CHARACTERISTIC OF ROMA ON HEMODIALYSIS TREATMENT IN NORTH MACEDONIA

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Abstract: The aim of this study was to find the differences between Roma and non-Roma Hemodialysis (HD) patient in their demographic and clinical parameters in Republic of North Macedonia. The Department of Nephrology in Skopje, the Republic of North Macedonia, engaged 169 HD patients in a prospective research on demographic features and survival. Patients were observed for a total of 37 months. Patients with HD were questioned regarding significant demographic characteristics, including ethical autonomy. With an AGE Reader, skin autoflurescence was assessed a measure of Advanced Glycation End Products (AGEs). The two dietary records, one from autumn and one from spring, were gathered from HD patients in order to examine the daily calorie, protein, and AGE intake and investigate the possibility of seasonal fluctuation. Regarding the Hemodialysis treatment, we discovered that Roma had statistically significant ($p=0.023$) lower participation or none of them were included in the extended duration of HD treatment programme, as they refused to remain in the HD unit for longer than the minimum time required for HD treatment. At 37 months, 49 out of 169 HD patients had died, or 29%. In the univariate Cox regression analysis, we discovered that alcohol consumption, age, hypertension as a cause of end-stage renal disease (ESRD), and Hepatitis B were related with a shorter survival time. Age, alcohol, hypertension, and Hepatitis B were all independent survival inhibitors in our HD patients.We found no difference in the survival of Roma and non-Roma HD patients. In this study was found a short HD session time in Roma patients. Roma hemodialysis patients suffer specific obstacles, such as stigma, prejudice, cultural restrictions, financial load, social isolation, and psychological distress. Knowing these obstacles and the cultural beliefs and practises of Roma patients can assist healthcare providers in providing culturally sensitive treatment and assistance to this vulnerable community.
Keywords: Roma, Hemodialysis, Survival

1. INTRODUCTION

End-stage renal disease (ESRD) is a severe form of kidney failure that is treated with hemodialysis (HD) as a life-sustaining treatment. An artificial kidney machine is used to remove waste and excess fluid from the blood during the surgery. Typically, it is conducted three times a week for three to four hours every session. Although its benefits, HD is connected with a number of emotional and physiological obstacles, especially for Roma patients.

The Roma are one of Europe's largest ethnic minorities, with an estimated 10-12 million people dispersed over the continent. They have a distinct culture, language, and history, but also experience substantial socioeconomic and health disparities. Specifically, they have a high prevalence of chronic diseases and restricted access to healthcare services, such as hemodialysis(1).

HD can have a substantial effect on patients' psychosocial health, especially that of Roma patients. Among the primary obstacles cited by Roma patients. Roma patients may encounter stigma and discrimination from healthcare practitioners and the broader public, which can result in feelings of isolation and marginalisation (2).Due to language and cultural obstacles, Roma patients may have restricted access to health information and services (3).HD can be costly, and Roma patients may struggle to pay for the treatment, transportation, and other associated expenditures (2). Because to their limited mobility, Roma patients may endure social isolation, especially if they reside in isolated places (4). Due to the long-term nature of HD, the need for regular treatments, and the physical and mental burden of the procedure, Roma patients may endure psychological distress (5).Patients receiving HD who are Roma may have pleasant experiences and find support from their family and communities despite these obstacles.

Moreover, Roma patients may have cultural beliefs and traditions that influence their HD experiences. For instance, some Roma groups may be resistant to contemporary medical procedures, such as HD, since they believe in ancient healing practises (2). In addition, Roma patients may have contrasting cultural perspectives on disease and death, and they may seek spiritual support from their communities and religious authorities (3).

The aim of this study was to find the differences between Roma and non-Roma HD patient in their demographic and clinical parameters in Republic of North Macedonia.

2. MATERIAL AND METHODS

The Department of Nephrology in Skopje, the Republic of North Macedonia, engaged 169 HD patients in a prospective research on demographic features and survival. The study protocol was approved by an Ethics Committee, and each patient provided signed informed permission. These exclusion criteria were applied: Less than three months on HD; acute illness or hospitalisation within three weeks of the study's commencement; neoplasm; prior kidney transplant. Patients were observed for a total of 37 months. Patients with HD were questioned regarding significant demographic characteristics, including ethical autonomy.

HD treatment

All patients received HD therapy three times per week for an average of four hours each session. Individually adjusting the duration of the HD session in accordance with Kidney Disease Outcomes Quality Initiative recommendations (6) in order to maintain an equilibrated Kt/V >1.2. Patients were dialyzed with bicarbonate dialysis solutions containing no glucose and low-flux polysulfone (Fresenius, Bad Homburg, Germany) or polyamide (Gambro, Stockholm, Sweden) membranes. The blood flow through the device was 300 ml/min, while the dialysate flow was 500 ml/min. The patients got regular medical care suited to HD patients.

The characteristics of the patient

The existence of cardiovascular disease, hypertension, and diabetes was characterised by the following criteria: (International Classification of Diseases, Tenth Edition, Clinical Modification codes I20, I21, I63, I70, and I73)(7). Hypertension was defined as a systolic blood pressure of >140 mmHg or a diastolic blood pressure of >90 mmHg recorded on at least three separate occasions.(8) Those using antihypertensive medication were also considered hypertensive. When nephrosclerosis was present, we also considered hypertension to be the etiology of end-stage renal disease.

Traditional American Diabetes Association criteria were used to define diabetes (9).

If anti-Hepatitis C antibodies were detected in certain patients, we considered them to have Hepatitis C.

HD vintage was defined as the time from the beginning of long-term HD treatment and the beginning of the study.

Advanced Glycation End-Products (AGEs)

With an AGE Reader, skin autofluorescence (AF) was assessed (DiagnOptics Technologies BV, Groningen, The Netherlands). This device has been discussed in full earlier (10). Briefly, the AGE-Reader illuminates roughly 4 cm2 of skin surface with excitation light primarily between 350 and 420 nm (peak excitation approximately 370 nm). The measured skin AF is the average intensity of reflected light between 420-600 nm divided by the amount of reflected light between 300-420 nm times 100. AF on the skin is measured in arbitrary units (AU). The measurements were conducted in triplicate at room temperature in near-darkness.

Nutritional Documents

The two dietary records, one from autumn and one from spring, were gathered from HD patients in order to examine the daily calorie, protein, and AGE intake and investigate the possibility of seasonal fluctuations. Patients were instructed on how to estimate portion sizes and record their food intake. It was encouraged to record the day and time of meals, snacks, and beverages, as well as a description of food, drinks, preparation techniques, missing meals, restaurant consumption, and processed food consumption. According to Goldberg et al. (11), the dietary questionnaire was utilised to determine AGEs intake using the food content of N-carboxymethyllysine as a common AGEs marker. We updated Goldberg's food content tables for regional traditional meals using the closest equivalent of a particular regional traditional meal. The number of calories and proteins was determined using tables from the Nutrition Database of the United States Department of Agriculture (12).

The BMI was computed as the ratio of dry end-dialysis weight (in kilogrammes) to height squared (in metres) [21].

Statistical Analysis

Depending on the relationship between the variables, Chi-square or an independent Student t-test was used to compare the variables. Using the Spearman rank approach, correlations were evaluated. Cox regression and Kaplan-Meier curves were utilised to examine the impact of AGEs accumulation and other factors on HD patients' overall mortality. In the multiple regression (linear, logistic, or Cox) models, only variables with p0.10 in the univariate analysis were utilised. SPSS statistical software (version 26.0 SPSS, Inc., Chicago, IL) was utilised; p 0.05 was deemed significant with two-tailed tests. Unless otherwise noted, data is presented as mean standard deviation.

3. RESULTS

According to the respondent, HD patients used Macedonian 105 (62.5%), Albanian 47 (28%), Roma 11 (6.5%), and other 5 (3%) as ethnic self-determination, or non-Roma 157 (93.5%), and Roma 11 (6.5%). We compared HD patients of Roma and non-Roma descent. Considering demographic and general medical characteristics, we observed no significant differences across groups, as indicated in Table 1.

Regarding the Hemodialysis treatment, we discovered that Roma had statistically significant (p=0.023) lower participation or none of them were included in the extended duration of HD treatment programme, as they refused to remain in the HD unit for longer than the minimum time required for HD treatment. Figure 1 demonstrates that Roma patients had considerably lower body weight (p=0.050) than non-Roma patients. The outcomes of all HD treatment and nutrition variables are shown in Table 2.

At 37 months, 49 out of 169 HD patients had died, or 29%. In the univariate Cox regression analysis, we discovered that alcohol consumption, age, hypertension as a cause of end-stage renal disease (ESRD), and Hepatitis B were related with a shorter survival time. Age, alcohol, hypertension, and Hepatitis B were all independent survival inhibitors in our HD patients. On Figures 1 and 2, the Kaplan-Meier curves of HD patients with hypertension as a cause of ESRD and other causes, as well as alcohol consumers and non-drinkers, are depicted. The log-rank test was significant (p=0.0001) between those with hypertension as a cause of ESRD and those with other causes of ESRD, but it was not significant (p=0.172) between those who consumed alcohol and those who did not.

4. DISCUSSION

We found no difference in the survival of Roma and non-Roma HD patients. In recent years, the survival rate of Roma patients on HD has become a matter of study. Research indicate that Roma patients on hemodialysis may have a shorter survival time than non-Roma patients. The average survival duration of Roma patients on HD was significantly less than that of non-Roma patients, according to a study conducted in Hungary (13). Similarly, a research in the Czech Republic indicated that the survival rate of Roma patients on HD was lower than that of non-Roma patients (14).Several variables may contribute to the reduced survival time of Roma patients. Their restricted access to healthcare services may result in delayed beginning of hemodialysis and insufficient management of co-morbidities (13). Moreover, Roma patients may have lower health literacy and restricted access to information about their condition, which might hinder their ability to self-manage their illness (14).

In this study was found a short HD session time in Roma patients. A normal hemodialysis session lasts between three and four hours and is conducted three times each week. The frequency and duration of HD treatments are dictated by a patient's particular needs and can vary depending on their age, overall health, and severity of kidney disease. Regarding the duration of their HD treatments, there is insufficient information on the specific experiences of Roma patients. Unfortunately, cultural and linguistic limitations, as well as restricted access to healthcare resources, may make it more difficult for Roma patients to receive proper hemodialysis care and support. In order to guarantee that Roma patients receive adequate and culturally sensitive treatment throughout their HD sessions, it is essential for healthcare staff to comprehend and solve these obstacles. In addition, Roma patients may face cultural and societal obstacles that hinder their participation in the healthcare system. For instance, individuals may experience prejudice and stigma from healthcare providers, and their mobility may be constrained due to poverty and lack of transportation (13). These factors can have a negative effect on patients' adherence to HD and overall health (14).

In conclusion, Roma hemodialysis patients suffer specific obstacles, such as stigma, prejudice, cultural restrictions, financial load, social isolation, and psychological distress. Knowing these obstacles and the cultural beliefs and practices of Roma patients can assist healthcare providers in providing culturally sensitive treatment and assistance to this vulnerable community.

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Table 1. Demographics and general medical descriptors

Variable	Non-roma	Roma	p-value
Age (years)	56.52±12.91	50.54±14.59	0.143
Female	63 (40%)	3 (27.3%)	0.399
Dead after 37 months	44 (28%)	5 (45.5%)	0.460
Consumers of alcohol	35 (23.3%)	4 (44.4%)	0.153
Cardiovascular Disease	27 (17.4%)	3 (27.3%)	0.412
Smokers	15 (10%)	1 (11.1%)	0.914
Hepatitis B (+)	16 (11%)	1 (9.1%)	0.902
Hepatis C (+)	108 (69.2%)	6 (54.5%)	0.312
Hypertension as a cause of ESRD	125 (75%)	9 (81.8%)	0.809
Diabetics	38 (24.2%)	4 (36.4%)	0.209

Percentages are from recoded cases. Missing cases are not included.

Table 2. Hemodialysis treatment and nutrition parameters

Variable	Non-roma	Roma	p-value
Time of survival (months)	31.7±10.13	26.95±12.71	0.136
Hemodialysis session longer than 4 hours	25 (16.6%)	0 (0%)	**0.023**
Hemodialysis vintage (years)	8.79±6.39	7.15±5.20	0.429
Weight (kg)	63.35±12.35	54.14±5.33	**0.050**
Hemodialysis Blood Flow (ml/min)	295.9±11.7	297.7±6.67	0.648
Ultrafiltration (L)	3.178±0.861	3.36±0.639	0.122
Kt/V	1.391±0.207	1.33±0.233	0.843
Heparin (IU)	3976±1553	3640±1677	0.556
BMI (kg/m2)	23.46±4.59	25.7±4.42	0.157
Malnutrition Inflammation score (points)	6.1±3.12	4.22±1.85	0.078
Calories per day	1914±652	2318±1196	0.094
Proteins per day (gram)	82.85±49.34	77.65±22.5	0.345
Advanced Glycation End-Products per day (IU)	9968±4466	10434±3496	0.486

Table 3. Cox Regression Analysis of survival of Hemodialysis patients using selected parameters

Variable	P-value	Exponent B	Confidence Interval Lower Border	Confidence Interval Upper Border
Univariate Analysis				
Gender (Male)	0.937	0.958	0.331	2.776
Alcohol consumption	**0.021**	**2.975**	**1.176**	**7.53**
Age	**0.004**	**1.063**	**1.02**	**1.108**
CVD	0.492	0.727	0.292	1.805
Duration of HD session	0.595	1.26	0.538	2.951
Roma	0.28	2.465	0.479	12.688
Hypertansion as a cause of ESRD	**0.048**	**2.213**	**1.006**	**4.871**
HbSAg	**0.032**	**3.085**	**1.099**	**8.663**
AntiHCV	0.749	0.869	0.368	2.053
HD Vinatge	0.507	1.026	0.952	1.105
BMI	0.798	1.015	0.907	1.136
KT/V	0.632	0.52	0.036	7.547
Ultrafiltaration	0.71	0.899	0.512	1.578
Advanced Glycation End-Products per day (IU)	0.644	1.002	0.994	1.009
Calories per day	0.518	0.982	0.93	1.037
Proteins per day (gram)	0.935	0.976	0.538	1.768
Final Model				
Alcohol consumption	**0.003**	**2.98**	**1.437**	**6.176**
Age	**0.001**	**1.053**	**1.022**	**1.085**
HTA as a cause of ESRD	**0.023**	**2.302**	**1.12**	**4.731**
HbSAg	**0.018**	**3.032**	**1.21**	**7.593**

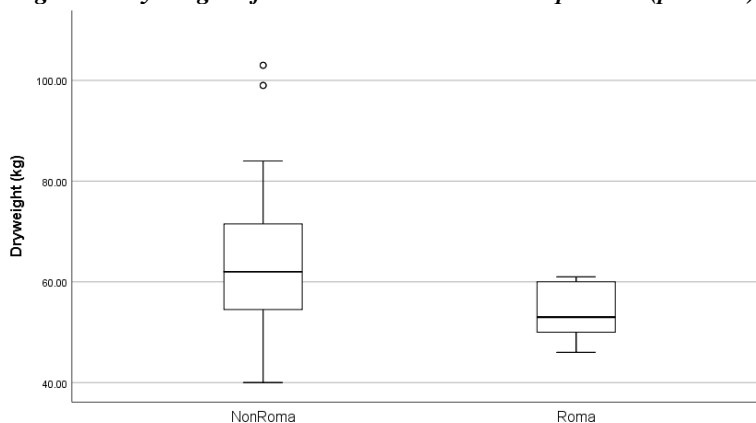*Figure 1 Dry weight of Roma and Non-roma HD patients (p=0.050)*

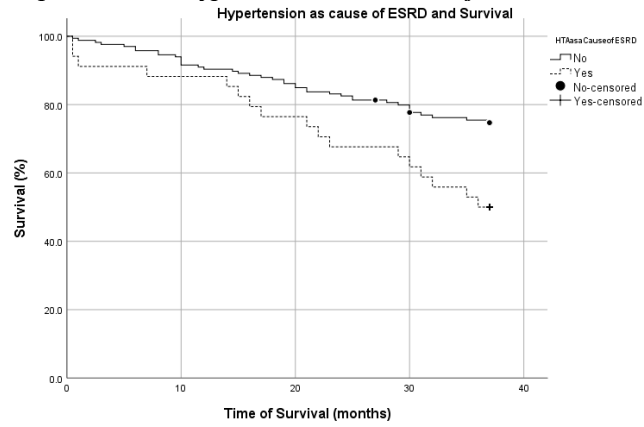*Figure 2 Survival of HD patients with hypertension as a cause of ESRD and other causes of ESRD (p=0.001)*

Figure 3 Survival of Hemodialysis patients the consumed alcohol and non-drinkers (p=0.172)