Perceptions of hemodialysis patients about dietary and fluid restrictions

Percepções de pacientes em hemodiálise sobre as restrições alimentares

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Abstract

Introduction: Dietary regimen for hemodialysis (HD) patients is complicate and identifying characteristics and reasons of those most likely to experience difficulty in adhering to dietary restrictions is important. **Objective:** To quantify HD patient's perceptions about dietary and fluid restrictions, acknowledge individual reasons that facilitate or complicate their adherence, and also their relationship with demographic, nutritional and clinical characteristics. **Methods:** Multi-center cross-sectional study in five dialysis facilities. HD patients (n = 147; 48% male; age: 51,3 ± 13,6 years) were encouraged to score on a scale of 0 to 10 their perception of the degree of difficulty to adhere the nutritional advice regarding control of sodium, fluid, potassium and phosphorus intake. **Results:** Sodium score was 4(1-7), fluids 6(3-8), potassium 4(2-6) and phosphate 6(3-8). Percentage of patients who perceived a greater difficulty (score ≥ 6) to control fluids and phosphate intake was higher than for sodium and potassium. Participants with excessive % interdialytic weight gain (%IDWG) had a higher score for fluids; the ones with hypercalemia perceived more difficulty to control potassium intake than others as well as hyperphosphatemic patients compared to normophosphatemic to control phosphorus intake. Participants with a greater difficulty to control sodium intake also perceived a greater difficulty to control fluids, potassium and phosphate intake. **Conclusion:** Participants perceived a greater difficulty to control fluid and phosphate intake rather than sodium and potassium, higher perceptions scores were associated with subgroups and with worse control of clinical parameters. Moreover, patients with a greater difficulty to control some dietary item also found harder to control the other ones.

Keywords: diet; hemodialysis; nutrition therapy.

Resumo

Introdução: as recomendações dietéticas para pacientes em hemodiálise (HD) são complexas e identificar as características e as razões das pessoas com maior dificuldade em aderir às restrições de alimentos e bebidas pode ser fundamental. **Objetivos:** quantificar as percepções dos pacientes em HD sobre as restrições alimentares e de líquidos, reconhecer as razões individuais que facilitam ou complicam sua adesão, bem como sua relação com as características demográficas, nutricionais e clínicas. **Métodos:** estudo transversal multicêntrico realizado em cinco unidades de diálise. Os pacientes em HD (n = 147, 48% do sexo masculino, idade: 51,3 ± 13,6 anos) foram encorajados a pontuar em uma escala de 0 a 10 a sua percepção do grau de dificuldade de aderir ao aconselhamento nutricional para o controle de sódio, líquidos, potássio e fósforo. **Resultados:** o escore de sódio foi 4 (1-7); de líquidos 6 (3-8); de potássio 4 (2-6); e de fosfato 6 (3-8). O precentual de pacientes que percebiam uma maior dificuldade (escore ≥ 6) no controle de líquidos e de fosfato foi maior do que para o sódio e o potássio. Os participantes com elevado ganho de peso interdialitico (%GPID) referiram maior pontuação para líquidos; os com hipercalemia perceberam mais dificuldade para controlar a ingestão de potássio que os demais, bem como os pacientes hiperfosfatêmicos em comparação com os normofosfatêmicos para controlar a ingestão de fósforo. Os participantes com maior dificuldade para controlar a ingestão de sódio também perceberam uma maior dificuldade para controlar o consumo dos demais itens investigados. **Conclusão:** os participantes perceberam maior dificuldade no controle da ingestão de líquidos e de fontes de fosfato do que de sódio e potássio. Maiores escores de percepção foram associados a alguns subgrupos e a pior controle dos parâmetros clínicos. Além disso, os pacientes com maior dificuldade para controlar algum item dietético também referiram ser mais difícil de controlar os outros itens investigados.

Palavras-chave: dieta; hemodiálise; terapia nutricional.

Introduction

Chronic hemodialysis (HD) requires significant patients and their families involvement in an extensive lifestyle change due to a complex and demanding medical regimen.[1,2] Self-care behavior includes adherence to prescribed medications, caring for vascular access, and as importantly, dietary recommendations that include selecting food items low in sodium, potassium and phosphorus, maintaining adequate protein intake, and limiting daily fluid intake.[2] Lack of compliance to these dietary recommendations may lead to accumulation of metabolic by products and excess fluid in the circulatory system, leading to increased morbidity and mortality for renal failure patients.[3] Furthermore, reduces the benefits of routine treatments, exacerbates symptoms, reduces the quality of life of the patient, as well as increasing costs to both the patient and the health system.[4,5]

To chronic HD patients, adherence to dietary regimens is challenging due to the burden of constant choices about food and drink, the adaptation to complex eating patterns, existing cultural practices, and the competing demands of this chronic disease and related illnesses.[6-8]

In fact, lack of compliance to this complex dietary regimen has been observed both by researchers that investigated HD patient´s reports[2,9] or the ones who found a high prevalence of its consequences such as excessive interdialytic weight gain (% IDWG), hyperkalemia and hyperphosphatemia.[10,11]

Although our HD patients have intensive support of specialized renal dietitians to provide an individualized nutritional counseling, in our dialysis clinics prevalence of patients with high % IDWG (> 4,5% of dry weight) and hyperkalemia is around 30%, while of hyperphosphatemia is even higher (around 45%). In previous investigations, we found in a sample of HD patients that almost 58% had a salt intake over recommendation[12] and in a study with only hyperphosphatemic patients, although participants demonstrated a good knowledge about hyperphosphatemia treatment, 61% reported lack of compliance to dietary recommendations regarding adequate phosphate intake.[11]

These and other investigations worldwide have shown that adequate knowledge about any treatment is undoubtedly important to increase chances of adherence to a regimen, but is not enough for all patients, mainly the ones with chronic diseases. Studies have found that adherence to treatment in patients receiving HD is influenced by personal characteristics such as age, gender, HD duration and comorbidity,[1,12,13] factors such as health-related beliefs,[14] cultural features, stress, depression, social support and satisfaction with healthcare personnel; as the perception of control over the illness and treatment.[15-17]

Since determinants of adherence may vary over different populations Clark-Cutaia *et al.*[18] stated that prior to developing targeted interventions, it is necessary to identify characteristics of those most likely to experience difficulty adhering to hemodialysis dietary restrictions.

In this study, we aimed to quantify HD patient's perceptions about dietary and fluid restrictions, their relationship with demographic, nutritional and clinical characteristics and also to acknowledge individual reasons that facilitate or complicate their adherence.

Methods

Participants and recruitment

Participants were recruited from 5 dialysis facilities from the same group situated in 4 different cities in the state of Santa Catarina, southern Brazil. From a total of approximately 400 patients on HD in all units, only patients aged over 18 years old, on HD treatment for at least 6 months, HD prescription 3 times a week, without cognitive impairment and that were able to give informed consent were included. Data was collected beteween January and February 2015. All the dialysis facilities have a renal dietitian that provides nutritional counseling for all patients in order to maintain or achieve an adequate nutritional status as well as important parameters related to dietary habits such as IDWG, serum potassium and phosphorus.

Besides initial nutritional counseling which happens in the first or second week on HD treatment, all patients are visited at least once a month by the renal dietitian in order to check nutritional status (appetite, changes in dry weight), current IDWG and blood tests (mainly serum potassium and phosphorus). Nutritional advice are reviewed and reinforced based on current results and dietary habits reported by patients.

Our goals are to maintain % IDWG, serum potassium and phosphorus when they are adequate, or improve % IDWG if > 4,5% of dry weight, serum potassium if > 5,5 mEq/L and serum phosphorus if > 5,5 mg/dL. During the visit, patients are orally informed and they also receive a small colored card filled with their tests results. Since our population has in general a low literacy, four different colors of cards are used according to their tests results to increase their understanding. A green card is given if serum potassium and phosphorus are adequate. Other cut points were determined and each one corresponds to other card colors (yellow, orange and red). All medical staff is involved and currently reinforces dietary counseling aiming to improve patient´s knowledge and adherence.

Regarding % IDWG, dietary advice focused on improving flavor of preparations with natural herbs and decreasing the cooking salt or salt-based condiments added in food as well as avoid or decrease intake of processed foods high in sodium. Other tips to decrease thirst and fluid intake are also provided, such as, prefer drinking water instead of sugary drinks.

Concerning potassium, patients are informed about the foods containing a significant amount of potassium, and also how much they should consume of that to decrease the risk of hyperkalemia.

About phosphorus intake, renal dietitians investigate usual protein and phosphorus intake and according to individual protein requirement, provide an advice in order to achieve an adequate protein intake based on foods with lower phosphorus to protein ratio as well as avoid or decrease intake of processed foods rich in this mineral. Phosphate binder is also prescribed by medical staff when necessary and the dosage is adjusted according to phosphate intake.

Data collection

Patients were addressed during the hemodialysis session by the renal dietitian and were encouraged to score on a scale of 0 to 10 their perception of the degree of difficulty to adhere the nutritional advice regarding control of sodium, fluid, potassium and phosphorus intake. The higher the score, the greater the perceived difficulty. Patients who reported a score ≥ 6 were considered as having greater difficulty.

Besides scoring their perception, participants were also stimulated to report main reason for choosing the score and the responses were noted.

Participants were also questioned about their schooling, which was assessed in years from the first year of elementary school, residual diuresis and use of antihypertensive drugs. Dry weight and stature were obtained to calculate body mass index (BMI). One month mean of % IDWG and the mean of three months of serum potassium and phosphorus were also obtained from data of medical records.

The study was approved by the Ethics Committee of the participating institution.

Statistical analysis

Variables are reported as the mean and standard deviation or median and interquartile or as percentages when appropriated. For correlation analysis, we used the Pearson or Spearman test according to the distribution of variables. T-test was used to compare groups where variables were normally distributed and the Mann-Whitney test was used if not. IBM SPSS Statistics for Windows version 21 was used to analyze the data. p value < 0.05 was considered significant.

Results

The main characteristics of the participants (n = 147) are presented in Table 1. Gender was almost equally distributed, age varied from 24 to 79 years old and HD vintage median was 4 years. Mean serum phosphate was above adequate levels.

Table 1 Main characteristics of the participants (n = 147)

Male (%)	48
Age (years)	51.3 ± 13.6
Schooling (years)	8 (4-11)
HD vintage (months)	48 (23-75)
Diabetes (%)	24
BMI (kg/m^2)	25.3 ± 4.9
% IDWG*	3.4 ± 1.1
Serum potassium (mEq/L)**	5.2 ± 0.6
Serum phosphorus (mg/dL)**	6.0 ± 1.4

HD: hemodialysis; BMI: body mass index; % IDWG: percentage of interdialytic weight gain. *Month mean **3 months mean.

Median and interquartile perception scores for the four dietary items are shown on Table 2. In the whole population, sodium and potassium scored less than fluids and phosphorus. Furthermore, the percentage of patients who perceived a greater difficulty to control fluids and phosphate intake was higher than 50%, while for sodium and potassium it was around 30%.

Table 2 Patient's perceptions scores for dietary items (n = 147)

Dietary item	Score	Score ≥ 6 (% patients)
Sodium	4 (1-7)	33
Fluids	6 (3-8)	56
Potassium	4 (2-6)	27
Phosphorus	6 (3-8)	52

Concerning the reasons for choosing the scores, some of the responses reported by participants were listed in Table 3.

We compared dietary items scores among some groups and found that higher scores for sodium intake were observed among patients that were on HD less than 4 years [5 (2-7) *versus* 3 (0-6); $p < 0,05$] and in the ones with lower literacy (until 8 years of formal education) compared to participants with higher education [5 (5-7) *versus* 3 (0-5); $p < 0,01$]. Women perceived more difficulty in control potassium intake than men [5 (2-7) *versus* 3 (1-5); $p < 0,01$] as well as participants with diabetes compared to others [5 (2,2-7,0) *versus* 3 (1-5); $p < 0,01$].

Greater difficulty in control fluid consumption was assumed by participants with higher BMI (cut point 23 kg/m^2) [7(5-9) *versus* 5 (2-8); $p<0,05$) as well by younger than 60 years old [7 (4,5-9) *versus* 5 (2,7-8); $p < 0,05$]. The last ones also demonstrated a worse perception in control the intake of phosphate food sources than older participants [6 (3,5-8) *versus* 4 (2-7); $p < 0,01$). We did not find any differences over patients with or without residual diuresis or the ones who take or not any antihypertensive drug.

Significant correlations between variables are demonstrated in Table 4. Regarding potassium and phosphorus, direct correlations were found between patient's perceptions scores and also between their plasma levels. We found a direct correlation between fluids score with % IDWG and with potassium and phosphorus scores with their correspondent serum levels.

The relationship between participants perceptions in controlling intake of dietary items and the clinical consequence was confirmed when perception scores were compared among participants with adequate and excessive levels of the studied variables. Participants

Table 3 Some responses obtained from patients about their reasons to choose scores between 0-5 (lesser difficulty) or 6-10 (greater difficulty)

Sodium 0-5	"I am used to eat with less salt." "It is not difficult, but you really need to want it." "Some foods I can eat with no salt, but in others I need to add it."
Sodium 6-10	"I like salty foods." "I usually have my meals in restaurants." "Food is tasteless without salt."
Fluids 0-5	"I do not feel very thirsty." "I pee a lot, so no need to control." "I use a small cup and it helps me to control."
Fluids 6-10	"I feel very thirsty." "It is more difficult when the weather is hot." "I've always loved water and soup."
Potassium 0-5	"I know what is rich in potassium and what is not." "I do not like fruits and vegetables." "I like fruits, but avoid the ones with more potassium."
Potassium 6-10	"I do not like to cook everything before eating." "I watch what I eat and take care, but it´s difficult because I love raw vegetables." "I feel a great desire to eat more fruits."
Phosphorus 0-5	"It´s not difficult, because I don´t like meat very much." "I´ve eliminated some of the phosphate food sources of my diet." "If I know that it´s not good for me, I don´t eat it."
Phosphorus 6-10	"Because everything has phosphate." "I like phosphate sources a lot." "It´s difficult to control meat and cheese intake. I was addicted to cheese. I use to buy small pieces to eat less."

Table 4 Correlations between studied variables (n = 147)

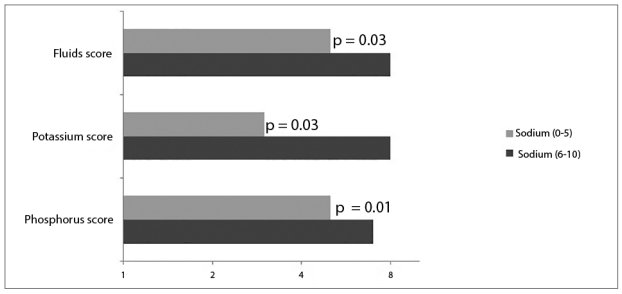
		R	*p*
Fluids score	% IDWG	0.35	< 0.001
Potassium score	Potassemia	0.22	< 0.01
Phosphorus score	Phosphatemia	0.33	< 0.001
Sodium score	Potassium score	0.24	< 0.05
Fluids score	Phosphorus score	0.37	< 0.01
Potassium score	Phosphorus score	0.41	0.001
Potassemia	Phosphatemia	0.43	< 0.001

HD: hemodialysis; % IDWG: percentage of interdialytic weight gain.

with excessive % IDWG (> 4,5%) had a higher score for fluids [8,5 (5,7-10) *versus* 6 (3-8); $p < 0,01$]; the ones with inadequate potassemia perceived more difficult to control potassium intake than others [5 (2-8 *versus* 3(1,25-5); $p < 0,05$] as well as hyperphosphatemic patients compared to normophosphatemic [7 (4-8) *versus* 4 (2-6); $p < 0,001$].

Fluids, potassium and phosphorus scores were compared between participants who perceived a greater (score 6-10) or lesser (score 0-5) difficulty to control sodium intake (Figure 1). It was observed that the ones with a greater difficulty to control sodium intake also perceived a greater difficulty to control fluids, potassium and phosphate intake, since the scores were higher compared to the ones with less difficulty.

Figure 1. Score comparision of dietary items between participants with lower (0-5) and greater difficulty (6-10) to control sodium intake.



Discussion

The study presented here found that HD patients perceived more difficulty in controlling dietary intake of fluids and phosphate than sodium and potassium; that worse perception was associated with poorer control of hydration status and serum markers and that participants with greater difficulty to control sodium intake also perceived a greater difficulty to control fluids, potassium and phosphate intake.

In general, our patients answered to be easier to control sodium and potassium than fluids and phosphate intake and some specific characteristics related to a greater difficulty were found.

Control sodium intake was easier to participants on HD for a longer period of time. This may occur because it is well established that preferred level of salt in food is dependent on the level of salt consumed and that this preferred level can be lowered after a reduction in sodium intake.[19] In fact, many patients reported that it was not so difficult to control because they were used to consume less sodium and did not miss the salty flavor anymore. Also, participants with lower literacy reported a greater difficulty to control sodium intake. This is in accordance with our previous investigation which found that the only variable correlated to total salt intake was schooling ($r = -0,29$; $p < 0,01$)[12] and also with national[20] and international surveys.[21]

Most participants also did not find hard to control potassium intake and we believe that it is consequence of two main reasons. First, according to the most important national survey, Brazilians consume around 2.500 mg of potassium daily,[20] and it is not different from the recommended intake for HD patients (1950 to 2730 mg/day).[22] Indeed some patients reported that they did not have the habit to consume lots of fruits and vegetables before the disease's diagnosis. Secondly, we provide a comprehensive dietary orientation in which no food is prohibited (except star fruit). It contains proper portion size intake according to potassium content of most common fruits and vegetables as well as cooking techniques and other tips to decrease its quantity.

Concerning fluids intake control, the perceived hardness was important, since 56% attributed a score ≥ 6 and almost 20% indicated the highest score. As expected, many participants justified their difficulty due to thirst. Indeed, as mentioned by Fitzsimons, "the sensation of thirst is basic to our very existence. Its gratification is universally held to be one of the pleasures of life; it cannot be ignored, and if water be lacking, the sensation comes to dominate our thoughts and behavior".[23]

So, fighting against this vital instinct might be really arduous and stressful for HD patients. In our sample, younger participants and the ones with higher BMI > 23 kg/m^2 perceived even more difficult to control fluid intake. These results are in accordance with a

recent publication that assessed thirst and xerostomia by validated questionnaires in HD patients. It was found that Dialysis Thirst Inventory score was directly correlated with BMI and inversely with age.[24]

On age, it is known there is a reduction of the thirst sensation with aging, due to cerebral dysfunction and decreased osmoreceptor sensitivity.[25] Also, it has been demonstrated that younger people consume more sodium, as well as the ones with higher BMI.[26,27] Sodium intake control is necessary to control fluid intake, since it is the main trigger of the osmometric thirst, which happens when the increase in extracellular osmolarity stimulates the hypothalamic osmoreceptors,[28] triggering the sensation of thirst and the resulting fluid intake. It is estimated that in anuric patients for each 8 g of sodium chloride (salt) ingested, they would need 1 liter of fluids to keep the concentration of serum sodium at normal levels.[22] Surprisingly, diuresis status did not influenced participants perceptions over fluid intake.

Controlling phosphate intake was also challenging for most patients. Although hyperphosphatemia is multifactorial, since conventional dialysis is insufficient to maintain a negative balance of phosphorus in most dialysis patients[29] and is also influenced by hormonal dysfunction, it is often related to dietary intake of this mineral. Meat products, dairy, eggs and processed foods are the main sources of dietary phosphate.

As described in methods we orient our patients to achieve an adequate protein intake based on foods with lower phosphorus to protein ratio as well as avoid or decrease intake of processed foods. However, as phosphate is present in a huge variety of common and "tasty foods", many patients justified the difficulty in controlling its intake because they simply like these foods. In fact, taste - obtained by the conjunct of sensorial characteristics and responsible by the pleasure of eating - is one of the main determinants of individual food choices.[30] We state that the stronger difficulty perceived by our younger participants can be explained by preference of this group for industrialized foods and drinks due to their flavor and convenience, extensively shown in literature in different populations.[20,31,32]

The influence of individual difficulty in controlling dietary and fluids intake on their clinical consequences was confirmed by the direct correlations between them and also by the higher perception scores found in participants with poorer control of % IDWG, serum potassium and phosphorus. In our opinion, these results show that our patients are well informed about diet and clinical results related to them and also that the perceived difficulty in controlling intake is related to lack of adherence to the dietary counseling.

Direct correlations between dietary items perception scores and the finding that participants with a greater difficulty to control sodium intake also perceived a greater difficulty to control fluids, potassium and phosphate intake suggests that when present, the distress over dietary restrictions is not specific of one aspect, but comprises the overall diet itself.

We believe that this behavior is due to the fact that dietary intake, which is determined by individual food choices is a complex process that involves biological, social, cultural, psychological factors and their interaction. As dietitians, our approach is mainly focused on food as a source of nutrients, as a rational decision to satisfy corporal nutrients requirement and we usually ignore the other components.[33] Indeed, food choices involve rational decisions based on external information, but is also automatic, usual and subconscious.[34,35] Food is at the same time a source of energy, pleasure and reward as well as a social bond[36] and so, choices reflect all these characteristics.[33]

Taking these points in consideration and the literature evidence that "know what to eat" is extremely relevant and brings good results in many cases, it is not enough to decrease all patient's distress about dietary restrictions and increase their adherence, different approaches to identify determinants of nonadherence have been performed. Some examples are: self-report questionnaires that provide a practical way of screening HD patients for nonadherence behavior; psychological determinants of adherence such as depression, illness and treatment perceptions, self-efficacy (individual's perceived ability to perform a certain behavior), and social support.

Regarding different approaches to improve compliance, psychological interventions have been shown to improve HD patient´s adherence.[18]

Christensen *et al*. developed and tested a behavior self-regulation intervention to improve fluid adherence in HD patients. At 8 weeks of follow-up, after a weekly one-hour group treatment sessions to facilitate self-monitoring, self-evaluation, and self-reinforcement of fluid behaviors, the intervention group had significantly lower IDWG compared with the control group.[36]

A randomized controlled trial of patients on HD tested an empowerment intervention which patients in the experimental group completed a six-week empowerment program that consisted of four individual and two group counseling sessions. Besides other benefits, improvements were seen in blood pressure and intradialytic weight gain.[37]

A systematic review of interventions designed to improve adherence in HD patients (n = 8 studies) found that six of the studies identified a significant improvement in adherence following an intervention including a cognitive component.[38]

Although promising, according to Clark *et al*, large-scale, prospective studies are needed to investigate the association between psychological factors and nonadherence. This may enable the development of psychological interventions to optimize adherence in end-stage renal disease, improve clinical outcomes and quality of life.[18]

Our study has some limitations. Our sample was relatively small, but representative of our HD population. Our results may not be seen in other populations, since dietary habits as well as perceptions may vary over different cultures. As strength, we used an innovative and simple method able to quantify patient´s perceptions over dietary restrictions.

In summary, the methodology applied enabled us to measure patient´s perceptions over main dietary restrictions as well as understanding individual reasons that facilitate or complicate their adherence. Furthermore, it was possible to identify groups with greater specific difficulties. We also found that higher perceptions scores were associated with worse control of clinical parameters and that patients with a greater difficulty to control some dietary item also found harder to control the other ones.

We believe that besides keeping continuous education on adequate dietary habits, it is necessary to implement behavioral interventions in order to decrease HD patients distress over diet and improve adherence and the control of clinical parameter that implicate on their quality of life.

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