choices constructed by individual uniqueness.³³

CONCLUSION

The study showed that the therapeutic itinerary of the interviewed patients was marked by the discovery of the renal disease, search for health care, dialytic treatment and future prospects. Therefore, the individuals have assumed different pathways during the trajectory of the disease, influenced and determined by their social context and life history.

The narratives have revealed that the renal disease is characterized as a silent condition, in which the discovery of the disease is closely related to onset of uremic symptoms, when the complications are already present, thereby indicating an often late diagnosis. Such discovery was marked by feelings of fear, sadness, surprise, depression, despair and sense of panic, which highlights the physical, psychological and social suffering.

With respect to the search for health care, it was notorious that most of the interviewed did not perform monitoring in primary care. In the case of those who performed such monitoring, the procedure was not characterized as resolute. Another observed point was the belated referral to the specialist, when the renal function is already largely affected, which often requires a dialytic treatment or even the accomplishment of urgent admissions.

The study showed that the beginning of the dialytic treatment gives rise to contradictory feelings of anger/gratitude and of revolt/acceptance. Despite such contradiction, the patient understands the importance of carrying out the dialytic therapy, which is occasionally characterized as synonymous with survival and well-being.

With respect to future prospects, the renal transplantation is characterized as the hope for a better quality of life and release from the dialytic therapy. The hope for healing also permeates the speeches, given that the faith in God is a support for coping with the disease.

Thus, the knowledge of the therapeutic itinerary is a valuable tool for the comprehension of certain behaviors in relation to health/disease/care process of users. Such knowledge allows us to enhance the operation of services, with respect to the qualification of care, which leads to the elaboration of intervention proposals that are focused on the individual and that might take into account their social context and life histories, thereby achieving more effective therapeutic outcomes.^{10,12,13} Thus, it is essential that the nursing adopt new care practices for patients with CRF, not only the technical care, but a holistic performance in the maintenance and restoration of quality of life.⁵

REFERENCES

1. Smeltzer CS, Bare GB. Brunner e Suddarth: Tratado de enfermagem médico-Cirúrgica. 10^a ed. Rio de Janeiro: Editora Guanabara Koogan; 2007.
2. Cherchiglia ML, Machado EL, Szuster DAC, Andrade EG, Acúrcio FA, Caiaffa WT, et al. Perfil epidemiológico dos pacientes em terapia renal substitutiva no Brasil, 2000-2004. *Rev Saúde Pública*. 2010; 44(4): 639-49.
3. Sesso RCC, Lopes AA, Thomé FS, Lugon JR, Burdmann LA. Censo brasileiro de diálise, 2009. *J BrasNefrol*. 2010; 32(4): 380-84.
4. Thomé FS, Karol C, Gonçalves LFS, Manfro RC. Métodos dialíticos. In: Barros E, Manfro RC, Thomé FS, Gonçalves LFS. *Nefrologia: rotinas, diagnóstico e tratamento*. 2^a ed. Artes Médicas; 1999. p. 272-8.
5. Silva FA, Salimena AMO, Melo MCSC. Conhecendo as práticas do autocuidado nos portadores de insuficiência renal crônica em hemodiálise: implicações para a enfermagem. *Enferm Atual*. 2007; 41:25-29.
6. Bertolin DC. Modos de enfrentamento de pessoas com insuficiência renal crônica terminal em tratamento hemodialítico [dissertação]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto Universidade de São Paulo; 2007.
7. Ministério da Saúde (BR). Política nacional do portador de doença renal. Secretária de Atenção à Saúde. Série B. Textos Básicos em Saúde: Brasília; 2004 [Acesso em 2012 jul 28]. Disponível em: http://bvsms.saude.gov.br/bvs/publicacoes/portaria_1168_ac.htm
8. Nardino D. A política de assistência ao portador de doença renal: a doença, seu tratamento e custos [monografia]. Santa Catarina: Universidade Federal de Santa Catarina; 2007.
9. Bastos, MG, Carmo WB, Abrita RR, Almeida EC, Mafra D, Costa DMN, et al. Doença renal crônica: problemas e soluções. *J BrasNefrol*. 2004 dez, 26(4): 202-15.
10. Alves PCB, Souza IMA. Escolha e avaliação de tratamento para problemas de saúde: considerações sobre o itinerário terapêutico. In: Rabelo MCM, Alves PCB, Souza IMA. *Experiência de doença e narrativa*. Rio de Janeiro: Fiocruz; 1999.
11. Muramoto MT, Mângia EF. A sustentabilidade da vida cotidiana: um estudo das redes sociais de usuários de serviço de saúde mental no município de Santo André. *Ciênc Saúde Coletiva*. 2011; 16(4):2165-77.
12. Mângia EF, Castilho LPV, Duarte VRE. A construção de projetos terapêuticos. *Rev Ter OcupUniv São Paulo*. 2006 maio/ago; 17(2): 87-98.
13. Mângia EF, Muramoto MT. Itinerários terapêuticos e construção de projetos terapêuticos cuidadores. *Rev Ter OcupUniv São Paulo*. 2008 set/dez; 19(3): 176-82.
14. Merhy EE. Engravitando palavras: o caso da integralidade. Palestra proferida no Congresso da Rede Unida, Belo Horizonte; 2005. Disponível em [<http://www.uff.br/saudecoletiva/professores/merhy/capitulos-06.pdf>].
15. Fontanella BJB, Ricas J, Turato ER. Amostragem por saturação em pesquisas qualitativas em saúde: contribuições teóricas. *Cad Saúde Pública*. 2008 jan; 24(1):17-27.
16. Bardin L. Análise de conteúdo. Tradução de Luís Antero Reto e Augusto Pinheiro. Lisboa: Edições 70; 2002.

17. Fermi MRV. Manual de diálise para enfermagem. 1ª ed. Rio de Janeiro: Medsi; 2003.
18. Dyniewicz AM, Zanella E, Kobus LSG. Narrativa de uma cliente com insuficiência renal crônica: a história oral como estratégia de pesquisa. *Revi Eletrônica Enferm.* 2004; 6(2): 199-212.
19. Lehmkuhl A, Maia AJM, Machado MO. Estudo da prevalência de óbitos de pacientes com doença renal crônica associada à doença mineral óssea. *J BrasNefrol.* 2009; 31(1): 10-17.
20. Silva, AS, Silveira RS, Fernandes GFM, Lunardi VL, Backes VMS. Percepções e mudanças na qualidade de vida de pacientes submetidos à hemodiálise. *RevBrasEnferm.* 2011 set-out; 64(5): 839-44.
21. Mattos M, Maruyama SAT. A experiência de uma pessoa com doença renal crônica em hemodiálise. *RevGaúchEnferm.* 2010 set; 31(3): 428-34.
22. Guzzon R, Caregnato RCA. Insuficiência renal crônica: significado atribuído pelo paciente à doença e à hemodiálise. *Enferm Atual.* 2008; 43:29-33.
23. Campos CJG, Turato ER. Tratamento hemodialítico sob a ótica do doente renal: estudo clínico qualitativo. *RevBrasEnferm.* 2010 set-out; 63(5): 799-805.
24. Flores RV, Thomé EGR. Percepções do paciente em lista de espera para o transplante renal. *RevBrasEnferm.* 2004 nov/dez; 57(6): 687-90.
25. Rocha RPF, Santos I. Necessidades de autocuidado entre clientes com doença renal crônica: revisão integrativa de literatura. *Rev de Pesq: cuid fundam.* 2009 set-dez; 1(2): 423-433.
26. Madeiro AC, Machado PDLC, Bonfim IM, Braqueais AR, Lima FET. Adesão de portadores de insuficiência renal crônica ao tratamento de hemodiálise. *Acta Paul Enferm.* 2010; 23(4): 546-51.
27. Filho NS, Brito DJA. Doença renal crônica: a grande epidemia deste milênio. *J BrasNefrol.* 2006; 27(3): 1-5.
28. Cruz LN, Polanczyk CA, Fleck MPA. Qualidade de vida em insuficiência renal crônica. In: Fleck MPA. *A avaliação de qualidade de vida: guia para profissionais de saúde.* Porto Alegre: Artmed; 2008. p. 208-17.
29. Sandri JVA, Schmitz J. Trajetória da família de portadores de insuficiência renal crônica: desafios e a emergência familiar. *RevNursing.* 2011; 13(154): 138-43.
30. Fayer AAM. Repercussões psicológicas da doença renal crônica: comparação entre pacientes que iniciam o tratamento hemodialítico após ou sem seguimento nefrológico prévio [dissertação]. São Paulo: Faculdade de Medicina da Universidade de São Paulo; 2010.
31. Terra FS, Costa AMD, Costa R, Costa M. Os sentimentos apresentados pelos renais crônicos durante a permanência na clínica de hemodiálise. *Enferm Atual.* 2008; 46: 15-18.
32. Paula ES, Nascimento LC, Rocha SMM. Religião e espiritualidade: experiência de famílias de crianças com Insuficiência Renal Crônica. *RevBrasEnferm.* 2009 jan-fev; 62(1): 100-6.
33. Maliska ICA. O itinerário terapêutico de indivíduos portadores de HIV/AIDS [dissertação]. Santa Catarina: Universidade Federal de Santa Catarina; 2005.

Received on: 30/09/2013
Required for review: No
Approved on: 06/01/2014
Published on: 01/04/2014

Contact of the corresponding author:
Rafaela Cristina de Souza Araújo
Avenida Doutor Silvio Bezerra de Melo, nº 27, Centro, Cruzeta, RN,
Brasil, 59375000.