RESEARCH

OVERVIEW OF TERMINAL KIDNEY DISEASE IN A STATE OF BRAZILIAN AMAZONIA

PANORAMA DA DOENÇA RENAL TERMINAL EM UM ESTADO DA AMAZÔNIA BRASILEIRA
PANORÁMICA DE LA ENFERMEDAD RENAL TERMINAL EN UN ESTADO DE LA AMAZONIA BRASILEÑA

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ABSTRACT

The objective of this study is to depict the social, demographic and clinical profile of hemodialysis patients and the costs of dialysis treatment in the state of Amapá. This is a cross-sectional study with quantitative approach. Data were obtained through the software Nefrodata and scripted interview questions which were analyzed using descriptive statistics. Research subjects were the hemodialysis population in the Nephrology Unit of Macapá. The social, demographic and clinical prevalence observed were: gender: male, age group: 50 to 59, married or in a domestic partnership, biracial, with little education, monthly income of one minimum wage, living on welfare, SUS users, born in Macapá, hemodialysis patients for up to three years, with arteriovenous fistula. Arterial hypertension was the initial pathology in most cases. In 2015, 31,139 hemodialysis sessions and an average of 213 patients per month were computed, with the death of 73 of them. The figures approved for funding hemodialysis treatment and diagnostic purposes exceeded five million reais. Vulnerabilities related to education, socioeconomic condition, comorbidities and high death rates were identified. These factors, combined with the high cost of dialysis, reinforce the challenge of the healthcare networks regarding early diagnosis and treatment of kidney disease, highlighting the need for health professionals to know the epidemiologic profile of the chronic kidney disease in their working context to offer culturally sensitive care.

Keywords: Kidney Failure, Chronic; Renal Dialysis; Health Profile; Health Care Costs.

RESUMO

Esta pesquisa objetivou retratar o perfil sociodemográfico e clínico dos clientes em hemodiálise e os custos do tratamento dialítico no estado do Amapá. Trata-se de estudo transversal, com abordagem quantitativa. Os dados foram obtidos por meio do software Nefrodata e roteiro de entrevista estruturado, os quais foram analisados por meio de estatística descritiva. Foi sujeito da pesquisa a população em hemodiálise da Unidade de Nefrologia de Macapá. As prevalências sociodemográficas e clínicas constatadas foram: sexo masculino, faixa etária entre 50 e 59 anos, casados ou com união estável, pardos, pouca escolaridade, renda mensal de um salário mínimo, assegurados por benefício assistencial, usuários do SUS, procedentes de Macapá, em hemodiálise até três anos, com FAV. Hipertensão arterial foi a doença de base mais evidenciada. No ano de 2015 contabilizaram-se 31.139 sessões de hemodiálise e média de 213 clientes/mês, sendo que 73 clientes evoluíram a óbito. Os valores aprovados para custeio do tratamento hemodialítico e finalidade diagnóstica ultrapassaram cinco milhões de reais. Identificaram-se vulnerabilidades relacionadas a escolaridade, condição socioeconômica, comorbidades e alto índice de óbitos. Esses fatores aliados ao alto custo da terapia dialítica vêm reforçar o desafio das Redes de Atenção à Saúde no que concerne ao diagnóstico e tratamento precoces da doença renal, em que se ressalta a necessidade de os profissionais de saúde conhecerem o perfil epidemiológico da doença renal crônica em seu contexto de atuação para um cuidado culturalmente sensível.

Palavras-chave: Falência Renal Crônica; Diálise Renal; Perfil de Saúde; Custos de Cuidados de Saúde.

RESUMEN

El presente estudio tuvo como objetivo retratar el perfil sociodemográfico y clínico de los clientes en hemodiálisis y los costos de dicho tratamiento en el estado de Amapá. Se trata de un estudio transversal de enfoque cuantitativo. Los datos fueron obtenidos a través del software Nefrodata y entrevistas estructuradas que se analizaron mediante estadística descriptiva. La población en hemodiálisis de la Unidad de Nefrología de Macapá fue sujeto de esta investigación. Las prevalencias sociodemográficas y clínicas observadas eran: personas del sexo masculino, con edad entre 50 y 59 años, casadas o en una relación estable, con poca educación, mestizos, con ingreso mensual de 01 salario mínimo, asegurados por beneficio asistencial, usuarias del SUS, procedentes de Macapá, en hemodiálisis desde hacía tres años, con FAV. La hipertensión fue la patología subyacente más evidente. En 2015 se realizaron 31.139 sesiones de hemodiálisis con un promedio de 213 clientes / mes, de los cuales 73 fallecieron. Las valores aprobados para financiar el tratamiento y con fines de diagnóstico superaron los cinco millones de reales. Se identificaron vulnerabilidades relacionadas con la educación, el nivel socioeconómico, comorbilidades y altas tasas de mortalidad. Estos factores, unidos al elevado coste de la diálisis, refuerzan el desafío de las redes de atención de la salud en relación con el diagnóstico temprano y el tratamiento de la ERC, donde se destaca la necesidad de que los profesionales de la salud conozcan el perfil epidemiológico de la enfermedad renal crónica en su contexto de actuación para poder brindar cuidados culturalmente sensibles.

Palabras clave: Fallo Renal Crónico; Diálisis Renal; Perfil de Salud; Costos de la Atención em Salud.

INTRODUCTION

Regarding the health-disease process, a publication reveals a Brazilian scenario characterized by an accelerated demographic transition and an epidemiological panorama marked by a triple burden of diseases: infectious diseases and deficiencies not yet overcome, a significant burden of external causes and the hegemonic presence of chronic conditions.¹

In the context of chronic noncommunicable diseases (CDN), a study conducted by the World Health Organization (WHO) indicated that these conditions are responsible for most diseases and deaths in most countries, whether high, medium or low socioeconomic status.² Among the CDNs, this study highlights chronic renal failure (CRF), a disease that leads to progressive and irreversible loss of kidney function, presenting a complex clinical picture, having diverse etiologies and having high morbidity and mortality rates. The CRF has been configured as a public health problem worldwide, and it is estimated that 200 million people are carriers of the disease.³

The Brazilian Society of Nephrology (SBN) performs an annually national dialysis survey with basic epidemiological information and technical data from the dialysis units distributed throughout the country to obtain an overview of renal disease in Brazil. This initiative enables to show the profile of the renal patients at an advanced stage to provide subsidies for policy planning for chronic dialysis, interlocution between government and specialized care providers, and improvement of care for renal patients requiring substitute renal therapy (SRT).⁴

Among the SRT modalities, data referring to the Brazilian Chronic Dialysis Inquiry 2014 indicate hemodialysis as the most prevalent treatment in the whole country (91.4%).⁵ In addition to these data, it should be noted that this percentage corresponds to information provided by only 312 (44%) active dialysis units in the 715 existing in the country⁴, indicating the low adherence of the dialysis centers that responded to the call of

the Census conducted by SBN in 2014, which implies inaccuracy of the results obtained.

Regarding the amounts approved and financed by the Ministry of Health (MH) regarding hemodialysis (three sessions per week), data from DATASUS show that in 2015 more than R\$ 2 billion of this treatment modality was spent, showing the significant financial burden associated with hemodialysis therapy.⁶

The state of Amapá is one of the 27 federative units of Brazil, being the last but one state in population number of the country with an estimated of 766,679 inhabitants distributed in 16 cities, being ahead only of the state of Roraima. It is located north-east of the northern region of the Guianas shield, constituting one of the newest states in the country. Its capital, Macapá, is located on the banks of the Amazon River and in 2015 the population was estimated at 456,171 inhabitants. The access to Macapá is only possible by river or air to have interconnection by road or railroad with other Brazilian capitals, and it is the only Brazilian capital cut by the Equator.

In the provision of specialized health services to patients with CRF, the Macapá Nephrology Unit, inaugurated on March 13, 1998, is the only clinic in the state for the treatment of patients with CRF, receiving a great demand from patients with end-stage renal disease from the capital, the interior of the state, and the islands of Pará.

There is no record of patients enrolled in any form of peritoneal dialysis now in the services offered by the Nephrology Unit of Macapá, with hemodialysis being the central focus of care. In November 2015, there were 225 patients enrolled in this modality of SRT, distributed in four shifts, three times a week. The Nephrology Unit has 37 hemodialysis machines, a water treatment and distribution system managed by a chemical engineer and a multi-professional team composed of doctors, nurses, nursing technicians, physiotherapists, nutritionists, social assistant workers, psychologists, maintenance technicians of hemodialysis machines, administrative staff and support personnel to meet this demand.

Due to the overcrowding of patients on hemodialysis that already exceeds the maximum limit of 200 patients established by the Resolution of the Collegiate Board of Directors (RDC 154), since 2011, works have begun on the construction of another nephrology clinic in a neighboring municipality, currently not finished.

To date, the state of Amapá does not have an accredited health institution to carry out renal transplantation, requiring the displacement of patients to other states in search of this modality of treatment.

Given such an approach and considering the lack of records that outline the CKD and hemodialysis therapy in the northern region of Brazil, the question is: what are the prevalence of CKD at the terminal stage and the cost associated with hemodialysis in the state of Amapá?

Thus, this study aimed to show the socio-demographic and clinical profile of hemodialysis patients of the Macapá Nephrology Unit and data related to the financial burden of hemodialytic therapy in the state of Amapá.

METHODS

According to the object of this research, a cross-sectional study was carried out with a quantitative approach. The population undergoing hemodialysis therapy at the Nephrology Unit of Macapá was the subject of the study. The study followed the guidelines of Resolution 466/12 CONEP/CNS, and it was approved according to Opinion N° 1,094,598 issued by the Ethics Committee of the Federal University of Amapá, in a meeting held on 05/27/2015.

Data collection was carried out by three researchers from the study and occurred between November 2015 and February 2016. Nefrodata software was used to identify the number of patients enrolled in the Nephrology Unit of Macapá in the modality of hemodialysis. For the registration of the socio-demographic and clinical variables, a questionnaire structured by the researchers was elaborated in which the following socio-demographic and clinical data were listed: gender, age, marital status, race, education, monthly income, occupation, health care, origin, time in hemodialysis, type of access and comorbidities.

The inclusion criteria were: to perform hemodialysis therapy, to be in stable physical, cognitive and emotional conditions and to sign the Informed Consent Term. After the approach to the invitation to participate in the study and the data collection that occurred face-to-face during the hemodialysis sessions, eight patients had no interest in participating in the study.

Two patients under 18 years old who participated in the study had their legal representatives as informants to the inquiries made and as responsible for signing the TCLE.

Data related to the demonstration of hemodialysis sessions and approved values for 2015 were provided by the administrative department of the Nephrology Unit of Macapá.

The data were tabulated in Microsoft Excel 2010 worksheet and presented by descriptive statistics: absolute and relative frequency or measures of central tendency and dispersion: mean and standard deviation.

RESULTS

The sociodemographic and clinical profile of 217 (96%) of the patients undergoing hemodialysis treatment at the Macapá Nephrology Unit, a reference in the state of Amapá, was obtained.

A prevalence of male patients was found, 138 (63.6%), aged between 50 and 59 years old: 63 (29%) and mean age 51.74 ± 15.51 .

Regarding the marital status, 108 (49.7%) were married or had a stable union, 136 (62.7%) declared to have brown skin color, and the predominant school level was incomplete elementary education: 87 (40.1%).

Most patients have monthly income corresponding to a minimum wage: 136 (62.7%) and 110 (50.7%) received care benefits.

Regarding health care, 186 (85.7%) are SUS patients, and 120 (55.3%) of them come from Macapá (Table 1).

Table 1 - Socio-demographic characterization of patients on hemodialysis treatment of the Unit of Nephrology of Macapá (n=217)

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Variables	(FA)	(FR)					
Gender							
Male	138	63.6					
Female	79	36.4					
Age (years old)							
10-19	3	1.4					
20- 29	81	37.3					
50- 69	109	50.2					
70- 79	24	11.1					
Marital status							
Married/Stable Union	108	49.7					
Single	77	35.5					
Widow	19	8.8					
Separated/Divorced	13	6.0					
Race							
White	30	13.8					
Black	51	23.5					
Brown	136	62.7					
Education							
Illiterate	14	6.5					
Complete Elem. Sch.	8	3.7					

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Table 1 - Socio-demographic characterization of patients on hemodialysis treatment of the Unit of Nephrology of Macapá (n=217)

Variables	(FA)	(FR)					
Education							
Incomplete Elementary School	87	40.1					
Complete High School	65	29.9					
Incomplete High Sch	19	8.8					
Complete Higher Ed.	22	10.1					
Incomplete Higher Ed.	2	0.9					
Monthly Income							
Waiting for benefit	13	5.9					
One minimum wage	136	62.7					
2 to 4 wages	44	20.3					
Five wages or more	24	11.1					
Occupation							
Care Benefit	110	50.7					
Continuing working	57	26.3					
Retired	50	23.0					
Healthcare							
SUS	186	85.7					
Health insurance	31	14.3					
Origin							
Macapá	120	55.3					
Interior and Pará islands	36	16.6					
Other states	61	28.1					
Total	217	100%					

Source: research protocol.

The clinical characterization of the patients (Table 2) shows that the time in predominant hemodialysis is between zero and three years: 127 (58.5%), with a mean of 4.03 ± 3.89 . Only 16 (7.4%) patients underwent hemodialysis therapy for more than ten years.

Table 2 - Clinical characterization of patients in the hemodialytic treatment of the Macapá Nephrology Unit (n=217)

Time of hd in years	(FA)	(FR)					
0 3	127	58.5					
3 6	41	18.9					
6 —— 12	37	17.1					
12 —— 21	12	5.5					
Type of access							
Catheter	84	38.7					
AVF	133	61.3					
*Comorbidities							
Diabetes mellitus	83	38.2					
Hypertension	177	81.6					
DM/SAH	83	38.2					
Cardiopathy	46	21.2					
Hepatitis C	8	3.7					
Lupus	3	1.4					
Others	21	9.7					

^{*} There was a reference of more than one comorbidity per interviewee. Source: research protocol.

The arteriovenous fistula (AVF) was the prevalent vascular access: 133 (61.3%). Arterial hypertension, 177 (81.6%) and diabetes mellitus, 83 (38.2%) were the most prominent underlying diseases.

Regarding the patient sample and the number of hemodialysis sessions for 2015, the Macapá Nephrology Unit registered an average of 213 patients/month and 31,139 hemodialysis sessions were counted, 30,262 of them corresponded to normal sessions and 877 to extra sessions, with an average of 2,595 sessions/month during the year (Table 3).

The amounts approved for the costing of clinical procedures and diagnostic purposes (laboratory tests) for 2015, identified R\$ 5,748,771.19 (Table 4).

Table 3 - Demonstration of hemodialysis sessions, patients, and deaths of the Nephrology Unit - Macapá-AP, 2015

Month	Jan	Feb	Mar	Apr	May	June	July	Aug	Sep	Oct	Nov	Dec
Patients	199	195	189	202	202	211	216	226	234	234	225	229
Deaths	10	04	10	2	8	7	5	4	6	6	8	3
Normal sessions	2.368	2.201	2.282	2.464	2.420	2.544	2.703	2.711	2.700	2.832	2.547	2.490
Extra sessions	80	41	30	56	50	39	31	33	52	16	31	418
Total	2.448	2.242	2.312	2.520	2.470	2.583	2.734	2.744	2.752	2.848	2.578	2.908

Source: Administrative Secretariat and PCPIEA of the Unit of Nephrology of Macapá -AP.

Table 4 - Approved amounts in R\$ referring to the procedures performed – Nephrology Unit, Macapá – AP, 2015

	January	R\$ 439.616,93
Clinical Procedures: Hemodialysis (maximum three sessions per week) Hemodialysis (maximum one session per week -exceptionality) Diagnostic procedures: Monthly laboratory exams Exceptional examinations per week	February	R\$ 407.720,37
	March	R\$ 423.581,67
	April	R\$ 453.298,34
	May	R\$ 454.476,74
	June	R\$ 488.600,97
	July	R\$ 521.711,66
	August	R\$ 506.483,50
	September	R\$ 520.756,33
	October	R\$ 514.467,02
	November	R\$ 465.795,94
	December	R\$ 552.261,72
	Total	R\$ 5.748.771,19

Source: Administrative secretary of the Macapá Nephrology Unit - AP.

DISCUSSION

Studies showing the regional realities related to CKD contribute to aggregate information to the panorama of Nephrology in Brazil and the world.

In this study, the prevalence of male patients (63.6%) corroborates other studies and the panorama that has been registered over the years by the Dialysis Survey conducted annually by SBN.^{5,9-11}

When evaluating the age group, it was observed a prevalence of patients between 50 and 59 years old: 29%; and the lowest rate in patients between 10 and 19 years old: 1.4%. Thus, it is observed that in the state of Amapá, the increase of patients in hemodialysis has been accompanied by the increase in the age, both associated with the greater life expectancy of the population, contributing to the increase in the incidence and prevalence of chronic diseases. Therefore, the current trend is an increasing number of elderly individuals who, despite living longer, present more chronic conditions, and the increase of these diseases is directly related to the increase in functional disability.^{12,13}

Regarding the marital status, a high percentage of married or stable union was found: 49.7%, confirming the findings of other studies. 14-17 This prevalence is presumed to be associated with the age group of the patients, contemplating people over 30 years old, the stage of life in which there is more search for a stronger relationship and constitution of family or lack of social support. From this point of view, a study associates the existence of a spouse with the best adherence of the patient to the dialysis treatment. 16

There was a prevalence of brown people - 136 (62.7%) -, corresponding to the prevalent race in the North region and patients with incomplete elementary education: 87 (40.1%). It is

estimated that the lower level of education is associated with limited conditions for patients to absorb information about their health, associated with more sickness and negative correlation with the prevention and control of CKD.

Regarding monthly income and occupation, there was a prevalence of patients with a minimum wage - 136 (62.7%) - and those receiving social security benefits - 110 (50.7%). These factors are closely related to the lack of education and loss of capacity for work or the exercise of activity ensuring subsistence.

A broad prevalence of patients with medical assistance from SUS was identified: 85.7%. In this context, SBN highlights the growth of chronic kidney patients on dialysis between 2011 and 2013, with SUS accounting for 84% of dialysis therapy funding.¹⁸

Another aspect is related to the city of origin of the patients, of which 55.3% are from Macapá, 28.1% come from other states, but they settled in Macapá, and 16.6% came from the interior and islands of the Pará. In this context, a study clarifies that SUS service providers are classified based on the principles of regionalization and hierarchization in the organization of care networks, aiming at distributing service according to demand and ensuring the breadth of the territory. From another perspective, the study points to the centralized distribution structure of the country's dialysis centers as a consequence of the lack of public investment in the opening of new hemodialysis centers in smaller cities, resulting in numerous problems for patients who need to travel long distances three times a week to access the treatment.

Regarding the clinical characterization of the patients, the variables used showed the time in hemodialysis, type of access and the most prevalent comorbidities in the study population.

Regarding the time in hemodialysis, there was a predominance of patients who have been on SRT for three years: 58.5% and an accumulated percentage of 22.6% of patients who have been in treatment for more than six years. In this context, there is a high incidence of patients who initiate dialysis and a high proportion of mortality after six years of treatment. In this context, the Program for Prevention and Control of Infection and Adverse Events (PCPIEA) of the Unit of Nephrology of Macapá registered 73 patients who died during 2015.

In this perspective, studies point out that it is essential that the patient acquires understanding, adaptation, and participation in the treatment to acquire more dialysis survival.^{19,20}

Regarding vascular access for hemodialysis, the prevalence of AVF: 61.3% is a favorable element for chronic kidney patients, since a reduced incidence of complications and infections involves permanent access to temporary accesses through catheters, besides the AVF being a more durable access.²¹

As for comorbidities, systemic arterial hypertension (SAH) as the underlying disease was present in 81.6% of the patients in this study, followed by diabetes mellitus (DM): 38.2%, reaf-

firming the relationship between SAH and DM as a factor of risk for kidney damage. Similar findings have been identified in other studies. Other research has identified that a significant portion of conservative patients and their families were not aware of hypertension and diabetes as causes and risk factors for CKD progression. ²³

Extra dialysis sessions are attributed to decompensated patients. However, in the data contained in the available spreadsheet, there were no specifications regarding the discrepancy occurred in December.

The study evidenced a variable quantitative of hemodialysis sessions during 2015, showing a decline in the first trimester and a gradual and significant increase from April to October. The variations correlate to patients who died and new patients who started hemodialysis therapy, respectively.

The total amount was R\$ 5,748,771,¹⁹ for the review carried out by the Ministry of Health to fund the hemodialysis sessions in 2015 at the Macapá Nephrology Unit.

In this perspective, the study highlights the high cost of maintenance of chronic dialysis programs and emphasizes not only the cost of hemodialysis procedures and the various types of peritoneal dialysis (PD) but also the supply of medications, transportation, hospital admissions, access to renal transplantation, among others.²⁴ Consequently, considering all nephrology care, the total to the area is estimated at R\$ 2.1 billion, representing about 10% of the entire budget of the Ministry of Health. Also, the use and cost of hemodialysis funded by the SUS in the Brazilian federal units from 2008 to 2011 were emphasized. Regarding the state of Amapá, in the period above, the amount by the SUS referring to the hemodialysis sessions reached US\$ 4,554,399, 37.²⁵

LIMITATIONS OF THE STUDY

One limitation of the study is the use of a non-standard instrument and not validated for the population studied. Also, about to comorbidities, the information provided by the patients could not be confirmed in the research done by the researchers in Nefrodata. The lack of data to verify the accuracy of this information is another aspect of limiting the reliability of this study.

CONCLUSION

Considering CKD a worldwide public health problem with a great impact on the quality of life of the families, significant mortality rate and high cost of the treatment, this work allowed to show the panorama of the CKD in Amapá. It shows singularities and what is common to the terminal CKD in a state of the Brazilian Amazon, expanding existing studies and

enabling to interconnect realities between micro and macroregions in the country.

Based on this study, the prevalence of age, low educational level, low income and basic diseases, such as hypertension and diabetes mellitus, highlight the main vulnerabilities in this region and reinforce the relevance of the Health Care Networks combined with new strategies to strengthen the prevention and early diagnosis of kidney disease. Combined with the high cost of dialysis therapy, these factors reinforce the challenge of the Health Care Networks in the early diagnosis and treatment of renal disease, in which the need for health professionals to know the epidemiological profile of chronic kidney disease in its context of action is highlighted to culturally sensitive care. The study has important implications for the need for more investments in the proposal of instruments and methodologies generating complete and permanently updated information on the population with chronic kidney disease in Brazil as a whole, organized by states and regions, contributing to future research to the needs of the different realities of the country.

ACKNOWLEDGE

To the patients, nursing professionals and Administrative Secretary of the Unit of Nephrology of Macapá, for the collaboration of the accomplishment of this study.

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