

Pilot project of implementation of a keto-kitchen for the treatment of refractory epilepsy

Projeto piloto de implantação de uma cozinha cetogênica para tratamento de epilepsia refratária

Proyecto piloto para implementar una cocina cetogénica para el tratamiento de la epilepsia refractaria

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REVISA

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RESUMO

Objetivo: Este estudo descreve a criação da primeira cozinha cetogênica para ensino de dieta cetogênica em um centro de referência no Brasil, com o objetivo de desenvolver receitas cetogênicas e realizar oficinas culinárias com cuidadores. **Método:** Nesse estudo prospectivo, 26 receitas foram testadas e avaliadas por painel sensorial. Dezoito receitas foram selecionadas para serem preparadas em oficinas de culinária com pais ou responsáveis legais de crianças com epilepsia refratária recebendo dieta cetogênica ambulatorialmente. Todas as receitas foram selecionadas, calculadas e aprovadas por nutricionistas. **Resultados:** Oito pais ou responsáveis participaram de quatro oficinas culinárias. As atividades foram extremamente satisfatórias: os participantes puderam tirar suas dúvidas, aprender, praticar receitas e desenvolver novas habilidades. Em geral, todos os participantes gostaram das receitas preparadas e elogiaram o workshop de culinária. **Conclusão:** A cozinha cetogênica de ensino possibilitou o desenvolvimento de receitas cetogênicas adaptadas aos hábitos alimentares brasileiros. Fornecer refeições alternativas para as crianças é essencial para melhorar a adesão à dieta cetogênica, pois elas contribuem para expandir o repertório alimentar desses pacientes. Estudos futuros com alta qualidade metodológica devem testar a eficácia da cozinha cetogênica no aumento da adesão à dieta cetogênica a longo prazo.

Descritores: Dieta cetogênica; Epilepsia; Educação alimentar e nutricional.

ABSTRACT

Objective: This study describes the creation of the first ketogenic diet-teaching kitchen at a ketogenic reference center in Brazil aimed at developing ketogenic recipes and holding keto-culinary workshops with caregivers. **Method:** In this prospective study, 26 recipes were tested and assessed by sensory panel testing. Eighteen recipes were selected to be prepared in culinary workshops with parents or legal guardians of children with refractory epilepsy receiving the ketogenic diet as outpatients. All recipes were selected, calculated, and approved by registered dietitians. **Results:** Eight parents or legal guardians participated in four culinary workshops. The activities were extremely satisfactory: participants were able to clear out their doubts, learn, practice recipes, and develop new skills. In general, all participants enjoyed the prepared recipes and praised the culinary workshop. **Conclusion:** The ketogenic teaching kitchen enabled the development of ketogenic recipes adapted to Brazilian eating habits. Providing alternative meals to children is essential for enhancing compliance with the ketogenic diet because they contribute to expand the dietary repertoire of these patients. Future studies with high methodological quality should test the efficacy of the ketogenic kitchen in increasing compliance with the ketogenic diet in the long term.

Descriptors: Dieta cetogênica; Epilepsia; Educación alimentaria y nutricional.

RESUMEN

Objetivo: Este estudio describe la creación de la primera cocina cetogénica para enseñar dieta cetogénica en un centro de referencia en Brasil, con el objetivo de desarrollar recetas cetogênicas y realizar talleres culinarios con los cuidadores. **Método:** En este estudio prospectivo, un panel sensorial probó y evaluó 26 recetas. Se seleccionaron dieciocho recetas para ser elaboradas en talleres de cocina con padres o tutores legales de niños con epilepsia refractaria que reciben una dieta cetogênica ambulatoria. Todas las recetas fueron seleccionadas, calculadas y aprobadas por nutricionistas. **Resultados:** Ocho padres o tutores participaron en cuatro talleres culinarios. Las actividades fueron sumamente satisfactorias: los participantes pudieron despejar sus dudas, aprender, practicar recetas y desarrollar nuevas habilidades. En general, a todos los participantes les gustaron las recetas elaboradas y elogiaron el taller de cocina. **Conclusión:** La cocina de enseñanza cetogênica permitió el desarrollo de recetas cetogênicas adaptadas a los hábitos alimentarios brasileños. Proporcionar comidas alternativas a los niños es fundamental para mejorar la adherencia a la dieta cetogênica, ya que contribuyen a ampliar el repertorio dietético de estos pacientes. Los estudios futuros con alta calidad metodológica deberían probar la efectividad de la cocina cetogênica para aumentar la adherencia a la dieta cetogênica a largo plazo.

Descritores: Dieta cetogênica; Epilepsia; Educación alimentaria y nutricional.

ORIGINAL

Introduction

The ketogenic diet (KD) is a high-fat, adequate-protein, low-carbohydrate diet that has been used in the treatment of patients with refractory epilepsy, especially children.¹⁻³ The objective of KD is to reduce the frequency of epileptic seizures or control it by inducing ketosis, which is induced by a high intake of fat.^{1,4,5} The first randomized controlled trial of the efficacy of KD was conducted in 2008 and clearly showed the benefits of the KD compared to no other changes to treatment. After three months of receiving KD, 38% of patients achieved greater than 50% reduction in their epileptic seizures and 7% had greater than 90% seizure reduction. Responder rates were similar to those seen in randomized controlled trials of newer antiepileptic drugs versus placebo.⁶ For some epilepsy syndromes and conditions KD has been consistently reported as more beneficial (>70%) than the average 50% KD response (defined as >50% seizure reduction). Anti-epileptic medications may be reduced after 1 month if KD is successful. KD has also been used in the treatment of metabolic disorders such as glucose transporter type 1 (GLUT-1) deficiency and pyruvate dehydrogenase deficiency, which require that the patient to follow the diet throughout his or her entire life.^{2,4,6-11}

The classic KD is generally performed on a 4:1 ratio (4 parts of fat for every 1 part of carbohydrate + protein), with as much as 90% of the calories coming from fats, or a 3:1 ratio (3 parts of fat for 1 part of carbohydrate + protein), with roughly 87% of calories coming from fats.^{1,2,12} Many patients do not adhere to treatment because of the diet's low palatability and severe carbohydrate restrictions, despite its positive effects in epileptic seizure control.⁴ To date, no studies that show alternatives or interventions to improve adherence to KD have been conducted in Brazil.

In children that achieve significant seizure control, KD can be continued for 2 to 3 years or more depending on the clinical response.¹³ Thus, it is important to propose strategies that increase treatment compliance, avoid diet monotony, and improve the quality of life of patients and their families. A ketogenic kitchen is an important tool to provide practical education for families with children in KD, and its goal is to improve the learning experience and make these families more confident in preparing meals.¹⁴ In addition, it allows dietitians to test and improve the sensory aspects of low-carbohydrate and high-fat recipes.

We aimed to describe the creation of the first ketogenic diet-teaching kitchen at a ketogenic reference center in Brazil aimed at developing ketogenic recipes and holding keto-culinary workshops with caregivers.

Method

This prospective study was conducted at the KD outpatient clinic of the Children and Adolescent's Institute at the Clinics Hospital, University of São Paulo Medical School (HCFMUSP), São Paulo, Brazil. The project was approved by the HCFMUSP Research Ethics Committee under number 3,735,637. When invited to participate in the culinary workshops, the parents or legal guardians of children with KD signed informed consent forms.

In the Children and Adolescent's Institute at the Clinics Hospital we have already one experimental kitchen to support teaching culinary classes for patients and help to develop recipes for some restricted diets (such as allergies,

kidneys diseases etc). The ketogenic diet team adapted the use of this place to improve Care of ketogenic diet patients. This is a pilot project to creation of a “ketogenic kitchen” first initiative in Brazil to improve compliance to KD.

Based on the demand at the outpatient nutrition clinic, recipes currently in use by national and international KD groups were adapted and subsequently tested in four phases to assess their organoleptic characteristics. Twenty-six recipes were chosen and recalculated to meet a 4:1 ratio of fat to carbohydrate and protein.

Of the 26 recipes selected for testing, 10 were taken from the “Collection of Classical Recipes – Matthew’s Friends” cooking book by Maureen Benn¹⁵ and adapted for ingredients readily found in Brazil. Because of these changes, macronutrient quantities were recalculated based on composition tables developed for national foods.¹⁶ Sixteen recipes based on traditional Brazilian dishes were adapted to the KD and had a few changes to meet the nutritional needs of a 4:1 KD.

The adapted 4:1 recipes were tested and assessed by sensory panel testing (Figure 1). Each recipe was evaluated by two to six registered dietitians. Some recipes needed adapting because their sensory properties were not satisfactory, and further testing was conducted on the modified recipes by the sensory panel. Each recipe was prepared twice on average, totaling 12 tests in the ketogenic kitchen.

Figure 1- Form used for the sensory panel test. São Paulo, 2020.

Evaluation form

Name: _____ Date: _____
_ / _ / _

Recipe: _____

Please rate the recipe for each of the attributes: **APPEARANCE, AROMA, FLAVOR, TEXTURE AND OVERALL GRADE**. Rate it from 1 to 9, saying how much you liked it or disliked, according to the scale.

<p>SCALE:</p> <p>1 - I really disliked it</p> <p>2 - I disliked it a lot</p> <p>3 - I disliked it moderately</p> <p>4 - I slightly disliked it</p> <p>5 - I neither liked nor disliked it</p> <p>6 - I liked it slightly</p> <p>7 - I liked it moderately</p> <p>8 - I liked it a lot; and</p> <p>9 - I liked it very much</p>	<p>ATTRIBUTES:</p> <p>Appearance: _____</p> <p>Aroma: _____</p> <p>Flavor: _____</p> <p>Texture: _____</p> <p>Overall grade: _____</p>
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Comments: _____

In addition to routine outpatient care, cooking workshops were hosted for caregivers, without patients to ensure attention in class. In each workshop, caregivers prepared the recipes to achieve the exact number of calories and ratio of the patient’s diet as if they were cooking at home. To accomplish this, participants had a hands-on cooking class: they did everything themselves, from weighing the ingredients and cooking to the final presentation of the recipes. Before the workshops, the ingredients were pre-prepared, including cutting

perishable foods and separating the ingredients, to facilitate the process and reduce the workshop time.

After preparing and tasting the recipes, a sub-sample of the participants was invited to complete a socioeconomic questionnaire and the same sensory analysis form completed by the registered dietitians, and describe their experience with the ketogenic kitchen.

Results

The present study systematized the use of a space within the hospital to promote cooking classes for caregivers of KD patients. This space was called ketogenic kitchen and made possible an innovation in the treatment of ketogenic diet in Brazil.

In the KD, heavy cream is commonly used as a fat source because of its higher concentration of fat compared to other commercial forms. However, heavy cream is a high-cost food that is difficult for some caregivers to access. Thus, an adaptation of the canned milk cream for equivalence in terms of fat content was also created.

The 18 most readily accessible recipes approved by the nutrition team at the KD outpatient clinic with the best sensory properties were compiled into four booklets to be presented to the patients' guardians in outpatient consultations and distributed at four culinary workshops throughout 2019 (Table 1).

Table 1- List of recipes and adapted ingredients developed in the ketogenic kitchen. São Paulo, 2020.

Recipes	Sweet recipes	Adapted ingredients
Cheese biscuit	Coconut candy	
Zucchini spaghetti	Ketogenic banana cake	
Beef stroganoff	Ketogenic cocoa cake	
Salted farofa	Sweet farofa	Adapted sour cream (35% fat)
Ketogenic mayonnaise	Eggnog ("gemada")	
Colorful omelet	Strawberry milk shake	
Ketogenic bread	Lemon mousse	
Vegetable tart	Avocado ice cream	
Tomato soup		

Over the four cooking workshops, eight patients' guardians (from seven patients) participated in the KD kitchen protocol. On average, three persons participated in each class, with some caregivers participating in more than one workshop and others attending only one meeting.

Results of the questionnaire revealed that most caregivers who participated in the cooking workshops were mothers (others were father and grandmother and/or people responsible for taking care of the patients) and had completed high school education. The average number of residents in the household was two persons. Most caregivers (67%) preferentially used vegetable fat sources to prepare the ketogenic diet.

In the sub-sample of preparations that were evaluated by caregivers, most recipes in (except for Sweet farofa) achieved positive ratings sensory properties as shown in Table 2.

Table 2- Sensory analysis of ketogenic recipes applied to a sub-sample of the caregivers in the cooking workshops. São Paulo, 2020.

Reviewer (n)	Recipe	Sensory property (mean ± SD)				Overall grade
		Appearance	Aroma	Flavor	Texture	
3	Ketogenic banana cake	8.3 (0.6)	8.7 (0.6)	9.0 (0.0)	8.7 (0.6)	9.0 (0.0)
3	Ketogenic cocoa cake	8.3 (1.2)	8.0 (0.0)	8.0 (1.0)	8.7 (0.6)	8.3 (0.6)
3	Cheese biscuit	5.7 (1.5)	8.3 (0.6)	8.3 (1.2)	7.3 (2.1)	8.3 (1.2)
3	Zucchini spaghetti	9.0 (0.0)	9.0 (0.0)	9.0 (0.0)	9.0 (0.0)	9.0 (0.0)
3	Sweet farofa	2.3 (1.5)	4.0 (1.7)	2.3 (1.5)	3.7 (3.8)	3.0 (1.7)
3	Salted flour	7.7 (1.5)	6.7 (1.2)	8.0 (1.7)	8.0 (1.7)	7.7 (1.5)
3	Ketogenic bread	7.0 (3.5)	5.7 (3.1)	6.0 (3.0)	6.7 (3.2)	6.3 (3.1)
3	Tomato soup	8.0 (1.7)	8.7 (0.6)	8.0 (1.7)	9.0 (0.0)	8.3 (1.2)
3	Avocado ice cream	8.3 (0.6)	6.3 (1.5)	7.3 (0.6)	8.0 (0.0)	8.0 (1.7)

Caption- 1: I really disliked it; 2: I disliked it a lot; 3: I disliked it moderately; 4: I slightly disliked it; 5: I neither liked nor disliked it; 6: I liked it slightly; 7: I liked it moderately; 8: I liked it a lot; and 9: I liked it very much.

Servings of different sizes (150, 200, 250, 300, 350, 400, 450, and 500 kcal), all at a 4:1 ratio, were calculated for each recipe. The recipes were made available to the other outpatient KD patients on a 4:1 diet as alternatives to the regular daily meals, and individualized to their caloric needs. Figure 2 shows some of the recipes created, calculated to offer 250 kcal per serving.

Figure 2- Examples of recipes created in the ketogenic kitchen. São Paulo, 2020.

Salted flour


Ingredients:

- 1g garlic
- 5g tomato
- 16g bacon
- 17g mayonnaise
- 8g flaxseed flour
- Salt to taste

Method:

- Cut the garlic, tomatoes and bacon into cubes.
- Fry the bacon for 2-3 minutes, until golden.
- Add tomatoes and garlic and cook for 5 minutes.
- Add mayonnaise and flaxseed flour and stir for 2 minutes.
- Place in a preheated oven at 200°C for about 20 minutes.

Yield: 1 serving (250kcal)



Tomato soup

Ingredients of soup:

- 42g tomato
- 13g onion
- 1ml vegetable oil
- 10g margarine with 80% fat
- Filtered water
- 17g fresh milk cream
- Natural seasonings to taste (Ex: basil, oregano, black pepper etc)

Accompaniment ingredients:

- 9g mayonnaise
- 9g cheddar cheese cut into sticks

Method:

- Remove the peel of the tomato, cut into very small cubes and relish.
- Sauté the onion with the oil and margarine.
- Add the tomatoes and seasonings you want.
- Put a little water to make it more liquid and the tomatoes cook.
- When it is cooked, turn off the stove and add the fresh cream.
- Serve with mayonnaise and cheddar cheese.

Yield: 1 serving (250kcal)

Zucchini spaghetti


Ingredients:

- 39g zucchini
- 6g onion
- 1g garlic
- 9g bacon
- 8ml vegetable oil
- 24g tomato
- 30g fresh milk cream
- 12g champignon
- Salt to taste

Method:

- Cut the zucchini into strips.
- Cut the onion, garlic, tomatoes, champignon and bacon into cubes.
- Fry the onion and the bacon in the oil for 2-3 minutes, until golden.
- Add tomatoes, garlic and champignon and cook for 5 minutes.
- Add zucchini and sour cream, season with salt and cook for 2-3 minutes.
- Serve while still hot

Yield: 1 serving (250kcal)



Source:

Discussion

This study describes the creation of the first ketogenic kitchen in Brazil, where ketogenic recipes were prepared and culinary workshops were held for the legal guardians of children receiving the KD. The ketogenic kitchen is an extremely important achievement that can help increase adherence to the KD by patients and their guardians. The activities were satisfactory: participants were able to clear out their doubts, learn, practice recipes, and develop new skills. In general, all participants enjoyed the prepared recipes and praised the culinary workshop.

KD has been shown to be effective in the treatment of epilepsy refractory to drug therapy.¹⁷⁻¹⁸ Freitas *et al.* [17] compiled data from 54 pediatric patients with drug-resistant epilepsy treated at the Children and Adolescent's Institute of the University of São Paulo who were initiated on a 4:1 KD protocol. After 24 months of receiving the KD, 62.1% of patients achieved > 75% seizure reduction. At Children's Hospital of Pittsburgh¹⁸, 71% of patients (n = 48) had ≥ 50% reduction in seizure episodes 45 days after they were started on a ketogenic diet. Other studies showed results beyond decrease of seizures: quality of life, interpersonal/social, psychological/emotional, cognition, behavior.¹⁹⁻²⁰

Despite its promising results, long-term compliance with KD remains a major challenge because of its dietary restrictions.²¹⁻²³ A meta-analysis of 11 studies on KD in adults showed that low patient compliance with a KD (~45%) was caused mainly by an association of psychosocial factors with the restrictive nature of the diet, in addition to intolerability caused by its side effects.²⁴ A randomized clinical trial conducted at the Johns Hopkins Adult Epilepsy Diet Center²⁵ with adults using the modified Atkins diet (MAD), a variant of the ketogenic diet, found that supplementing MAD with a commercially available ketogenic formula increased patient compliance, demonstrating the importance of providing more practical alternatives to the KD for encouraging compliance.

A recent study conducted at Children's Hospital of Philadelphia¹⁴ showed that a ketogenic teaching kitchen in the hospital has greatly improved the dietary treatment by better preparing families and making them more confident to implement the KD. In addition, the continuous development of new recipes has contributed to expanding the patients' taste preferences.

There are some limitations in the current study. First of all, the lack of control group to compare the results of Ketogenic Kitchen. Another big issue was the small sample size. Few caregivers attended the workshops because they were unable to leave patients in other people's care to participate in the classes. Moreover, the culinary workshops took place on dates other than appointment dates, making it difficult for caregivers to go to the hospital.

Efforts will be made to incorporate the keto kitchen workshops into the dietary treatment program at the Children and Adolescent's Institute, with routine cooking workshops offered as part of the outpatient treatment. Further studies are required to evaluate the efficacy of this strategy for encouraging compliance with the ketogenic diet in children with refractory epilepsy.

Conclusion

The ketogenic teaching kitchen enabled the development of ketogenic recipes adapted to Brazilian eating habits. Providing alternative meals to children is an essential strategy for enhancing compliance with the KD because they contribute to expand the dietary repertoire of these patients. Moreover, all recipes were carefully selected, calculated, and approved by registered dietitians, which guarantees the safety of their use by patients on a 4:1 KD. Future studies with high methodological quality should test the efficacy of the ketogenic kitchen in increasing compliance with the KD in the long term.

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