

PERCEPTION OF PATIENTS WITH CHRONIC KIDNEY DISEASE REGARDING CARE TOWARDS THEIR HEMODIALYSIS ACCESS

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ABSTRACT: The aim of this study was to describe the care of patients with chronic kidney disease towards their hemodialysis access, and report on the guidelines and care given by the nursing staff. This is a descriptive study, developed in a hemodialysis clinic located in the city of Fortaleza, state of Ceará, between October and November 2014, with 28 patients on hemodialysis. Semi-structured interviews were undertaken to collect data. The thematic analysis technique was chosen, with the following categories: Care towards the hemodialysis access and its implications in self-care, and Perception of patients with chronic kidney disease on guidance and care received from the nursing staff. Patients highlighted the doubts related to changes in habits, and concerns of the nursing staff about patency of access, with guidance on home care and interventions in the dialysis service. Educational strategies to the patient in the acquisition of new skills for the preservation of hemodialysis access are necessary.

DESCRIPTORS: Arteriovenous Fistula; Central Venous Catheters; Nursing Care; Renal Dialysis; Chronic Renal Insufficiency.

PERCEÇÃO DO PACIENTE RENAL CRÔNICO ACERCA DOS CUIDADOS COM ACESSOS PARA HEMODIÁLISE

RESUMO: Objetivou-se descrever os cuidados do paciente renal crônico com seu acesso para hemodiálise e relatar sobre as orientações e cuidados recebidos pela equipe de enfermagem. Estudo descritivo, desenvolvido em uma clínica de hemodiálise localizada em Fortaleza, estado do Ceará, no período de outubro e novembro de 2014, com 28 pacientes em tratamento hemodialítico. Utilizou-se entrevista semiestruturada para coleta de dados. Optou-se pela análise temática, sendo elencadas as categorias: Cuidado com o acesso e suas implicações no cuidado de si, e Percepção do paciente renal crônico acerca das orientações e cuidados recebidos da equipe de enfermagem. Os pacientes destacaram as dúvidas relacionadas às mudanças de hábitos e a preocupação da enfermagem na perviade dos acessos, com orientações quanto aos cuidados domiciliares e as intervenções no serviço de diálise. Percebe-se a necessidade de estratégias educativas junto ao paciente na aquisição de novas habilidades para a preservação do acesso para hemodiálise.

DESCRIPTORIOS: Fístula Arteriovenosa; Cateteres Venosos Centrais; Cuidados de Enfermagem; Diálise renal; Insuficiência renal crônica.

PERCEPCIÓN DEL PACIENTE RENAL CRÓNICO RESPECTO AL CUIDADO DE SU ACCESIBILIDAD A LA HEMODIÁLISIS

RESUMEN: Se objetivó describir el cuidado del paciente renal crónico respecto de su acceso a hemodiálisis e informar sobre indicaciones y cuidados recibidos del equipo de enfermería. Estudio descriptivo, desarrollado en clínica de hemodiálisis en Fortaleza, estado de Ceará, entre octubre y noviembre de 2014, con 28 pacientes en tratamiento de hemodiálisis. Datos recolectados mediante entrevista semiestructurada. Se eligió el análisis temático, surgiendo las categorías: Cuidado de la accesibilidad e implicancias en el cuidado en sí; y Percepción del paciente renal crónico respecto de indicaciones y cuidados recibidos del equipo de enfermería. Los pacientes destacaron dudas relacionadas a cambios de hábitos y a la preocupación de enfermería por la permeabilidad de los accesos, con indicaciones referentes a cuidados domiciliarios y a intervenciones en servicio de diálisis. Se observa necesidad de estrategias educativas con el paciente para la adquisición de nuevas habilidades de preservación de la accesibilidad a la hemodiálisis.

DESCRIPTORIOS: Fístula Arteriovenosa; Catéteres Venosos Centrales; Atención de Enfermería; Diálisis Renal; Insuficiencia Renal Crónica.

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● INTRODUCTION

The care of patients with chronic kidney disease (CKD) undergoing hemodialysis involves encouraging self-care, infection prevention, providing information to the patient and family regarding their treatment and complications, as well as providing a safe and comfortable place for the provision of treatment⁽¹⁾.

Kidney disorders may be acute or chronic. Acute renal failure (ARF) occurs due to a lesion in the kidney. In this case, the treatment consists of the transient replacement of renal function to reduce probable complications, and to reduce the risk of lesion enlargement. Chronic kidney disease is also caused by a kidney lesion, accompanied by a decrease in glomerular filtration rate (GFR)⁽²⁾.

In 2013, the number of active dialysis units in Brazil was 658 units, with an estimated total of 100,397 patients a year. Of those, 84% underwent dialysis through the Unified Health System (SUS), and 16% using other healthcare plans. As for dialysis modality, 90% of patients were on hemodialysis, and only 10% on peritoneal dialysis. The age group of 19 to 64 years old showed the highest incidence. The predominant gender was male, with 58%⁽³⁾.

When the kidney gets smaller or loses its ability to function normally, it is necessary to use substitutive methods to keep it alive and with quality of life, such as peritoneal dialysis (PD), hemodialysis (HD), or kidney transplantation. Of these, the most common is hemodialysis, which consists of removing solutes accumulated in the blood, such as creatinine, urea, potassium, phosphates, and water, with a partial restoration of the function performed by the kidneys⁽²⁾.

To perform hemodialysis, the patient needs a vascular access, such as an arteriovenous fistula (AVF), a double lumen venous catheter (DLC), or a graft. AVF has become an important means for the patient on dialysis to carry out treatment, considered a safe method that provides comfort and autonomy compared to the DLC⁽⁴⁾.

The nursing staff is directly involved in the hemodialysis patient care, and nurses should encourage the development of their self-care capacity through knowledge, which will guide patients to acquire skills to act in situations of complications with their vascular access⁽⁵⁾.

From this perspective, the care of these patients and their vascular accesses by the multi-professional team is not enough; the patients need to be focused and know about their contributions to its maintenance. In addition, this care should be performed both in the treatment facility and in the home environment, encouraging these patients to self-care. Self-care should be jointly built between professionals and patients, from a chosen priority⁽⁶⁾.

Patients' quality of life can be improved by encouraging self-care. Thus, the nursing staff should provide support to the patients and make them able to do so, through continuing education reporting on the illness, limitations, signs and symptoms and, especially, the care with access for dialysis⁽⁴⁾.

Because of the complexity of chronic renal failure, kidney disease patients need to receive guidelines from the nursing staff to act in self-care, because they usually show some difficulty in performing daily activities related to the treatment⁽⁷⁾.

In this context, the aim of the present study was to describe the care of CKD patients towards their hemodialysis access, and to report on the guidance and care received from the nursing staff.

● METHOD

This descriptive qualitative study was carried out between October and November 2014 in a dialysis clinic in the city of Fortaleza, which currently assists 164 patients from the private network and healthcare plans. Monthly, it receives an average of 10 new patients. The facility consists of two hemodialysis rooms, one with 32 machines, and one with four machines. It provides peritoneal dialysis service and operates with a team of five nurses, 19 nursing technicians, a psychologist, a social worker, a nutritionist and four physicians.

Participants were patients with CKD on hemodialysis who met the following inclusion criteria: being over 18 years old, undergoing hemodialysis, and using a catheter or AVF within a maximum period of 6 months. The exclusion criterion was: patients with no clinical conditions during the collection period.

Data were collected through a semi-structured interview, recorded with the help of a tape recorder, with the following questions: How do you care for your venous access (catheter or fistula)? What are the guidelines you received at the service?

The collected data were submitted to thematic analysis(8), by means of the following stages: full transcription of the interviews, pre-analysis with thorough reading, synthesis of content and exploratory reading. Data were grouped into sets and subsets that showed the same ideas and were subsequently reclassified based on the relevance of this study. Thus, two categories emerged: I - Care towards the hemodialysis access and its implications in self-care; II – Perception of CKD patients on guidance and care received from the nursing staff.

Initially, the research project was presented to the management of the institution and the nursing management of the hemodialysis unit, for getting authorization for data collection from patients, and allowance to access medical records, through a letter of agreement and trustee statement. The study was submitted to the Ethics Committee of the State University of Ceará - UECE with report no. 229772. The recorded content was transcribed, protecting the confidentiality and anonymity of patients, replacing their names with the names of precious stones.

● RESULTS

Twenty-eight patients were interviewed. According to the categorization in Table 1, there was a predominance of women, the prevalent age group was 41-60 years. Of the total, 15 (53.6%) were married, with an average income greater than or equal to two minimum wages. The main comorbidities associated with chronic kidney disease were systemic hypertension and diabetes mellitus. Regarding their venous access, 15 (53.6%) patients were using some kind of central venous catheter, either of short- or long-term, 13 (46.4%) were using AVF. Nineteen patients (67.8%) started dialysis treatment in other clinics.

From the analysis of the reports, two categories were listed: I - Care towards the hemodialysis access and its implications in self-care; II – Perception of CKD patients on guidance and care received from the nursing staff.

Care towards the hemodialysis access and its implications in self-care

In the statements collected, there was a greater concern for the permanence and maintenance of the access, which required many home care procedures, with significant changes in lifestyle. The use of a central venous catheter for hemodialysis causes them more distress when compared to the arteriovenous fistula, as can be seen in the following reports:

[...] I'm not doing anything, I'm standing, not to hurt [neck]. It made taking a bath very difficult. (Fuchsita)

I try not to wet the catheter. Never wet it, I always put a washcloth on top, or I put a plastic film, and then I pass a micropore on the sides to try to take a relaxed bath, but I can't because I can't get it wet. The only way I have is to try to prevent the most I can. (Diamond)

Now in the state that I am I just wash it well [AVF] with asseptol, and always use band aid. I change it every day. Twice a day. (Sapphire)

However, it was observed that each patient adjusts the routines to his/her daily life in the presence of the access.

[...] I do not sleep on its side [AVF], I always protect it, make exercises with the little ball, when there is a hematoma, I put ice and hot water. (Carnelian)

I take great care not to lift weight, I clean my arm very well [AVF arm]. At night I put an ice pack, or warm cloth [...]. When I take a shower I use a special soap for it. (Pyrite)

[...] the only thing I do is to tie a strip here in my head for it [catheter] not to shake a lot, put a cap and I'm ready. (Fuchsita)

Perception of CKD patients on guidance and care received from the nursing staff

Patients' reports show that the main guidelines received from the nursing staff on the care for a central venous catheter were to avoid wetting and manipulating the central venous access.

[...] They [nursing staff] asked us not to move, to do everything not to wet it! Not to handle it, they prefer to handle it here [clinic]. So we do not touch it [catheter], that is exactly not to have contamination, anything. (Emerald)

He [nurse] told me not to wet it when having a shower, to avoid infection. (Ruby)

They tell us not to let anyone touch it, nor leave it getting dust, [...] to avoid any kind of contamination. (Tourmaline)

As for care of AVF, patients highlighted the following guidelines: avoid lifting weight and sleeping over the arm, do not check blood glucose on the limb with AVF, do exercises and clean the arm with AVF.

[...] Do not sleep over the arm, do not lift weight, do not put anything like that, my diabetes, do not stick on the arm [do not apply insulin], do not measure the pressure, anything. (Pyrite)

The required care of washing and doing that exercise with the ball, always do it. (Bronzite)

Patients also mentioned care in the maintenance of the central venous catheter performed by the nursing staff of the dialysis service. They highlighted the concern from the staff with the maintenance of the access and prevention of infection.

Because here, when we get here, he [nurse] thoroughly cleans it, cleans to avoid infection [...] and do not have fever [...]. It is very great care that they [professionals] have with us here. (Ruby)

The dressing is put when in the clinic. (Tourmaline)

For the catheter, the dressing is also put here. Only here! They [nurses] do not even want us to

Table 1 - Characterization of CKD patients on hemodialysis, Fortaleza, Brazil, 2014

Characteristics	N	%
Gender		
Male	11	39
Female	17	61
Age (in years)		
20 - 40	8	28.6
41 - 60	13	46.4
> 60	7	25
Marital status		
Single	6	21.4
Married	15	53.6
Divorced	3	10.8
Widowed	4	14.2
Level of education		
Primary - Complete	4	14.3
Primary - Incomplete	8	28.6
High school - complete	8	28.6
High school - incomplete	3	10.7
Undergraduate course - complete	2	7.1
Undergraduate course - incomplete	3	10.7
Family income (in minimum salaries)		
≤ 1	10	35.8
≥ 2	16	57.1
Does not know	2	7.1
Comorbidities		
Systemic hypertension	9	32.1
Diabetes mellitus	1	3.7
Systemic hypertension + Diabetes mellitus	10	35.7
Systemic hypertension + LUPUS	2	7.1
Heart diseases	3	10.7
None	3	10.7
Current access		
Catheter Permcath	7	25
Short-term	8	28.6
AVF	13	46.4
Report of infection		
Peritonitis	1	3.6
Catheter infection	1	3.6
AVF infection	2	7.1
Treatment beginning		
Hospitals and other clinics	19	67.8
Studied clinic	8	28.6
Does not know	1	3.6

get near [...]. (Hematite)

According to patients' reports, the main interventions performed by nursing technicians in the maintenance of the arteriovenous fistula were antisepsis before puncture and hemostasis at the end of a hemodialysis session.

[...] Even if they will put the needle [nursing technicians] they clean the arm, even when it is already washed. [...] They put like a band aid to stop bleeding. (Aragonite)

Contradictorily, some reports have highlighted the lack of guidance related to the care of the venous access.

No, I didn't receive either. (Carnelian)

No. It seems that it is not to wet it. (Moonstone)

No, the only advice I received was from my vascular physician. (Diamond)

The preference of a patient for the use of an indwelling catheter (Permcath) instead of fistula was highlighted, because of the technical inability of professionals at the time of fistula puncture, with consequent loss of function, according to the report:

I prefer to use the catheter instead of a fistula because it is no use to fabricate a fistula if there isn't a qualified professional for punching it, I have already lost two fistulas, they [nursing staff] got it wrong when they had to put the needles. (Diamond)

● DISCUSSION

At the time of data collection, a strong link was observed between the nursing staff and the patients, each professional knows the particularities of each patient, treats them by the name, and families demonstrate confidence in the team.

In the first category, CKD patients on hemodialysis were concerned about maintaining their access, reflecting changes in habits and self-care, such as while bathing and the way they sleep, to avoid complications of the central venous catheter, or of the arteriovenous fistula. It is considered that self-care emerges from the knowledge and acceptance of the current condition, with new habits, allowing maintenance of treatment through care with access, and other changes in their daily lives⁽⁹⁾.

For self-care to be incorporated in the life context of CKD patients, it is essential to stimulate their abilities, skills and potential of human reaction, allowing patient's positive adaptation to the new lifestyle and control of treatment. This adaptation can be facilitated by the nurse who, through care, plans educational interventions to help them relearn how to live with the new reality and to survive with chronic kidney disease⁽¹⁰⁾.

In the second category, the perception of patients on the guidelines regarding care with access for hemodialysis was observed. Noteworthy, the reports mainly emphasized the patency of the central venous access and maintenance of AVF operation in order to continue the hemodialysis treatment to stay alive, since access malfunction is directly involved in the interruption of the procedure, which brings fatal consequences.

Knowing the operation of hemodialysis is critical for the patients' process of adaptation to restrictions, thus improving their contribution to the treatment. Therefore, the nurse, besides assisting in the procedure, should act as an educator, facilitating the patients' development in self-care in their daily lives⁽¹⁰⁾.

It is noteworthy that, for hemodialysis to be performed, the fistula is considered the safest access as there is low incidence of infection. In this context, a catheter is indicated only in emergency cases of hemodialysis, or while a fistula matures⁽¹¹⁾.

It was noticed that patients prefer the fistula, because it improves quality of life by providing greater convenience and safety in hemodialysis. The catheter, on its turn, although not requiring a puncture

every time hemodialysis is performed, requires more specific care, and attention with hygiene and dressings, besides being an inconvenient and aesthetically unpleasant device.

Conversely, a patient highlighted her preference for using the catheter instead of the fistula, and reported that two fistulas were produced, but were lost because of improper puncture, and that she was using an indwelling catheter. It is inferred from this report that there is some unreliability about the inability of some professionals at the time of puncturing the arteriovenous fistula.

Thus, the specificity and complexity of the nursing team performance with the dialysis procedures; the fragility of CKD patients; the importance of maintenance and competent use of the vascular access; and the performance of the arteriovenous fistula puncture are the responsibility of the nurse or nursing technician, provided that they are properly trained; and in the case of a nursing technician, under guidance and supervision of nurses. Importantly, the first puncture of the fistula is an exclusive competence of nurses⁽¹²⁾.

It is considered that the nurse's role is to promote well-being of CKD patients undergoing hemodialysis, within their limits and respecting each one's choice, emphasizing that each individual is responsible for the success of their treatment⁽¹¹⁾.

Participants also reported, in the second category, how care is provided by the professionals at the service. They expressed the professionals' concern, especially regarding hygiene and maintenance of their access, with an emphasis on the prevention of infections.

Catheter infection is associated with lack of aseptic techniques and inadequate handling of these devices, corroborating the present study⁽¹³⁾. To prevent damage to the health of CKD patients undergoing hemodialysis, the nursing team needs to remain able to act in the promotion and prevention of complications, providing greater patient confidence in relation to the team⁽¹⁴⁾.

The study showed that the situations experienced by patients in home care with a central venous catheter or arteriovenous fistula are unique, and that lack of information causes serious losses in preserving hemodialysis access, which requires individualized multidisciplinary care, with continuous guidance in order to achieve autonomy in self-care.

It is clear in this context that the role of the nurse-educator should be one of negotiation of care, enhancement of knowledge, care practices and beliefs of the CKD patients in life restructuring and coping with daily challenges. In this regard, there is a need for greater involvement of the team in promoting continuing education of patients with an emphasis on care for the maintenance of means of treatment and prevention of infection, favoring an effective hemodialysis treatment, thereby improving quality of life.

● FINAL CONSIDERATIONS

In the categories described, it was observed that CKD patients have prior knowledge about the care for their access; however, they show they are attached to a single speech: do not wet the catheter and do not sleep or lift weight with the arm with the fistula.

Regarding the work of the nursing staff, the reports pointed out that some patients were not properly informed about the care for the hemodialysis access; on the other hand, some emphasized the concern of professionals regarding maintenance and prevention of complications.

Therefore, one should consider the perception that every patient with chronic renal failure has of the guidelines received for home care in hemodialysis access maintenance. By valuing their suggestions and questions about daily care, nurses will develop creative strategies in hemodialysis rooms that will allow communication and understanding of the themes approached.

The findings of this study are restricted to the institution where it was carried out and refer to a reduced number of participants; however, they were similar to other services. Thus, it is noticeable that this issue needs further investigation to acquire knowledge from other patients with hemodialysis access about home care. From this approach, it will be possible to develop training and update courses

for professionals involved in the planning and implementation of educational activities to CKD patients, and their family-caregivers.

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