Emotional aspects and self-care of patients with Type 2 Diabetes Mellitus in Renal Replacement Therapy¹

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Abstract: Introduction: Diabetes mellitus (DM) is considered to be an important public health problem, both due to the number of people affected, the disabilities and mortality, and the costs involved in controlling and treating its complications. Objective: To evaluate the emotional aspects and self-care of patients with T2DM undergoing hemodialysis (HD) and to correlate these variables with the time of dialysis and the time of diagnosis of DM. Method: Individuals over 40 years of age, with Type 2 DM in HD for at least 3 months at the State Hospital of Bauru. Sociodemographic information was collected, and the participants answered the B-PAID questionnaires (perspective of the impact of DM on quality of life and emotional aspects) and the QAD (self-care). The data were presented descriptively and used Spearman's Correlation and the Chi-square Association Test (p <0.05). Results: Fifty-four individuals, aged 62 ± 9 years, predominance of white skin color and incomplete elementary school were studied. In the B-PAID the mean score was 23 (7-43) points, demonstrating low emotional distress, and in the QAD the lowest adherence was in the "Physical Activity" domain and greater "Foot care and medication use". There was a positive correlation between DM time and HD time (p = 0.04, r = 0.27) and association between heart disease and B-PAID (p = 0.02). Conclusion: The individuals studied presented low emotional distress, good foot care and those with a lower incidence of heart disease suffer less from DM.

Keywords: Diabetes Mellitus, Renal Insufficiency, Chronic, Self-care, Surveys and Questionnaires, Quality of Life.

Aspectos emocionais e autocuidado de pacientes com *Diabetes Mellitus* Tipo 2 em Terapia Renal Substitutiva

Resumo: Introdução: O Diabetes Mellitus (DM) é um problema de saúde pública de grande impacto, tanto pelo número de pessoas afetadas, pelas incapacitações e mortalidade, quanto pelos custos envolvidos no controle e tratamento das suas complicações. Objetivo: Avaliar os aspectos emocionais e o autocuidado de pacientes com DM tipo 2 submetidos à hemodiálise (HD) e correlacionar estas variáveis com o tempo de tratamento dialítico e tempo de diagnóstico de DM. Método: Participaram indivíduos acima de 40 anos com DM tipo 2 em HD há pelo menos 3 meses no Hospital Estadual de Bauru. Foram coletadas informações sociodemográficas e os participantes responderam aos questionários B-PAID (perspectiva do impacto do DM na qualidade de vida e aspectos emocionais) e ao QAD (autocuidado). Os dados foram apresentados de forma descritiva e analisados através da Correlação de *Spearman* e o Teste de associação *Qui-quadrado* (p<0,05). Resultados: Foram estudados 54 indivíduos, com idade 62 ± 9 anos, predominância da cor de pele branca e ensino fundamental incompleto. No B-PAID o escore médio foi 23 (7-43)

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pontos, demonstrando baixo sofrimento emocional, e no QAD a menor aderência foi no domínio "Atividade Física" e maior "Cuidado com os pés e uso de medicamentos". Houve correlação positiva entre o tempo de DM e tempo de HD (p=0,04; r=0,27) e associação entre as doenças cardíacas e o B-PAID (p=0,02). Conclusão: Os indivíduos estudados apresentaram baixo sofrimento emocional, bom cuidado com pés e aqueles com menor incidência de doença cardíaca sofrem menos com o DM.

Palavras-Chave: Diabetes Mellitus, Insuficiência Renal Crônica, Autocuidado, Inquéritos e Questionários, Qualidade de Vida.

1 Introduction

Diabetes Mellitus (DM) is currently considered one of the main health problems for the number of people affected, generating disabilities and high mortality, and for the high investment to control and treat their complications (SANTOS, 2017). According to the Brazilian Society of DM (SOCIEDADE..., 2016), there are about 13 million individuals with DM in Brazil, which represents 6.9% of the population. This number tends to grow as a result of population aging, economic development, and urbanization, which triggered important changes in lifestyle, marked by the presence of sedentarism and obesity (CECÍLIO et al., 2015).

Diabetes mellitus type 2 (DM2) is the most common in 90 to 95% of cases and is characterized by disorders in the action or secretion of insulin (BRITO; LISBOA, 2016). It is a health condition with high morbidity and mortality rates that currently affects more than 20% of the older adults between 65 and 76 years old (SANTOS et al., 2015).

The diabetic nephropathy (DN) is one of the most serious complications of DM, characterized by loss of the kidney function, which can progress to chronic kidney disease (CKD), classified in stages I through V according to the glomerular filtration rate (GFR). In stage V, with GFR <15 mL/min/1.73 m², it is called renal failure, when patients have the option of Substitute Renal Therapy (SRT). The costs of the disease treatment with dialysis are high to Public Health. In 2008 and 2011, the Unified Health System spent US\$ 723 million and US\$ 970 million, respectively, on hemodialysis (HD) procedures in Brazil, estimating an average annual cost per patient of US\$ 7 thousand in 2008 and US\$ 9 thousand in 2011 (ROSA, 2017).

When adopted in isolation, these therapeutic resources do not guarantee the preservation of quality of life and patient survival, despite of advances in dialysis treatments. Patients with CKD, particularly those in HD, have severe metabolic and physical limitations, which directly contribute to a significant increase in hospitalization and mortality rates. There were 21,281 deaths in 2014, corresponding to a gross mortality rate of 19.0% per year (ROSA, 2017; SESSO et al., 2016).

Diabetic patients face major changes in lifestyle, such as changes in eating habits and adherence to restrictive therapeutic regimens. Also, patients must cope with living with a disease that is responsible for several clinical complications and, the higher the number of complications, the worse the QOL. The complications resulting from DM compromise not only the patient's physical condition but also the psychological and socio-cultural. It is important that the patient is committed to self-care, which involves the diet, physical exercise and correct use of medications. With such care, blood glucose levels are expected to improve with a lower risk of complications.

Thus, this study aimed to evaluate the emotional aspects and self-care of patients with DM2 undergoing HD and to correlate these variables with the time of dialysis treatment and time of DM diagnosis.

2 Method

This is a cross-sectional study. The sample consisted of individuals diagnosed with DM2 from the State Hospital of Bauru - SP, aged 40 and older, of both genders, with CKD, submitted to outpatient HD for at least three months (three sessions/week), from February to April 2016. The individuals who refused to participate in the survey and those who were unable to respond to the questionnaires were excluded. Patients who agreed to participate in the study signed a free informed consent form, where we will maintain confidentiality regarding the identification of patients. The study was approved by the Research Ethics Committee of Faculdades Integradas de Bauru, under opinion 1,511,476.

There was information collected in a directed interview and consultation of medical records on sociodemographic data, educational level, presence of risk factors (smoking, alcoholism), family history, presence of comorbidities (cardiac diseases, dyslipidemia), time of diagnosis of DM and time in treatment. The body mass used was the "dry weight" (measured after HD session) and the nutritional status was obtained by calculating the body mass index [BMI] = weight/height²].

Two specific, easily understood, validated and translated Portuguese questionnaires, Problems Areas in Diabetes (B-PAID) and the Self-care Activity with Diabetes questionnaire (QAD) were used as instruments to collect data about distress and self-care. The B-PAID is a questionnaire composed of 20 questions that focus on aspects related to living with DM and its treatment, including guilt, anger, depression, worry, and fear. This instrument produces a total score ranging from 0-100, using a five-point scale ranging from 0 to 4, where zero represents that there is no problem and four that there is a serious problem. The total score of 0-100 is reached by the sum of the answers multiplied by 1.25. A high score indicates a high level of emotional distress (MACHRY et al., 2018; SIAW; TAI; LEE, 2017).

The QAD has six dimensions and 15 items of self-care assessment with DM: general feeding, specific feeding, physical activity, blood glucose monitoring, foot care, and medication use. Also, there are three other items for the evaluation of smoking. During the evaluation, patients should answer to how often they perform activities or behaviors over the last seven days. These answers should range from 0 to 7, where 0 is the least desirable situation and 7 is the most favorable situation. The scores indicate the performance of the activities., the mean greater than four points to indicate desirable self-care and less or equal to four as undesirable were used as the cutoff point (VERAS et al., 2014), except for items with reverse values presented in the specific feeding domain. Tobacco-related items are converted considering the proportion of smokers, mean cigarette consumption, and the last time the individual smoked (MICHELS et al., 2010).

The data obtained were analyzed by the SPSS 20.0 program. The results were presented in a descriptive way using position measures for data with normal distribution (parametric) (mean and standard deviation) and for non-normal distribution (non-parametric) (median and percentiles). For the purpose of analysis, the B-PAID questionnaire was dichotomized in "no moderate-problem" and "serious problem" according to the scores 0 to 2 and 3 to 4, respectively. The Kolmogorov Smirnov test was applied to analyze the normality of the data. The Spearman Linear Correlation was applied to correlate the HD time and DM diagnosis time with the questionnaire scores. Chi-Square test was used to associate the clinical and sociodemographic profile

with the scores of the questionnaires. The level of significance was 5%.

3 Results

About 200 chronic kidney patients are currently submitted to HD on HEB and 100 of them are diagnosed with DM. Two were excluded because they presented DM type 1, 12 were excluded because they participated in an exercise protocol performed by another researcher, seven were hospitalized, seven were considered confused or unable to answer the questionnaires, two did not agree to participate in the study, five died and 11 were not present in the HD sector on the days of data collection. The final sample consisted of 54 individuals, of which 34 were men (64%) and 20 were women (37%), aged 62 ± 9 years old, 36 (67%) were white skin color, 31 (57%) were married, 26 (48%) lived with a partner and children and 32 (59%) had low education level (incomplete elementary school). The mean body mass was 80.8 ± 18.2 kg and the BMI was 29.2 ± 6.1 kg/m², and 80% of the patients were overweight according to the Brazilian Obesity Guidelines (ASSOCIAÇÃO..., 2009). The main associated comorbidity was hypertension in fifty-three (98%) patients. Risk factors for cardiovascular disease and clinical data are shown in Table 1.

In the B-PAID questionnaire, the median was 23 (7-43) points. Only four patients had the minimum score (zero) indicating no emotional distress with the disease, and only one patient presented a maximum score (100) indicating a high level of emotional distress. The women had a higher total score of 35 (13-56) and the men 24 (6-34). In Table 2, greater distress in the field of emotional problems related to DM are observed, 40.74% of patients worry about the future and complications from the disease. In the field of diet-related problems, 29.63% of patients consider a serious problem in social situations uncomfortable where people say what they should or should not eat. Regarding their treatment, the lack of clear and concrete goals for DM represents a serious problem in 29.63% of the cases.

The self-care activities assessed by the QAD questionnaire are shown in Table 3. The mean over four indicates desirable self-care and less or equal to four as undesirable (VERAS et al., 2014), except for items with reverse values presented in the specific diet domain. There was a lower adherence to the physical activity domain $(1 \pm 2 \text{ days})$ and the greater one to control of the medication (all items had $6 \pm 2 \text{ days})$, followed by foot care (the item "Drying the inter-digital spaces after washing the feet" was

the highest in this questionnaire with 6 ± 3 days of adherence). In the "General food" domain, most of the patients presented undesirable self-care behavior $(4 \pm 3 \text{ days per week})$. In the specific diet, where the

score is the opposite, self-care was desirable. The item with the highest incidence was the consumption of high-fat foods (red meat or whole milk products) with 4 ± 3 days, the other two items presented 2 ± 3 days

Variables		n	(%)
Family history	Yes	35	65
	No	19	35
Smoking	Yes	3	5.5
	No	29	54
	Former	22	40.5
Sedentarism	Yes	48	89
	No	6	11
Diagnostic Time	1 to 5 years	11	20
	6 to 10 years	18	33
	More than 10 years	25	47
HD Time	Less than 1 year	17	31
	1 to 2 years	10	19
	2 to 4 years	13	24
	More than 4 years	14	26
DM Complications	Visual Changes	17	31
	Lower Limb Amputation	4	8
	No	33	61

Data expressed in absolute (n) and relative frequency (%).

Table 2. Distress Assessment Questionnaire (B-PAID).

	0 to 2 points Low distress	3 to 4 points HIgh distress	
	n (%)	n (%)	
Problems related to treatment			
The lack of clear and concrete goals in the care of your diabetes	38 (70)	16 (30)	
Feeling discouraged with your diabetes treatment	43 (80)	11 (20)	
Feeling unsatisfied with the doctor who cares for your diabetes	51 (94)	3 (6)	
Problems related to feeding			
Facing uncomfortable social situations related to diabetes care	38 (70)	16 (30)	
Having feelings of deprivation about food and meals	44 (81)	10 (19)	
Worrying about food and what to eat	43 (80)	11 (20)	
Problems related to social support			
Feeling alone with your diabetes	44 (81)	10 (19)	
Feeling that your friends and family do not support you in dealing with diabetes	50 (93)	4 (7)	
Emotional problems related to DM			
Feeling afraid when you think about living with diabetes	46 (85)	8 (15)	
Get depressed when you think about having to live with diabetes	42 (78)	12 (22)	
Feeling that your diabetes is a burden to you	41 (76)	13 (24)	
Worrying about low glucose episodes	38 (70)	16 (30)	
Getting angry/annoyed when thinking about living with diabetes	43 (80)	11 (20)	
Worrying about the future and the possibility of serious complications	32 (59)	22 (41)	
Feeling guilty or anxious when you stop taking care of diabetes	39 (72)	15 (28)	
Not accepting your diabetes	41 (76)	13 (24)	
Feeling that diabetes is taking so much of your mental and physical energy	39 (72)	15 (28)	
Dealing With Diabetes Complications	35 (65)	19 (35)	
Feeling exhausted with the effort you need to take care of diabetes	42 (78)	12 (22)	
Data expressed in absolute (n) and relative frequency (%).	42 (78)	12 (22)	

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Table 3. Self-care	acuvity	with Diabetes	o Ou	CSHOIII	Ianc I	UID.
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	0 to 4 days	5 to 7 days	Mean ± SD
	n (%)	n (%)	- Mean \pm SD
General food			
1 Following a healthy diet (D)	33 (61)	21 (39)	4 ± 3
2 Follow food guidelines (D)	41 (76)	13 (24)	3 ± 3
Specific diet			
3 Eating five or more servings of fruits and/or vegetables (D)	43 (80)	11 (20)	2 ± 3
4 Eating high fat foods (UN)	34 (63)	20 (37)	4 ± 3
5 Eating sweets (UN)	42 (78)	12 (22)	2 ± 3
Physical activity			
6 Performing physical activity for at least 30 minutes (D)	45 (83)	9 (17)	2 ± 3
7 Performing specific physical exercise (D)	50 (93)	4 (7)	1 ± 2
Glucose Monitoring			
8 Assessing blood sugar (D)	18 (33)	36 (67)	6 ± 2
9 Evaluating the recommended amount of blood sugar (D)	28 (52)	26 (48)	4 ± 3
Care of the feet			
10 Examining the feet (D)	27 (50)	27 (50)	4 ± 3
11 Examining inside the shoes before putting them (D)	26 (49)	28 (52)	4 ± 3
12 Drying the inter-digital spaces after washing the feet (D)	12 (22)	42 (78)	6 ± 3
Medication			
13 Taking your diabetes medications as recommended (D)	6 (11)	48 (89)	6 ± 2
14 Taking your insulin injections as recommended (D)	14 (26)	40 (74)	6 ± 2
15 Taking the indicated number of diabetes pills (D)	6 (11)	48 (89)	6 ± 2

Data expressed as absolute value (n), percentage (%), mean ± standard deviation. (D): desirable (UN): undesirable.

of consumption. Regarding glucose monitoring, a desirable behavior was analyzed for this domain.

There was a positive correlation between the time of diagnosis of DM and time of HD, that is, the longer the diagnosis of DM, the longer the time in HD (p=0.045, r=0.273). There was also association with the Chi-square test between heart disease and B-PAID, which showed that patients with lower incidence of heart disease suffer less from DM (p=0.024).

4 Discussion

In this study, people with diabetes undergoing hemodialysis were evaluated for self-care and distress in relation to DM. A predominance of males and a majority of patients over 60 years old were observed. In an agreement with other studies carried out on patients with the same pathology, this study shows that chronic diseases such as DM are common in the older adults due to sedentary lifestyle and changes in senility (MORAES, 2017; MAXIMINO et al., 2017; PEREIRA et al., 2016).

Most of the patients in this study were married and lived with their partners and children, agreeing with Silva et al. (2013), who surveyed 220 patients mostly males, low education level, and 78.6% were married. Ghannadi et al. (2016), Snoek et al. (2000) and Bernini et al. (2017) also studied patients with this same profile, married and living with partners and children, emphasizing that the family plays an important role in supporting and helping to control diseases such as DM and nephropathy, which require constant care for the maintenance of life.

The time of diagnosis of DM was greater than 10 years in 46.30% of the patients, as well as in other studies (SILVA et al., 2013; SNOEK et al., 2000). Pace et al. (2006) studied 659 patients with DM2, most of them were men and the average disease time was greater than ten years. In the Brazilian population, a significant part of the individuals with this pathology are unaware of the diagnosis, which is usually found with complications (LEITE et al., 2015).

Regarding education, a low level of education was found in 59% of the patients (less than eight years of education). A total of 659 patients with DM2 were studied in Ribeirão Preto - SP and found that low levels of education may limit and/or reduce the access to health care related to the learning opportunity, especially when recognizing that, in general, adult patients are responsible for their own care (PACE et al., 2006). A survey conducted in Iran with 117 older adults diabetics in HD also found low level of knowledge and unfavorable attitude (GHANNADI et al., 2016). These results are determinant for the success of preventive approaches of DM since a low level of education can hinder the access to information, bringing less possibilities of learning about self-care, and difficulties in understanding the therapeutic behaviors. These patients tend to seek medical care late, which implies a major health impact and a higher incidence of chronic diseases (PACE et al., 2006). According to Leite et al. (2015), the presence of a considerable number of diabetic elderly people with low education level is worrisome, since the lower level of education seems to be directly associated with depressive symptoms, compromising mental health and QOL. Thus, good knowledge of the diabetic patient is fundamental for the care and control of the disease and, consequently, to prevent or delay the appearance of complications.

Hypertension was the main comorbidity associated with DM2 in HD, being present in 98.1% of the patients analyzed, followed by heart disease with 37%. In the present study, the association between DM2 and arterial hypertension is the main cause of DN, which generates high rates of patients with both pathologies (PEREIRA et al., 2016; TEIXEIRA et al., 2015).

Regarding the risk factors, this study evidenced a considerable presence of obesity, sedentary lifestyle and smoking, which can cause complications and cardiovascular risks. In the study by Gross, Gross and Goldim (2010) with similar patients, mostly men, mean age close to 60 years old, low education level, most were obese and sedentary. Souza et al. (2012) also studied individuals with the same profile, where most of the 170 patients (51.8%) with DM2, elderly, low education level, obese and ex-smokers were sedentary, which indicated that the incorporation of physical activities and diet balanced maintenance of QOL.

In this study, B-PAID presented a score of 23 (7-43) points, indicating low emotional distress, which agrees with Bernini et al. (2017) who studied 59 individuals with DM2 and the mean score was 19 points. Also Gross, Gross and Goldim (2010), who studied 152 patients, 57.3% elderly men, 75.4% obtained lower scores than 40 indicating low emotional distress. Another study with the same profile of patients, having 68 elderly, 60% of them studied until elementary school, showing that in general, DM did not have negative emotional impact (LEITE et al., 2015). However, in the study by Papelbaum et al. (2010), with a sample of 100 diabetic older adults, the mean score was 50.3,

which showed high emotional distress, showing that the education level was a differential in the analysis of B-PAID. The group in which individuals studied more than elementary school presented a lower mean (44.4) when compared to the group with lower educational level (57.6) and the difference was statistically significant (p=0.01), while in this study, there was no correlation with education level.

Studies with the QAD questionnaire to evaluate self-care in DM2 presented similar results to this research, in which the domain with greater adherence was the "Medication" and lower adherence "Physical activity", observing that patients with DM2 in HD recognize the importance of a good glycemic control, correct medication use and daily foot care (COELHO et al., 2015; FERREIRA et al., 2014). However, when talking about healthy eating, the undesirable behavior of these patients is observed, agreeing with the study of Francioni and Silva (2007) with diabetics aged 44 to 56 years old in Florianópolis - SC, showing low adherence of patients to the recommended diet.

According to Souza and Silvestre (2013), the first step in the treatment of diabetic patients is the achievement and maintenance of good nutritional status. Francioni and Silva (2007) argued that this may be due to a negative perception regarding dietary treatment for disease control, associating it with condemnation to be deprived of pleasures, such as restricted participation in family feasts involving food.

Low education level may have been a limitation of this study since it hinders to understand the questionnaires, and not understanding the disease and its complications may have influenced the evaluation of emotional distress. Further studies are needed with these individuals in a chronicity state of the disease, to expand the research to other HD centers and to associate the work with educational groups.

5 Conclusion

When applying the B-PAID questionnaire, there was a low emotional distress in relation to DM, and in the QAD, there was greater adherence in relation to foot care and medication use and low adherence to physical activity practice. Also, there was an association between heart disease and B-PAID, which demonstrated that patients with a lower incidence of heart disease suffer less from DM and a positive correlation between the time of diagnosis of DM and time of HD, that is, the longer the diagnosis of DM, the longer the time in HD. These evidences pointed to a negative attitude regarding care, evidencing the need for educational programs and strategies, not only as prevention but also as a way to slow the progression of the disease and minimize its complications. Failure to understand their condition and the consequences of poor care means that the individual does not understand the need for deprivations and regulated routines related to DM.

It is expected that this study will contribute to guide health interventions and bring information about the patients in a state of chronicity of DM to understand the reality of these individuals, gaining adherence to self-care.

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Author's Contributions

Beatriz Cristina Murari Nogueira: Participated of the conception and planning of the work as well as the results interpretation, writing, and review of the preliminary and definitive versions. Camila Afonso de Souza: Participated in the results interpretation and writing. Roberta Munhoz Manzano, Silvia Regina Barrile and Maria Amélia Ximenes: Participated of the results analysis and interpretation and the writing of the preliminary and definitive versions. Clara Suemi da Costa Rosa: Participated of the data collection, results interpretation and writing. Camila Gimenes: She is the main author, participated of the conception and planning of the work as well as results interpretation, writing, and review of the preliminary and definitive versions. All the authors approved the final version of the text.

Notes

¹ Unpublished, cross-sectional study. Patients who agreed to participate in the study signed a free and informed consent form and the study was approved by the Research Ethics Committee of Bauru's Faculdades Integradas