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Molecular Genetics and Metabolism Reports



## MGM Reports

journal homepage: www.elsevier.com/locate/ymgmr

# The influence of parental food preference and neophobia on children with phenylketonuria (PKU)



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ARTICLE INFO	A B S T R A C T		
<i>Keywords:</i> Metabolic disorders Phenylketonuria (PKU) Neophobia Taste preferences Food frequency questionnaire L-amino acid supplements	<ul> <li>Background: In a previous case-control study, we demonstrated that children with PKU and non-PKU controls preferred sweet foods. Additionally, children with PKU exhibited food neophobia, with no preference for bitter tasting foods associated with the taste of phenylalanine (Phe)-free L-amino acid supplements. Objective: In an observational extension study, we evaluated the influence of parental food choice and neophobia on their children's taste preferences and food neophobia.</li> <li>Methods: Male and female parents/caregivers of 35 children with PKU and 35 control parents, completed a neophobia and food frequency questionnaire for comparison using the same questionnaires that they completed for their children.</li> <li>Results: Both groups of children (PKU and non PKU control) were rated as more food neophobic and exhibited more neophobic behaviour than parents, although children with PKU more so than non-PKU controls (PKU food neophobia p &lt; 0.0001vs control 0.001; PKU general neophobia p = 0.003 vs control p = 0.04). Both groups of children ate significantly more sweets, sweetened drinks and potato fries than their parents but differences were greater for children with PKU who also consumed more high carbohydrate (low protein) staple foods such as bread and pasta, and more sweet snacks such as biscuits than their parents. Non-PKU control children's food choices were closer to their parent's choices.</li> <li>Conclusions: In PKU, parental food choices and their food neophobia have limited influence on their children's parents parents is not previous the parent's choices.</li> </ul>		
	eating habits. Food neophobia in children with PKU may be associated with fear of eating unfamiliar foods potentially containing a source of protein or aspartame. Their preference for sweet foods may be influenced by limited food choices and habitual consumption of artificially sweetened L-amino acid supplements.		

#### 1. Introduction

In phenylketonuria (PKU), an essential component of management is a low phenylalanine (Phe) diet, and in newborn screened infants is usually commenced within the first 2 weeks of life. Dietary management involves a severe restriction of high protein foods such as meat, fish, eggs, cheese, nuts, seeds and pulses; in addition to supplementation with bitter-tasting Phe-free L-amino acids. Due to severe restriction of high protein foods, the diet by necessity is high in carbohydrate, particularly plant and cereal starches to meet energy requirements. In addition, the artificial sweetener aspartame, that contains phenylalanine, must be avoided thereby limiting intake of some sugar-free products. It is well established that low Phe diets are high in carbohydrate (59–67% of energy) but lower in fat (23–26%) [1–5] than the general populations diet (50–52% carbohydrate and 33% fat) [6]. Eating behaviours evolve in the early years of development, and in PKU, a high carbohydrate diet may influence taste preferences and eating behaviour, potentially influencing the development of obesity in later life [1,7–9]. Parents help mould children's early experiences with food, providing both the genes and the environment for children [10]. It is important to understand the influence of parents on food preferences in PKU.

Although children with PKU might be expected to have a preference for bitter tasting foods associated with frequent exposure to bitter tasting Phe-free L-amino acid supplements from early infancy, a recent study in children with PKU aged 4–13 years [11], concluded that food neophobia (avoidance of unfamiliar foods) played a more significant role in food refusal than taste preferences. Children with and without PKU were given 10-blinded puree foods to taste and rank in order of preference; parents also completed questionnaires about their children's

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http://dx.doi.org/10.1016/j.ymgmr.2017.10.007

Received 20 September 2017; Received in revised form 23 October 2017; Accepted 23 October 2017

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neophobia. Both groups demonstrated a strong preference for sweet foods, although children with PKU did show a stronger preference for savoury foods (i.e. vegetables) than control children. Fruits and vegetables were consumed in similar quantities in both groups of children.

Studies have identified that food neophobia (avoidance of unfamiliar food) in children is associated with less healthy food choices, [12] reduced variety [13] and fewer new foods being served in the family home thereby influencing everyday food choices [14,15]. Neophobia and food choice particularly in mothers, has been shown to influence the development of food neophobia in children [15–20]. In non-PKU studies, it is observed that food neophobia is familial i.e. children whose caregivers or siblings are food neophobic, are more likely to exhibit food neophobia [17,18,20,21]. The impact of parental food choice and general neophobia (fear of anything new or unfamiliar) is unreported in PKU.

The aim of this study was to evaluate the influence of parental food choice on food preferences and neophobia in children with PKU and control children.

#### 2. Methods

#### 2.1. Subjects

Male and female parents/caregivers of thirty-five children with PKU aged 4–13 years, and thirty-five age and gender matched control children previously studied and described [11] were recruited. PKU children were all following a low phenylalanine diet providing  $\leq 10$  g/day of natural protein allocated from 50 mg phenylalanine exchanges (equivalent to 1 g natural protein) from diagnosis (< 14 days of life).

This study was conducted according to the guidelines laid down in the Declaration of Helsinki and the local research ethics committee gave a favourable opinion. Written informed consent was obtained from all parents/caregivers.

#### 2.2. Study design

This was a single-centre, observational, prospective, follow-on, casecontrol study. Male and female parents/caregivers from PKU and control groups completed a food and general neophobia questionnaire using a 7-item scale (ranging from "always" to "never"). This was modified from an existing questionnaire [22] and was the same questionnaire used in the previous study for the children [11]. This included 9 questions specifically related to food and 5 questions on general neophobia. A lower score indicated more neophobia. Parents/caregivers from the PKU and control groups also completed a food frequency questionnaire to assess the number of times 60 commonly eaten foods from all the major food groups (milk and dairy products; fruit and vegetables; cereals, pasta and bread; meat and meat alternatives; ready meals; snack foods; fats and oils; and drinks) were consumed each day/ week.

#### 2.3. Statistical methods for data analysis

Neophobia and food frequency were compared between parent (male and female) and child. Descriptive statistics were used for quantitative outcome measures and more detailed analysis of all parameters was assessed using Kruskal Wallis and Mann Whitney nonparametric tests.

#### 3. Results

#### 3.1. Subjects (Table 1)

The control parents of one child were lost to follow-up and only 31 of 35 fathers were available in both groups. Therefore, 35 mothers and 31 fathers of children with PKU and 34 mothers and 31 control fathers

#### Table 1

Subject demographics – parental age, ethnicity and highest educational level achieved.

	PKU		Control	
	Mother n = 35	Father n = 31	Mother n = 34	Father $n = 31$
Median age range (years)	36–40	41–45	41–45	41–45
Ethnicity	80% white 9% Asian 11% Mixed/ other	84% white 6% Asian 10% Mixed/ other	85% white 9% Asian 6% Mixed/ other	94% white 6% Asian 0% Mixed/ other
Highest educational level	% (n)	% (n)	% (n)	% (n)
None	14% (5)	10% (3)	6% (2)	3% (1)
GCSE	46% (16)	26% (8)	9% (3)	10% (3)
A-level	9% (3)	13% (4)	3% (1)	6% (2)
NVQ	3% (1)	16% (5)	21% (7)	0
Diploma	17% (6)	26% (8)	6% (2)	19% (6)
Degree	9% (3)	6% (2)	6% (2)	35% (11)
Post Grad	3% (1)	3% (1)	21% (7)	0
Masters	0	0	18% (6)	13% (4)
PhD	0	0	9% (3)	13% (4)
Unknown	0	0	3% (1)	0

were studied. Median 'age range' for mothers of children with PKU was 36–40 years, and for fathers of children with PKU and both control parents median age was 41–45 years. Eighty two percent of parents of children with PKU and 89% of parents of control children were white Caucasian, 8% in both groups were of Asian origin and the remainder were of other descent. Parents in the control group generally achieved a higher level of education (p < 0.0001).

#### 3.2. Neophobia

#### 3.2.1. Food neophobia (Fig. 1)

When total scores were calculated, children with PKU were significantly more food neophobic than both their mother (p = 0.004) and father (p < 0.0001). Control children were also more food neophobic than their parents (mother p < 0.0001; father p = 0.0003) but overall, less significantly than children with PKU. Children with PKU were more food neophobic than control children (p = 0.0001). There was no difference between mothers and fathers of children with PKU or between control mothers and fathers, but the parents of children with PKU were more food neophobic than control parents (mothers)

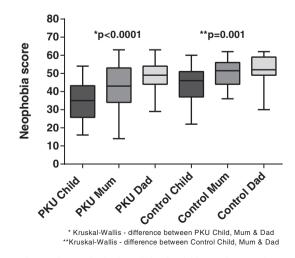


Fig. 1. Median total scores for food neophobia for children with PKU and Control children and their parents (lower score = more neophobic).

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