

HEALTH LITERACY AMONG DIALYSIS PATIENTS

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ABSTRACT

Background: Health literacy has been defined by the World Health Organization (1998) as the "set of cognitive and social skills which determines the ability of people to gain access to, understand and use information in ways which promote and maintain good health."

Objectives: To determine the Health Literacy among haemodialysis patients; to analyze the influence of socio-demographic variables and of family in patients' Health Literacy; to establish a relationship between the duration of the treatment received and haemodialysis patients' Health Literacy. Methods: Quantitative, non-experimental, descriptive, correlational and cross-sectional study based on the information gathered from 68 patients suffering from chronic renal failure who were undergoing haemodialysis at the Nephrology Service at the Tondela/ Viseu Hospital Centre, EPE, and at the Beirodial Clinic - Medical Centre and Dialysis, in Mangualde and who were between 21 and 88 years old, which gives an average age of 66.74 (± 14.927 Sd.). The data collection instrument was a questionnaire that included socio-demographic questions and others about the patients' clinical profile, the Family Apgar Scale (Smilkstein, 1978) and the European health literacy Survey (HLS- EU-Q) validated for Portuguese participants (Nunes & Sorensen, 2013). Results: Most patients seem to exhibit inadequate health literacy (61.8%). The independent variables that might interfere with health literacy were: the patients' age- middle-aged patients are more likely to exhibit better health literacy ($X^2=10,340$; $p=0.006$); their educational qualifications- higher literacy levels were evident among patients with higher academic qualifications ($p<0.05$ in all dimensions); the family's monthly income- patients with higher monthly income tend to exhibit better health literacy ($p<0.05$ in all dimensions) with a marginal

difference regarding health care ($X^2=5.869$, $p=0.53$); family relationships - patients who live in a functional family manifest better literacy (prevention of disease $p=0.010$; total literacy in health $p=0.034$); the amount of time required for treatment- where we have to include patients with shorter treatment time (health promotion $X^2=6.077$; $p=0.048$).

Conclusion: The results show a prevalence of haemodialysis patients with inadequate literacy levels. This situation requires the development of action plans that will contribute to improve the levels of health literacy.

Keywords: *Dialysis patient; Health Literacy*

1. INTRODUCTION

Over the past few years, there has been a substantial increase in the number of people suffering from chronic illnesses, as a result of the ageing process which affects our population and because of the development of scientific techniques (Bastos, 2012, p.15). This way, and according to the same author, chronic pathologies, Chronic Renal Failure notably, have started to be studied more intensely by healthcare community, since they play an important role in the gradual increase in morbidity and mortality rates.

Chronic Renal Failure (CRF) strongly affects patients' routine and quality of life, for it is a disease that causes short term and long term pathological changes and whose treatment requires renal replacement therapy, dialysis (haemodialysis or peritoneal dialysis) and/or kidney transplant. These patients have to go through drastic changes that will affect their health and their lives, since they have to learn to live with this chronic and irreversible disease and with a vast set of situations that will limit their Quality of Life (QOL)

End-stage Renal Disease is defined by an irreversible Glomerular Filtration Rate (GFR) below 15 ml/min/173 m²

End-stage Kidney or Renal Disease is the final stage of chronic kidney disease, the stage V of the disease (Chronic Renal Disease Classification/KDOQI (2002) corrected by the *Kidney Disease Improving Global Outcomes* (KDIGO), in 2004 and, more recently, in 2012) in which the patient is already experiencing end-stage kidney failure, despite all the nutrition and fluid restrictions and different therapies that a patient suffering from Chronic Renal Failure has to go through. Although the disease aetiology may be quite vast, the most frequent diseases to which we may associate its origins are glomerulonephritis, polycystic kidney diseases, diabetes *mellitus*, high blood pressure and some autoimmune diseases (Santos & Pontes, 2007).

When there is a complete kidney inability to carry out the excretion of products caused by metabolic degradation, patients should start their dialytic therapy. This treatment will allow the removal of the different toxic metabolites (excessive levels of urea, Creatinine) and of other excessive substances that can be found our body and, at the same time, will allow doctors and nurses to replace some of the substances that were missing in the patients' bodies (Gama, 2014). Portugal has a very high prevalence and incidence of patients suffering from End-stage renal disease. According to the Portuguese Nephrology Society (2015), 2200 new cases of End-stage Renal Disease are reported every year. Currently, there are 15 thousand patients suffering from this health condition (10 thousand of them depend on dialysis and five thousand had already undergone a kidney transplant). The population ageing is one of the most important risk factors, along with diabetes and high blood pressure, among others (Macário, 2015).

These are important aspects to be taken into account and that show the economic burden of this medical condition on the National Health System and the kind of responsibility it represents to the

people who have to live with this disease, an illness that affects people from every gender, every age, every race or who belongs to every kind of social status.

Health literacy is defined as the learner’s awareness of the development of his understanding, management and investment abilities towards health promotion. Health literacy implies the achievement of a good level of knowledge, personal skills and confidence that will allow people to take action to improve personal and community health by changing lifestyles and living conditions (Almeida, Silva, Gaspar, & Fonseca, 2014). The concept of Health literacy has been used in many occasions as a synonym for Health Promotion or Health Education. However, there are important differences between health literacy and health education, since literacy is associated with a planned process of learning, an intentional activity which is closely linked to an individual willingness and to individual and group abilities, that will influence ways of thinking, clarify values and beliefs in a way that people will be able to obtain certain skills that will trigger changes in their behaviours and lifestyles (Loureiro, Dinis, & Oliveira, 2012).

Health literacy should be developed among patients who suffer from any chronic disease, and particularly among those who suffer from renal failure, so that they may have a better knowledge of their disease and may adapt their lives to this condition. Health literacy promotes the adoption of appropriate behaviours that will, in turn, promote people’s Quality of Life (Loureiro, 2015). Low levels of health literacy are directly associated with a higher prevalence of hospital admission cases, a greater and preventable use of emergency care services, a lower use of medication and a poorer ability to interpret labels and health messages and are responsible for poor health outcomes (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011).

2. METHODS

The current study is a quantitative, descriptive and correlational research work that will allow us to create a socio-demographic profile of the patients who have to undergo haemodialysis and of their health literacy levels to determine which socio-demographic variables will interfere with their health literacy, to analyse the relationship between family and clinical variables that affect these patients’ health literacy and to assess the influence the duration of the treatment has on health literacy. Keeping these issues in mind, we outlined a set of questions that will guide our research: What is the level of health literacy of patients who have to undergo haemodialysis? Which socio-demographic and family variables will influence the health literacy of patients who have to undergo haemodialysis? Does the duration of the treatment provided have any influence on the health literacy of these patients?

With this in mind, we defined the following objectives, that meet the research questions we had asked earlier: to determine the level of health literacy of patients who undergo haemodialysis; to analyse the influence of socio-demographic and family variables on these patients’ health literacy; to analyse the relationship that exist between the duration of the treatment and the patients’ health literacy. We used a non-probability convenience sample, or accidental sampling, composed of 68 patients suffering from chronic renal failure who had to undergo haemodialysis.

We used a data collection protocol composed of the following instruments: the socio-demographic profile questionnaire distributed to the participants and that included 6 closed format questions (gender, age, marital status, residence, monthly income and academic qualifications); the socio-family questionnaire that included a closed format question (who do you live with?); the Apgar Family Scale, created by Smilstein in 1978, that allows us to assess the functionality of the participants’ family; the clinical profile questionnaire that includes 3 questions: an open format question (duration of the dialysis treatment), a closed format question (type of treatment received)

and an open and closed format question (medical background); the *European Health Literacy Survey Questionnaire* (HLS- EU-Q) in its Portuguese version (HLS-EU-PT) adapted by Nunes and Sorensen (2013).

3. RESULTS

Statistics report the existence of a 22.04 (± 9.669 Sd.) average Health Literacy value. The highest average value regarding the dimensions that form the health literacy has to do with health care (M=38.10 ± 9.144 Sd). The lowest average value is associated with health prevention (M=35.49; ± 9.120 Sd). Most of the participants show an inappropriate health literacy (61.8%): 57.9% of the elements who belong to this particular group of respondents are male, while 66.7% are female participants. Right after, comes a group of participants who exhibit a problematic kind of health literacy (27.9%) , a group mainly formed by men (34.2%).

When it comes to the influence of age over health literacy, we observed that most of the participants exhibit appropriate health literacy: this kind of knowledge is mostly possessed by people who have just entered their elderly age (73.1%) and by elderly/ older people (68.2%). We could also observe that 27.9% of the participants display problematic health literacy. Middle aged participants (45.0%) and the elderly/older participants (22.7%) are the predominant groups in this category.

When we analysed the influence of age on health literacy, we verified that there was a prevalence of inadequate literacy among most of the participants (61.8%). This lack of literacy was more evident among 57.7 % of the people who were living with a partner and 64.3% of those who were living by themselves. The percentage of participants who exhibited problematic health literacy was quite expressive, too (27.9%). 30.8% of those participants were living with a partner and 26.2% were living alone.

As far as the participants' place of residence was concerned, we could observe that 60.0% of those who were living in a rural environment and 63.6% of those who were living in an urban area exhibit inappropriate health literacy (61.8%). Then, we analysed the case of participants who showed problematic health literacy (27.9%): 28.6% of those participants were living in a rural area, while 27.3% of them were living in an urban environment.

When we checked the dimension associated with the family monthly income, we verified the existence of a high prevalence of participants who exhibited inadequate health literacy (61.8%). 66.0% of those participants earned less than 500 euros /month and 68.8% of those participants had a family monthly income that ranged between 500 and 1000 Euros. We also observed the existence of participants with problematic health literacy (27.9%): 23.4% of them had a lower monthly income and 31.3% a monthly income between 500 and 1000 Euros. 10.3% of the respondents showed a sufficient level of health literacy. This specific group was mostly formed by participants with lower monthly incomes. When we studied the participants' academic qualifications dimension, we could, once more, observe a clear predominance of participants with inadequate health literacy (61.8%). 77.6% of the respondents had concluded their primary education and 30.8% of them had finished their basic education. In this dimension, we could also verify that 27.9% of the participants exhibited problematic health literacy. 14.3% of the participants who were part of this group had concluded their primary education and 61.5% of those participants had only concluded their basic education.

10.3% of the participants exhibited a sufficient/excellent level of health literacy. The highest mean value (33.3%) was related to those who had higher academic qualifications, that is to say those who had graduated from high school.

When we analysed the dimension that paid attention to the family functionality dimension, we observed, as it had occurred in the previous dimensions, that there was a high prevalence of participants with inadequate health literacy (61.8%). 83.3% of the participants who belonged to this particular group had already experienced some kind of family dysfunctionality and 57.1% of them came from a functional family. 27.9% of the participants exhibited inadequate health literacy. 30,4% of them came from a functional family. 12.5% of the participants who came from a functional family exhibited a sufficient/excellent level of health literacy.

Middle-age patients were those who exhibited a better health literacy level. Among those patients, the highest mean ordination value corresponds to health care; the next values were related to health promotion and health prevention. Elderly patients and patients who were older exhibited lower health literacy, except for health promotion, a dimension in which the lower health literacy levels were exhibited by people who had just entered the elderly stage of their lives. We have to stress out that there is a statistically significant difference when it comes to health care ($X^2=10.340$; $p=0.006$). Patients with a higher family monthly income were those who exhibited a better level of health literacy, since the mean ordination values were higher among this group of participants. The main dimensions were illness prevention, followed by health promotion. There were statistically significant differences in the health literacy dimensions ($p<0.05$). The marginal difference was associated with health care, which suggests that health literacy depends on the family monthly income. As for the differences of the mean ordination values between academic qualifications and health literacy, we could observe that the patients who had higher academic qualifications were those who exhibited a better level of health literacy, followed by patients who had concluded their basic education. This evidence has statistically significant differences for all the health literacy dimensions ($p<0.05$). As far as the role played by family functionality in the participants' literacy level was concerned, we can state that the patients who live in a functional family exhibit a higher level of health literacy, with a mean ordination value which is higher when it comes to health care and health promotion.

We have to stress that there are statistically significant differences in illness prevention ($p=0.010$) and in the total health literacy ($p=0.034$) dimensions. The mean ordination difference between health literacy and the treatment duration shows that the patients who have to undergo shorter haemodialysis treatments are those who exhibit a higher level of health literacy, mainly in the health promotion dimension, in which we observed the highest mean ordination value. The patients whose treatment has been going on for a 3-5 years period of time are those who exhibit a lower level of health literacy, a fact that has statistical relevance in health promotion ($X^2=6.077$; $p=0.048$).

4. CONCLUSION

The most important results obtained from this empirical study show that most of the elements that formed our sample were male, and that the men who have participated in our study were slightly older than the women participants. More than half of the elements who composed our sample were living with a partner, and most of them were living in a rural area. Most of them have monthly incomes below 500 Euros and most of them had low academic qualifications, since the majority of these participants had only concluded their primary education. Most of our respondents come from a functional family and more than half the sample was living with their family. Most of the

patients exhibit inadequate level of health literacy. As for the influence socio-demographic, family and treatment duration variables have over healthy literacy of the patients who undergo haemodialysis, we could observe that age, academic qualifications, family monthly income and the patients' family functionality may affect the level of health literacy. The same can be said for these patients' treatment duration: we concluded that this variable interferes with health literacy, since the patients whose treatment was shorter were those who exhibited a better level of health literacy, mainly in the health promotion dimension in which we observed the highest mean ordination value. Those results show that we need to develop intervention plans that will help improve the levels of health literacy among patients who undergo haemodialysis, always taking into account that psychological (motivation and self-efficiency perception), social and environmental factors will always influence health-related choices and behaviours.

This suggestion is based on the evidence that any health promotion action has to include policies seeking the reduction of inequality and that intend to create environments that will in turn favour healthy choices, policies that will develop health education, social awareness and empowerment strategies. On the other hand, this suggestion is based on the evidence that the investment in health literacy asks for a holistic approach so that it may help the patients who need haemodialysis treatments deal with their disease, help them use healthcare services properly and handle their own pathology and its consequences. These improvements will undoubtedly allow them to achieve a much higher quality of life.

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