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Evaluation of Parents' Knowledge about Nutritional Management of Children with Phenylketonuria

Mustafa S. Abdulnabi*, MScN; Qahtan Q. Mohammed, PhD**

*** Baghdad Health Directorate**

**** University of Baghdad, College of Nursing, Baghdad, Iraq.**

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ABSTRACT

Objective(s): to evaluate parents' knowledge about nutritional management of children with phenylketonuria and to find out the differences between parents' knowledge about nutritional management and their demographic variables of parents such as (parental age and socioeconomic status).

Methodology: A non-experimental design; was conducted on parents of phenylketonuria child, from the period 3 June to 5 October 2022. A Non-probability sample of 35 PKU children and their parents were selected conveniently from the hospitals that are select for the study. A questionnaire is constructed for the purpose of the study. It composed of two parts: The validity analysis shows very good evaluation for knowledge scale. Data are analyzed using Statistical Data Analysis by using SPSS.

Results: Results showed that (62.9%) of the parents showing moderate knowledge of Parents about and nutrition knowledge of children with phenylketonuria.

Conclusions: Overall evaluation of Parents' knowledge showing moderate knowledge about nutritional management and the study confirms that older parents are better knowledge.

Recommendations: The study recommends that parents of phenylketonuria children should be very well-oriented and greatly aware about the importance of nutritional management, and also offers an educational program for parents' of children with PKU.

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* Corresponding author at: Baghdad Health Directorate, Baghdad, Iraq;

E-mail address: mustafasalih997@gmail.com (MS Abdulnabi). ORCID: 0000-0002-0251-2064

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تقويم معارف الوالدين حول التدابير التغذوية للأطفال المصابين ببيلية الفينول الكيتونية

المستخلص:

الأهداف: تقويم معارف الوالدين حول التدابير التغذوية للأطفال المصابين ببيلية الفينول الكيتونية ولكشف الاختلافات بين معارف الوالدين حول التدابير التغذوية والمتغيرات الديموغرافية للآباء مثل (عمر الاب والام , الحالة الاجتماعية الاقتصادية للوالدين).

المنهجية: دراسة غير تجريبية. أجريت على آباء الأطفال المشخصين ببيلية الفينول الكيتونية خلال الفترة 3 حزيران إلى 5 تشرين الاول 2022.تم اختيار عينة غير احتمالية (35) طفلًا من بيلية الفينول الكيتونية مع والديهم والتي تم اختيارها بالطريقة المناسبة من المستشفيات. تم تصميم الاستبيان لغرض الدراسة. اظهر تحليل الثبات تقييمًا جيدًا جدًا لمقياس المعرفة. تم جمع البيانات في مدينة بغداد الرصافة/مستشفى ابن البلدي للنسائية والاطفال .تم تحليل البيانات باستخدام برنامج التحليل الاحصائي.

النتائج: اظهرت النتائج أن(62.9%) من الآباء يظهرون معرفة متوسطة عن تغذية الأطفال المصابين ببيلية الفينول الكيتونية.

الاستنتاجات: اظهر التقييم العام لمعارف الوالدين حول التدابير التغذوية للاطفالهم المشخصين ببيلية الفينول الكيتونية معارف متوسطة. وأيضا تؤكد الدراسة ان الآباء الأكبر سنا لديهم معارفهم أفضل.

التوصيات: أوصت الدراسة بضرورة أن يكون آباء الأطفال الذين يعانون من بيلية الفينول الكيتونية على دراية تامة وكبيرة بأهمية التدابير التغذوية لاطفالهم. كذلك تقديم برنامج تثقيفي لوالدين الاطفال المشخصين ببيلية الفينول الكيتونية.

الكلمات المفتاحية: معارف الوالدين, التدابير التغذوية ،الاطفال, بيلية الفينول الكيتونية.

Introduction

Phenylketonuria identified as (phenylalanine hydroxylase deficiency) is an autosomal falling syndrome of phenylalanine metabolic rate, in which particularly high phenylalanine focuses cause mind dysfunction. If crude, these mind dysfunction consequences in severe knowledgeable disability, epilepsy and behavioral difficulties. PKU controlling has been for history complex, demanding lifelong adherence to a Phe limited diet (i.e., escaping consumption of great protein nutrition, such as meat, fish, eggs, breads, and milk produces) [1] [2] [3].

Early Phenylketonuria diagnosis and treatment is vital in order to prevent irreversible damage such as neurological impairment and intellectual disability .Largely, PKU have not been systematically evaluated and reported in Iraq including Kurdistan Region; Northern Iraq. Because of that, metabolic disorders, including PKU, have possibly been underestimated. The important of this letter is to raise awareness and bring to the forefront the urgent need for appropriate treatment of children in Iraq, in addition to highlighting solutions for going forward.[18]

The Importance of study in PKU treatment is to maintain blood Phe under rigorous nutritional management control, especially during the first years of life. Nutrition for children with PKU must be significant importance and focused, to prevent increased phenylalanine in the blood, which negatively affects the lives of children and causes them to mental and intellectual problems. The protein substitute is usually given at mealtime at least three times per day in order to optimize its metabolism [5] [6] [17].

The study aims to evaluate parents' knowledge about nutritional management of children with phenylketonuria and to find out the association between parents' knowledge about nutritional management and their demographic variables of parents.

Methodology

A non-experimental design. was conducted on parents knowledge of phenylketonuria child in Baghdad city from the period 3 June to 5 October 2022.

A convenience sample of 35 PKU children with their parents (father and mother) was selected conveniently from Ibn Al-Baladi for Maternity Which are located in Baghdad city/Al-Rusafa from Ibn Al-Baladi hospital for Maternity and children.

The Scientific Research Ethical Committee at the University of Baghdad, College of Nursing has approved the study to be conducted. All participants have signed a consent form to present their agreement for such participation and protect their human rights.

The study instrument was constructed through reviewing the literature related to object of study. It includes two sections: Demographic characteristics concerning parents' such as age, Residential environment and Socio-Economic-Status [7].

Parents' knowledge about nutritional management of Phenylketonuria Disorder; Describes how parents following a healthy nutritional program for children with phenylketonuria, and the benefit of this program, and it contains (12) items. It is recorded according to the likert standards of 2 points: (1 = I know, 0= I don't know).

Content validity of the study instrument is determined through panel of experts and internal consistency reliability is obtained through split-half technique and computation of Cronbach alpha correlation coefficient of (r=0.887).

The data was collected through an interview parents' children, it took a time of (20-30) minutes.

The following statistical data analysis approaches were used application of the statistical package (SPSS) ver. (26.0). Descriptive Statistical Data Analysis; Frequency, percent, mean of scores, mean, standard deviation, total scores and ranges. Inferential Statistical Data Analysis; T-test and one - way analysis of variance (ANOVA).

Results

Table (1): Distribution of Parents According to their Socio-demographic Characteristics

No	Characteristics		F	%
1	**Father's age (year)**	20 – 29	8	22.9
	M±SD= 34±7	30 – 39	17	48.6
		40 – 49	8	22.9
		50 +	2	5.6
		Total	***35***	***100***
2	**Mother's age (year)**	Less than 20	2	5.7
	M±SD= 30±6	20 – 29	14	40
		30 – 39	15	42.9
		40 +	4	11.4
		Total	***35***	***100***
3	**Socioeconomic status**	Low	11	31.4
		Moderate	15	42.9
		High	9	25.7
		Total	***35***	***100***

No: Number, f: Frequency, %: Percentage, M: Mean, SD: Standard deviation

This table shows average age for fathers is 34±7 years and age refers to 30-39 years among 48.6% of them. The mother's average age refers to 30±6 years and age group refers to 30-39 years also among 42.9 %, and show moderate socioeconomic status (42.9%).

Table (2): Evaluation of Items Related to Parents' Knowledge about Nutrition of Children with PKU

List	Parents' Knowledge about Application of Nutritional Management for Children with Phenylketonuria	(N=35)	
		Mean	Eva.
1	Nutrition program of phenylketonuria patients is great importance and contribution to the improvement of the child's health condition.	.40	Moderate
2	Children with the disease need to obtain essential nutrients through special dietary supplements due to the limited diet.	.60	Moderate
3	Therapeutic milk is considered as a substitute for breast milk, according to the names (PKU, Phenex Phenylfree).	.71	Moderate
4	Therapeutic milk (phenylalanine-free) is considered a treatment for children as an alternative to breast milk or general alternative milk.	.57	Moderate
5	Infant is given only two feedings, a mixture of breast milk or artificial milk with therapeutic milk.	.63	Moderate
6	Infant (1 day-6 months) is given milk No. (1) of Phenyl Free-1	.66	Moderate
7	Child from the age of (2 years onwards) is given milk number (3) of (PKU3, phenex-3, phenylfree-3).	.40	Moderate
8	Sugars burn the phenyl in the blood, so the patient feels better.	.57	Moderate
9	Meat of all kinds, white and red, such as beef, sheep, chicken and fish is considered a prohibited food for all ages.	.57	Moderate
10	Fats are harmless foods for phenylalanine patients due to their low protein content. The fats are in butter, olive oil, and ghee.	.34	Moderate
11	Avoid all dairy products and foods made from dairy products such as cheese, yogurt, ice cream and high-fat milk.	.57	Moderate
12	Yolk is given from one day to the next and up to.	.49	Moderate

F: Frequency, %: Percentage, Eva. Evaluation, (Mean: Poor= 0-0.33, Moderate= 0.34-0.67, Good= 0.68-1)

This board presents the objects related to parents' knowledge around application of nutritional management for children with phenylketonuria; the mean scores for item during the evaluation indicate moderate side by side of knowledge as seen amongst all items.

Table (3): Overall Evaluation of Parents' Knowledge about Nutrition of Children with Phenylketonuria

Evaluation	(N=35)			
	F	%	Mean	SD
Poor	**6**	**17.1**	**3.86**	**1.81**
Fair	**22**	**62.9**		
Good	**7**	**20**		
Total	***35***	***100***		

f: Frequency, %: Percentage, M: Mean, SD Standard deviation

Poor= 0 – 2.66, Moderate= 2.67– 5.33, Good=5.34 – 8 This table revealed that 62.9% of parents are showing fair knowledge about nutrition of children with phenylketonuria.

Table (4): Analysis of Variance for Parents' Knowledge with respect to Father's Age (N=35)

Father Age / Knowledge	Source of variance	Sum of Squares	Df	Mean Square	F	Sig.
Knowledge about concept	Between Groups	1.230	3	.410	.100	.959
	Within Groups	126.941	31	4.095		
	Total	128.171	34			
Knowledge about nutrition	Between Groups	32.146	3	10.715	4.145	**.014**
	Within Groups	80.140	31	2.585		
	Total	112.286	34			
	Within Groups	284.485	31	9.177		
	Total	292.286	34			
Overall Knowledge	Between Groups	75.275	3	25.092	1.222	**.018**
	Within Groups	636.610	31	20.536		
	Total	711.886	34			

df: Degree of freedom, F: F-statistic, Sig: Significance

This table shows that there is significant differences in parents' knowledge with respect to their father's age at p-value= .018 and particularly with parents' knowledge about nutrition at p-value= .014.

Table (5): Analysis of Variance for Parents' Knowledge With Respect to Mother's Age (N=35)

Mother Age / Knowledge	Source of variance	Sum of Squares	Df	Mean Square	F	Sig.
Knowledge about concept	Between Groups	3.481	3	1.160	.288	.833
	Within Groups	124.690	31	4.022		
	Total	128.171	34			
Knowledge about nutrition	Between Groups	30.279	3	10.093	3.815	**.020**
	Within Groups	82.007	31	2.645		
	Total	112.286	34			
	Within Groups	268.448	31	8.660		
	Total	292.286	34			
Overall Knowledge	Between Groups	17.921	3	5.974	.267	.849
	Within Groups	693.964	31	22.386		
	Total	711.886	34			

df: Degree of freedom, F: F-statistic, Sig: Significance

This table revealed that here is no significant differences in parents' Knowledge with respect to mother's age but show significant in parents' knowledge about nutrition with concern to mother's age at p-value= .020.

Table (6): Analysis of Variance for Parents' Knowledge With Concern to Socioeconomic Status (N=35)

SES / Knowledge	Source of variance	Sum of Squares	Df	Mean Square	F	Sig.
Knowledge about concept	Between Groups	11.973	2	5.987	1.649	.208
	Within Groups	116.198	32	3.631		
	Total	**128.171**	**34**			
Knowledge about nutrition	Between Groups	4.888	2	2.444	.728	.491
	Within Groups	107.398	32	3.356		
	Total	**112.286**	**34**			
Overall Knowledge	Between Groups	4.063	2	2.032	.092	.912
	Within Groups	707.822	32	22.119		
	Total	**711.886**	**34**			

This table shows that here is no significant difference in parents' knowledge with concern to their socioeconomic status.

Discussion

The results show parents are middle age adults, one third of them is with moderate socioeconomic status**.**

In the current study 42.9% of mothers were aged between (30 _39) years with mean=30 years, and 48.6% of fathers were aged between (30 _ 39) years with mean=34 years. These results agrees with Van Calcar and his colleagues study (2010). Who found that half of mothers' aged from (29-39 years) [(8) (9) (10)].

Results indicate that most of the parents have moderate socioeconomic status (42. 9%).This result was congruent with van Spronsen and his colleagues (2010) who found socio-economic Status was moderate at (53%) [(11).]

This result disagrees with Hussein, & Aziz, (2016). Who reported record of the mothers (60%) are production low socioeconomic position [(10)].

This result was supported by Saeed, and AL-Mosawi, (2020). who found the financial situation illustrations (76.7%) 23 nurses are moderate [(12)].

Parents' knowledge about nutrition of children with Phenylketonuria was fair.

This result was congruent with Rocha and his colleagues (2019), which shows the level of nutritional status and program toward PKU children by parents are moderate and suitable for the sample size [(13) (14)].

These results agree at over all with Rajih and mohammed, (2020). Who found totally the study illustration responses at the pretest are just knowledge with a numerical mean of scores (1.342). Additional than the posttest, the board

exemplifies the (100%) of the research sample have great knowledge at the mean of scores, (1.879) [15].

This result is supported by Jameson and Remmington (2020), who found the parents of PKU child follow up low protein nutrition protocol with better nutrition indicators (higher fruit and vegetable consumption) was high level of practices. Furthermore, encouraged low protein eating consumption for PKU children. Still and indeed logical to use low protein diet guidance [16].

Through the course of information analysis, the research findings depict that knowledge' about nutrition are affected by father's age and mother's age. Such results can be understood in a way that the older the parents the better are the Parents' Knowledge.

Related concerning father's age, the results show significant difference in overall parents' Knowledge with concern to father's age at (p-value, 0.018) and mainly with parents' knowledge about nutrition at (p-value, 0.014) and there is no important difference in overall parents' Knowledge with regard to mother's age at (p-value, 0.849) but show significant in parents' knowledge about nutrition with regard to mother's age at (p-value, 0.020).

These findings disagree with MacDonald et al., (2015), who create no important relation among parents' age (p-value, 0.601) and phenylketonuria dietary [17].

Concerning socioeconomic status, the findings show that around is no important difference in parents' Knowledge with concern to their socioeconomic status (p-value, 0.912).

A researcher believes that the socio-economic status is no important difference in the study, an indication of the burden on the parents of children with PKU.

Conclusions

The study concluded that parents' knowledge about PKU disorder is fair, also the older parents and the older age of marriage are more knowledgeable.

Recommendations

Created on the early listed conclusion, the study recommends that; Parents of phenylketonuria children should be very well-oriented and greatly aware about the importance of nutritional management, and also offers an educational program for parents' of children with PKU. should be supported in order to help them dealing effectively with such public health problem.

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