Sociographic Profile of Hemodialysis Patients in Portugal

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The study outlines the sociographic profile of patients on hemodialysis treatment in Portugal through a descriptive study of 3114 chronic renal failure patients. The dominant sociographic profile indicates that participants were male (59%), over the age of 65 (52.54%, M = 67.6), married (58.70%), with a low educational level (1st to 4th grade: 53.18%), and retired (77.62%). They were born in Portugal (89.56%), living in Lisbon (51.48%), living with nuclear families with children (46.47%) and had informal support networks (72.22%). Other social indicators point to vulnerable situations: 8.6% were unemployed, 2.5% were living in a precarious housing situation; 10.45% were displaced patients; 11.37% lived alone; 9.18% had single-parent families; and 10.69% did not have any source of support. Knowledge of sociographic profiles is a determinant of successful social work and social epidemiology in order to develop social and multidisciplinary intervention programs and social policies that promote individual and social well-being of chronic kidney disease patients.

INTRODUCTION

The social relevance of chronic renal failure is increasing. As a global public health problem, the prevalence of chronic kidney disease (CKD) in the world, including Portugal, has increased significantly (Ruggenenti, Schieppati, & Remuzzi, 2001). The proportion of kidney problems in the population of Portugal over the age of 15 increased from 1.8% in 2005/2006 to 4.6% in 2014 (Instituto Nacional de Estatística (INE), 2016). According to data from the Portuguese Nephrology Society (Macário, 2016), in 2015 there were 18,928 patients in Portugal, 11,514 of those patients were enrolled in a regular hemodialysis program and the others were undergoing other therapeutic approaches (peritoneal dialysis, transplantation and conservative treatment). In 2015, Portugal had the highest incidence of renal failure in Europe in 2015 (Macário, 2016). Of all Portuguese patients who started renal replacement therapy, 89.54% started hemodialysis treatment, 9.74% started peritoneal dialysis treatment, and 0.72% received a transplant, the latter number reflecting only those who received a transplant without undergoing dialysis treatment (Macário, 2016). The majority of those who started hemodialysis treatment were over the age of 65.

This higher prevalence of kidney disease is related to the increase in the incidence of other diseases, such as diabetes mellitus and arterial hypertension. An increase in the average life expectancy and greater access to general healthcare, simultaneously lead to an increase in the diagnosis of kidney disease (Parsi, Kanni, & Malhotra, 2015; Wild, Roglic, Greene, Sicree, & King, 2004). The disease process, as well as the hemodialysis induction, irreversibly marks the lives of chronically dialyzed patients. Physical, psychological, familial, work and social impacts, force them to adjust to a life with different demands.

Studies of hemodialysis patients and renal transplant patients have demonstrated the correlation of socio-demographic, socio-familial, socio-occupational, and psychosocial characteristics in adherence to treatment (Dobrof, Dolinko, Lichtiger, Uribarri, & Epstein, 2002) and in resulting outcomes, and highlight the differences between women and men (Vourlekis, & Rivera-Mizzoni, 1997). As determinants of health, several social factors have been associated with quality of life in CKD patients (Kao, Lai, Tsai, Jan, Chie, & Chen, 2009), adaptation to the disease (O'Brien, 1980), and selection of peritoneal dialysis over hemodialysis (Stack, 2002). Gender, age, and social support are predictive variables of physiological indicators throughout treatment (Boyer, Friend, Chlouverakis, & Kaloyanides, 1990). Social determinants have a clear effect on referral timing, delaying or halting the progression of CKD (Blythe, & Benoit, 2004). A twenty-four study (Morton et al., 2016) analysis of social disadvantage factors among dialysis patients (gender, race/ethnicity, religion, education, socio-economic status, occupation, and place of residence) and their effect on health outcomes shows that low education, no health insurance, low occupational level, or no home ownership were significantly related to less healthcare. Thus, knowing and understanding the sociographic profiles of the patients is fundamental.

OBJECTIVES

In order to broaden knowledge of the hemodialysis population in Portugal, the study aimed to outline the sociographic profile of patients undergoing treatment in 25 hemodialysis clinics, characterizing the participants' gender, age, education level, place of birth, residential area, marital status, family typology, support networks, housing, and professional situation.

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METHOD

Instruments, Procedures, and Data Analysis

This is a descriptive study based on patient data, obtained through semi-structured interviews, concerning the sociographic characteristics of the CKD population (age, gender, marital status, occupation, education level, and family typology). The organization's research ethics committee approved the study. This data was compiled and analyzed through the statistical software R [1], version 3.3.1. A descriptive and inferential statistical analysis was performed. The Mann-Whitney test was used in the comparison of averages between two groups; the Kruskal-Wallis test was used in the comparison of three groups; and the Wilcox test was used for paired samples to verify which groups differ from each other.

Participants

The study involved 3114 hemodialysis patients in treatment in 25 clinics in mainland Portugal during the year 2016. The clinics are located in three major geographical areas of the country: 1) North (Régua, Riba D'Ave, Marco de Canavezes, Paredes, Penafiel, Vila do Conde, Braga, Vila Verde, Vila Nova de Gaia, and two clinics in the city of Porto); 2) Centre (Águeda, Aveiro, and Figueira da Foz); and 3) Lisbon (The greater metropolitan area of Lisbon: Torres Vedras, Sintra, Amadora, Estoril, Odivelas, Linda-a-Velha, Almada, Loures, and Lisbon—Saldanha, Benfica, Lumiar). In Portugal, there is a dominant public healthcare system (universal and tendentiously free). Dialysis care is mainly provided by private clinics that have conventions with the Portuguese State, making the treatment free of charge to the patients. The sample included 1262 women (41%) and 1852 men (59%), with an average age of 67.6 (SD = 14.88). The majority of the patients only had basic education, from 1st to 4th grade level (53.18%), followed by those with 5th and 6th grade education (11.53%), and those with 7th to 9th grade education (10.63%); 10.18% did not have formal schooling, and only 7% had higher education qualifications **(Table 1)**.

RESULTS

Age By Gender, By Region, and According to Treatment Phase

The average age of the patients was 67.6 years old, the youngest being 18, and the oldest 96, noting that women in treatment were, on average, older than men (M = 68.16 versus M = 65.5, $p < 0.001$) **(Table 2)**.

When analyzing the age distribution according to the geographical areas where the clinics are located, we noticed that the average age in the Centre region (M = 69.39) was higher than in the North (66.44) or the greater metropolitan area of Lisbon (65.77), which had the lowest value, with statistically significant differences in the average age in the different regions ($p < 0.001$), pointing out that the Centre region was the one with the highest value **(Table 2)**. As for age groups, the majority of users were between the age 65 and 84 (52.54%), in contrast to the minority who were under age 25 (0.58%). This applied regardless of gender and residential area. The Lisbon area had the largest percentage of age groups below 64. The Centre region stood out as the group that had the most patients over 85, and presented a greater percentage of patients equal or greater than age 65 (**Table 3**).

The patients' average age at the time of their first hemodialysis treatment was 60.9 (with a minimum age of 7 and the maximum of 93). We noticed a greater number of people aged 65 to 84, coinciding with the age group where there were more patients being treated **(Table 4)**. Women in the sample were older than men when starting treatment ($M = 61.93$ vs. $M = 60.12$ years, $p \leq 0.001$). In the greater metropolitan area of Lisbon, hemodialysis was started earlier (59.40 years old), and the Centre region had the highest concentration of older people undergoing hemodialysis and a later start on treatment ($M = 64.20$ years old). A statistically significant difference was observed regarding the other geographical regions and the average age of initiation of treatment ($p < 0.001$) **(Table 5)**.

Origin of Patients: Place of Birth and Residential Area

This study had participants from 27 different countries, though the majority were Portuguese (89.56%). There was a significant proportion of African-born patients, mostly from the African Countries of Portuguese Official Language (PALOP; Paises Africanos de Lingua Oficial Portuguesa), such as Cape Verde, Guinea-Bissau, São Tomé e Príncipe, Mozambique, and Angola ($n = 270$; 8.68%), which was the result of healthcare agreements between Portugal and these countries. The largest concentration of patients was in the Lisbon area, where there were 11 clinics. Although there were also 11 clinics in the North, there were fewer people undergoing treatment at those locations **(Table 6)**.

Family and Social Support Networks

We found that most of the patients were married (58.7%), followed by widowed people (17.79%). As for family type, the majority were part of a nuclear family with children (46.47%), followed by those with extended families (12.68%), those who lived alone and constituted single-person families (11.37%), and then single-parent families (9.18%). The majority of patients had informal support from family, friends, and neighbors as their primary source of support (72.22%); formal support by social services was less relevant. It should be noted that 10.69% of the sample presented with no support network at all **(Table 7)**.

Housing

The majority of patients lived in apartments (47.47%) or in houses (44.48%). The remaining types of housing (collective housing, improvised housing, mobile housing, shack, part of a house, homeless, other) were less frequent. Relevant to social concerns were the precarious housing situations (2.5% of the cases), and collective housing (5.33%). As for the type of housing occupancy, the majority lived in their own houses without mortgages (52.34%), followed by those who lived in rented houses (26.36%) **(Table 8)**.

Table 1. Socio-demographic Characterization of the Sample: Gender, Age, and Educational Level

	***n* = 3114**	**% (100)**
Gender		
Female	1262	41.00
Male	1852	59.00
Educational Level		
No Education	371	10.18
1st to 4th Grade	1656	53.18
5th to 6th Grade	359	11.53
7th to 9th Grade	331	10.63
10th to 12th Grade	232	7.45
Higher Education	219	7.03

Age	***M***	***SD***	***Mo***	***Mín***	***Máx***
	67.6	14.88	72	18	96

***n* = frequency; *M* = average; *SD* = standard deviation; *Mo* = mode; *Min* = minimum; *Máx* = maximum**

Table 2. Age of the Patients By Gender And Geographical Area

	Average Age	**IC 95%**	
Gender			
Female	68.16	(67.36 ; 68.96)	$p < 0.001$
Male	65.50	(64.82 ; 66.18)	
Geographical Area			
G.M.A. Lisbon*	65.77	(65.03 ; 66.51)	
Centre	69.39	(68.19 ; 70.58)	$p < 0.001$
North	66.44	(65.52 ; 67.36)	

*** G.M.A. Lisbon = Greater Metropolitan Area of Lisbon**

***p* = *p*-value Significance Level**

Table 3. Age Group by Geographical Area

	Portugal		G.M.A. Lisbon*		Centre		North	
	n = 3114	% (100)	*n* = 1603	% (100)	*n* = 507	% (100)	*n* = 1004	% (100)
Age Group								
< 25	18	0.58	12	0.75	–	–	6	0.6
25 – 44	280	8.99	153	9.54	32	6.31	95	9.46
45 – 64	917	29.45	502	31.3	128	25.25	287	28.59
65 – 84	1636	52.54	804	50.16	292	57.39	540	57.78
85+	263	8.45	132	8.23	55	10.85	76	7.57

*** G.M.A. Lisbon = Greater Metropolitan Area of Lisbon**

Table 4. Age at First Treatment

Age group at first treatment		***n* = 3114**		**Valid %(100)**	
< 25		98		3.25	
25 – 44		420		13.93	
45 – 64		1040		34.49	
65 – 84		1347		44.68	
85+		110		3.65	
MD		99		–	
	M	***SD***	***Mo***	***Mín***	***Max***
Age group at first treatment	60.9	16.5	68	7	93

n = frequency; *M* = average; *SD* = standard deviation;
***Mo* = mode; *Min* = minimum; *Max* = maximum**
***MD* = Missing Data**

Table 5. Age At First Treatment by Gender and Geographical Area

	M	**IC 95%**	
Gender			
Female	61.93	(61.02 ; 62.83)	$p \leq 0.001$
Male	60.12	(59.36 ; 60.87)	
Geographical Area			
G.M.A. Lisbon*	59.40	(58.55 ; 60.25)	
Centre	64.20	(62.82 ; 65.57)	$p < 0.001$
North	61.68	(60.70 ; 62.66)	

***M* = average; IC = confidence interval; *p* = *p*-value significance level**

*** G.M.A. Lisbon = Greater Metropolitan Area of Lisbon**

Table 6. Place of Birth And Geographical Residential Area

	***n* = 3114**	**% (100)**
Place of Birth		
Portugal	2789	89.56
Europe – other countries	12	0.38
PALOP		
Angola	46	1.48
Cape Verde	127	4.08
Guiné-Bissau	36	1.16
Mozambique	25	0.8
São Tomé e Príncipe	36	1.16
Africa – other countries	3	0.1
America	22	0.71
Asia	18	0.58
Geographical Residential Area		
G.M.A. Lisbon*	1603	51.48
Centre	507	16.28
North	1004	32.24
Districts (Mainland Portugal)		
Aveiro	360	11.56
Braga	215	6.90
Coimbra	98	3.15
Leiria	1	0.03
Lisbon	1496	48.04
Porto	638	20.49
Setúbal	189	6.07
Vila Real	24	0.77
Viseu	93	2.99

* G.M.A. Lisbon = Greater Metropolitan Area of Lisbon

Table 7. Marital Status, Family Typology in Terms of Composition and Support Networks

	***n* = 3114**	**% (100)**
Marital Status*		
Married	1828	58.70
Separated or divorced	224	7.19
Single	412	13.23
Domestic partnerships	96	3.08
Widowed	554	17.79
Family Typology		
Nuclear with children	1447	46.47
Nuclear without children	133	4.27
Extended family	395	12.68
Reconstituted	74	2.38
Single-parent female	223	7.16
Single-parent male	63	2.02
Foster family	10	0.32
Single-person family	354	11.37
In an institution	166	5.33
Co-housing with non-relatives	35	1.12
Another type of family	23	0.74
NA**	191	6.13
Support Networks		
With informal and formal support network	297	9.54
With informal support network	2249	72.22
With formal support network	235	7.55.
With no support network	333	10.69

* The marital status was considered taking into account the de facto (domestic partnership) situation regardless of the legal situation.

**NA = non-available data

Table 8. Housing Typology and Occupation Regimes

	n = 3114	% (100)
Housing Typology		
Collective housing**	166	5.33
Improvised housing*	9	0.29
Mobile housing*	1	0.03
Apartment with a lift	870	27.94
Apartment without a lift	608	19.53
Shack*	10	0.32
House	1385	44.48
Part of a house*	57	1.83
Homeless*	1	0.03
Other***	7	0.22
Occupation Regimes		
Rented	821	26.36
Assigned	180	5.78
Social housing	188	6.04
Illegally occupied	4	0.13
Homeowner with mortgage	249	8.00
Homeowner without mortgage	1630	52.34
Other	42	1.35

* Precarious housing situations

** Collective housing: nursing home, shelter hotel, and guesthouse

*** Other: provisional situation in host family home (of relatives or non-relatives)

Professional Situation

We found that the majority of patients were retired (77.62%), followed by those who were employed (10.6%), and then unemployed (8.6%). The majority of retired people were men (46.11%) and over the age of 65 (57.55%). However, we highlight the fact that 20.07% of the sample were retired under the age of 65. The unemployed and employed people were mostly males of working age **(Table 9)**.

DISCUSSION

The results showed that the majority of the 3114 individuals with CKD were men over 65, and the average age of the women in the sample was higher than the men, a profile that is in line with national health trends (GID, 2017; Macário, 2016). However, the mean age was higher than in a study with samples from several European countries (Locatelli et al., 2004), which may mean an older sick population or a later referral in the Portuguese context. Most of the participants were married, with a significant percentage of widowed people.

The National Health Survey of 2014 (INE, 2016), which studied a sample of 406,460 people with chronic kidney problems (including renal failure), presented a higher prevalence among men. A study conducted in 12 countries (Hecking et al., 2014) corroborates a greater representation of men on hemodialysis treatment, associated with a higher rate of comorbidity with other diseases and with more frequent risk factors. This may have a cultural component, namely the tendency for men to seek medical care in more advanced stages of the disease, particularly as kidney disease is often a "silent disease" in symptomatology (Gomes, Nascimento & Araújo, 2007; Thomé, 2011). The predominant age group poses a set of challenges that are compounded by the problems associated with senescence and social vulnerability factors associated with the elderly.

Geographically, although Lisbon was the area with the largest number of participants, the Centre region registered an older and sicker population in the sample, since it is a geographical area with a higher rate of the aged than the North and Lisbon regions (PORDATA, 2017). Patients from the greater metropolitan area of Lisbon seemed to be younger.

The majority of people undergoing treatment were from Portugal, but there was also a significant number of patients from PALOP, namely Cape Verde, Angola, São Tomé e Príncipe and Guinea-Bissau because of international healthcare agreements that were established between Portugal and these countries. Patients of other nationalities (other European and African countries, American and Asian countries) comprised less than 2% of the patients (general immigrants). Patients from PALOP are displaced for treatment, younger, and are more concentrated in the Lisbon area, contributing to a lower age range in this area than in the North and Centre regions. In an additional analysis of the average age of a sub-sample of 249 PALOP patients, we found that 119 were undergoing treatment through the international agreements, but 130 were not covered by those same agreements, with an average age of 48.9 for covered and 58 not covered; those from Angola were the youngest in both groups. Although the statistics in Portugal did not classify the race and the ethnicity of these populations, the African origin of these individuals could indicate a set of social disadvantages, pointed to by other studies of the differences between white and black people in CKD rates and outcomes explained by the social determinants of each group (Norton et al., 2016), as well as disparities in CKD incidence, prevalence and progression across different socioeconomic, racial and ethnic groups (Nicholas, Kalantar-Zadeh, & Norris, 2015), appearing to be relevant cultural differences affecting our study. This group of patients presented specific monitoring and support needs, taking into account the marked cultural differences, the uprooting from their communities of origin, and issues of integration into a new population. It will be very important to examine this variable, backed by clinical data, in future studies.

Most of the patients were part of nuclear families with children, the most common families in the Portugal (PORDATA, 2017). Two typologies also emerged, which deserve our attention: those who lived alone (single-person families) and those who represented single-parent families, located mostly in urban centers. These two family compositions have increased significantly in Portugal in the last decades, with specific implications for those who deal with a chronic disease that has a high impact on daily life (Delgado & Wall, 2014; PORDATA, 2017). Those who live alone do not have someone, on a permanent basis, to care for them. Whereas in single-parent families, the patients accumulate non-shared care roles for their children which can make it difficult to reconcile family life with treatments and self-care.

Regarding support networks, we found that the majority of patients had an informal support network, and a minority relied exclusively on a formal support network. It should be noted that in 10.69% of cases no source of support was identified. As the study population was mostly elderly, these results reveal the informal, essentially familial, nature of elderly subjects' networks in Portugal (Cabral, Ferreira, Silva, Jerónimo, & Marques, 2013). It should be noted that 5.33% of the participants were institutionalized, and that 11.37% lived alone, which may generally justify the use of formal networks as a source of primary support or in coordination with their informal networks. Social support is fundamental in situations of illness (Guadalupe, 2012), either to favor the adaptation to treatment or to enhance the access to resources; effective support is associated with better medical outcomes in hemodialysis patients (Boyer et al., 1990) and is a predictor of survival, because of the importance of psychosocial risk factors in mortality of dialysis patients (Thong, Kaptein, Krediet, Boeschoten, & Dekker, 2007). Social workers must increase efforts to improve social support for these patients, focusing on those who do not have support networks, those with small networks, and those with weak support.

Table 9. Professional Situation by Age Group and Gender

	Unemployed with benefits*	Unemployed without benefits**	Domestic	Employed	Student	Inmate	Retired
N = 3114	*n* = 20 (0.64%)	*n* = 248 (7.96%)	*n* = 68 (2.18%)	*n* = 330 (10.60%)	*n* = 30 (0.96%)	*n* = 1 (0.03%)	*n* = 2417 (77.62%)
Age Group							
< 25	0 (0)	7 (0.22)	0 (0)	4 (0.13)	6 (0.19)	0 (0)	1 (0.03)
25 – 44	7 (0.22)	71 (2.28)	3 (0.10)	101 (3.24)	19 (0.61)	0 (0)	79 (2.54)
45 – 64	13 (0.42)	141 (4.53)	23 (0.74)	192 (6.17)	3 (0.10)	0 (0)	545 (17.5)
65 – 84	0 (0)	28 (0.90)	37 (1.19)	32 (1.03)	2 (0.06)	1 (0.03)	1536 (49.33)
85+	0 (0)	1 (0.03)	5 (0.16)	1 (0.03)	0 (0)	0 (0)	256 (8.22)
Gender							
Female	4 (0.13)	117 (3.76)	67 (2.15)	85 (2.73)	8 (0.26)	0 (0)	981 (31.5)
Male	16 (0.51)	131 (4.21)	1 (0.03)	245 (7.87)	22 (0.71)	1 (0.03)	1436 (46.11)

* Unemployed with unemployment benefits

** Unemployed without unemployment benefits

Regarding the educational level of the population under analysis, we found that most of the had a basic education level (1 to 6 years), which was essentially related to the dominant age group of the participants. Lower educational level is associated with lower economic resources and fewer opportunities to access healthcare services (Costa, Baptista, Perista, Carrilho, & Carmo, 2008; Cotta et al., 2007), as well as problematic and inadequate levels of poorer health literacy, and are associated with poor health. Additionally, low health literacy may also promote lower treatment adherence and self-care (Pedro, Amaral, & Escoval, 2016). The selection of treatment modality can also be determined by social variables, such as education, autonomy, and social support systems (Stack, 2002), which reinforces the need for social workers in the multidisciplinary healthcare team.

When we analyzed patients' occupational situations, we had to consider that the majority of participants in the study were retired. It is important to note that only 20.7% of the patients were retired, though 39.02% of the population were under the age of 65. Therefore, a relevant proportion of the retired patients, of an active working age, were unable to work because of the disease. Among the unemployed, there was a higher number of long-term unemployed without benefits, who had gone beyond the guaranteed period in which the benefits were available, than unemployed with active benefits. This was due to the difficulty CKD patients encounter finding a job compatible with their limitations and flexible for treatment times. CKD represents significant implications for the difficulty or even inability to return to the labor market, and we know that work status and income level influences quality of life, progression, and treatment (Kao et al., 2009).

The decrease in income level because of chronic illness is generally irrecoverable, and makes patients and their families vulnerable (Kao et al., 2009); it is difficult to fully compensate for this situation through the available social protection measures and policies, necessitating continuing social work advocacy.

CONCLUSION

In summary, the sociographic profile of 3114 subjects with chronic renal failure undergoing hemodialysis treatment in Portugal indicates that the majority were men, over the age of 65, married, with basic educational level. They were homeowners, lived in apartments or houses, retired, born in Portugal, and resided in the greater metropolitan area of Lisbon. They were part of nuclear families with children and had mainly informal support networks.

However, a representative profile, in line with the national statistics, does not point out obvious social problems present in several minority profiles, with indicators that point to situations of social vulnerability. The percentage of unemployed patients, those who presented with precarious housing, who were displaced PALOP patients, those who lived alone, who had single-parent families, or did not have any source of informal or formal support was highly relevant. Under current conventions and agreements, PALOP patients are not provided with any kind of formal support. Their displaced situations and the demands of treatment make it difficult to create informal social ties. Due to these facts, they became a vulnerable population with weak support systems, and are a special target for social work interventions.

The sample size and the lack of literature defining the sociographic profile of the hemodialysis patient population in Portugal give this study particular importance in promoting knowledge and redefining social and clinical interventions. The present study constitutes the first step towards an analytical broadening and deepening of these patient characteristics, allowing us to consider a set of hypotheses, as well as the correlational exploration with other relevant variables in treatment and follow-up for these patients, namely the study of associations between clinical, social, and psychosocial aspects.

The complexity of social work interventions is determined, in part, by the diversity of social profiles presented by patients, and is crucial to categorizing the population to determining groups at higher risk and needing social work interventions (Dobrof et al., 2002; Furr, 1998). We consider that knowledge of these sociographic profiles is decisive in improving specific social work intervention programs, as well as organizational and social policy measures that are able to meet the needs of those who are ill and to promote their individual and social well-being.

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