Effect of Online Education on Mothers' Knowledge and Practice regarding Caring for Children with Phenylketonuria

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Abstract

Background: Phenylalanine hydroxylase activity is deficient in phenylketonuria. Phenylketonuria is an inherited metabolic disease of protein metabolism. **Aim:** The study aimed to determine the effect of online education on mothers' knowledge and practice regarding caring for children with phenylketonuria. **Design**: A quasi-experimental research design was used in this study (pre/post-test). **Setting**: The research was carried out in a genetic counselling clinic in a basic health care facility affiliated with the Ministry of Health in Sohag City. **Sample**: A non-probability purposive sampling technique included 50 mothers and their children with Phenylketonuria. **Tools**: Two tools were used: Tool (I) Self-administering questionnaire included Part (1): Demographic data of the mothers and their children, Part (2): Children's medical history, and Part (3): Mothers' knowledge about phenylketonuria, and Tool (II): Mothers' reported practice about phenylketonuria. **Results**: The study indicated that there was a statistically significant improvement in mothers' knowledge and reported practices regarding caring for children with phenylketonuria post- online education than pre- online education. A statistically significant correlation was observed between mothers' knowledge and reported practices post- online education**. Conclusion**: The study results concluded that online education had positive effects on improving mothers' knowledge and practice in caring for their children with phenylketonuria. **Recommendations**: Online education for mothers regarding caring for children with phenylketonuria is recommended to increase their knowledge and reported practices.

Keywords: Children, Mothers, Online education, Phenylketonuria

Introduction:

Phenylketonuria (PKU) is an autosomal recessive inborn error of phenylalanine (Phe) metabolism caused by deficiency of phenylalanine hydroxylase (PAH). On the basis of blood Phe concentrations, PAH deficiency can be classified into, mild PKU (Phe 600–1200 mol/L), classical PKU (Phe N 1200 mol/L), and moderate hyper phenylalaninaemia (Phe b 600 mol/L) **Giżewska et al., 2016).** Excess phenylalanine in the blood can be caused by PAH gene mutations, which result in reduced or complete inactivation of the PAH enzyme. If not addressed, this can lead to severe and irreversible intellectual disability. Furthermore, in untreated children, the clinical manifestations of PKU include mental retardation, behavior problems, fair skin and hair, eczema, and a mousy odor (**Williams et al., 2018**).

PKU is found in different geographic places around the world. It's also popular in a few sections of China, On the other hand, high rates of PKU have been reported in populations such as Yemenite Jews in Israel (1 in 5,300 individuals), Arabic populations (up to 1 in 6,000 individuals) and the highest rate of PKU was reported for the Turkish population (1 in 2,600 newborns). **(Ford et al., 2018).** Furthermore, in Egypt, in the governorate of Menoufiya, the prevalence was 1/3000 **(Morad et al., 2019).** Also, the prevalence of PKU varies with ethnicity. It affects around one in every 10,000 white European births in the UK, with approximately 70 newborns born with PKU each year, meaning that over 6000 people in the UK have the condition **(Said & Draz 2019).**

PKU diagnosis is performed by biochemical and molecular genetic diagnosis. The biochemical diagnosis through detecting an elevated serum Phe concentration, which is the standard method for confirming the positive neonatal screening results. While in molecular analysis, the families with confirmed affected individuals, carriers can be identified by genetic testing. The infant was admitted to the outpatient clinic during the second month after birth with global developmental delay, right focal seizures, decreased visual perception, delayed head control, and rolling eyes **(MacDonald, 2017).** Physiotherapy and anti-

epileptic drugs are being used in treatment of PKU **(Van et al., 2017).** Respect for this treatment regimen is taken into account. In addition to the use of Phe-free L-amino acid supplements for children who require special diets. As well as closely Phe monitoring, daily Phe planning, low-Phe meal preparation and regular clinic visits **(Hanley, 2017).** However, starting a low-Phe diet as soon as possible after diagnosis and maintaining it for the remainder of child's life could prevent such irreparable effects **(Abd-Elkodoos et al., 2018).** As, long-term elevated Phe levels in the blood can cause significant cognitive decline, seizures, behavioral issues, and signs like autism in untreated children **(Furlong et al., 2018).**

Blood tests should be performed at home by parents once a week for children under the age of five, and twice monthly to monthly for children over the age of six. As a result, some aspects of PKU management tend to be time-consuming for mothers who are also in charge of regular child care **(Saudubray and GarciaCazorla, 2018).** PKU has previously been reported to have an influence on mothers, including their ability to perform regular work tasks, with 11% of parental caregivers in one survey claiming that they had to discontinue working and 20% reporting that they had to shift employment to meet the child's demands (**Loeber, 2017**).

Phenylketonuria is treated with a low-Phe diet that significantly limits the intake of natural protein in order to maintain blood Phe concentrations under control. The low-Phe diet consists of organic foods. Fruit, vegetables, fats, and oils are all low in protein, are specially formulated low-protein foods like low-protein flour, pasta, and bread (**Blau, et al., 2018**). Phe-free L-amino acids are required for all patients on dietary treatment, which is commonly supplemented with additional carbs, with or without fat, vitamins, and minerals. Dietary therapy compliance is crucial and needs meticulous planning, dietary supervision, and monitoring by the caregivers and mothers (**Fouad & Abd Elmoneem, 2016**).

Online education and distance learning were first established in wealthy countries (**Cassum, et al., 2020**). Mothers could use online education to increase and enhance their existing skills and knowledge, resulting in higher quality treatment and care for their children. Furthermore, continuing education led to upgrading their knowledge and practices. As a new option for mothers to acquire continual education, online educational models have emerged (**Abd Elaziz, et al., 2021**). Mothers are crucial in the care of their children with phenylketonuria, which necessitates daily effort to deal with the children's disabilities and to maintain a unique rehabilitation and diet program (**Kaakinen et al., 2018**).

Nurses play an important role in assessing PKU children and educating the general public about the condition and mothers specially to ensure that they can provide the recommended care for their children with Phenylketonuria which include; early case detection to avoid problems, nutrition and diet limitations, and referral for phenylketonuria disease treatment (**Roberts et al., 2017**). Furthermore, nurses offer premarital counselling concerning consanguineous marriage at the preconception period to see if parents have the PKU gene **(Khaton, 2016**). Additionally, follow-up calls or e-mails after each clinic consultation can aid in the examination of children with PKU (**Abd-Elkodoos et al., 2018).**

Significance of the study:

The Egyptian Ministry of Health and Population did not run a PKU screening program at the national level until November 2015. Untreated PKU causes infants to appear normal at birth but lose interest in their environment by the time they are 3 to 6 months old. The symptoms of elevated blood Phe in PKU children include seizures and tremors, problems with executive function, behavioral and psychological issues, social difficulties, poor growth, irritability, and dermatitis. By the age of one year, children are already developing slowly. If untreated, it is typically severe, necessitating institutional care for the majority of children. Mothers of children with PKU can lower their blood Phe concentrations through dietary and/or pharmacological therapy (**Khaton, 2016**). Overall, it was calculated that the incidence rate in Egypt was 1 in 7500 (**Gad et al., 2019**).

On the other hand, a Sohag preliminary study was published in this study that comprised 18,000 cases seen in the pediatric clinics of Sohag University hospital over the course of three years, of which 100 were suspected to have PKU and two were verified (**Sadek et al., 2018 & Morad et al., 2019**). The spread of consanguineous or relative marriage between family members has negative

effects on children's development, mental retardation, and behavior. Mothers in Upper Egypt are uninformed about how to deal with daily care related to their children who suffering from phenylketonuria. PKU continues to have a negative impact on children there (**Abdel Rahim et al., 2017**). So, the current study aimed to determine the effect of online education on mothers' knowledge and practice in caring for children with phenylketonuria.

Operational Definitions:

Online education: Is a technique for learning that involves accessing the internet through electronic devices including computers, smartphones, and laptops.

Phenylketonuria: Is a hereditary condition that causes an increase in the quantity of phenylalanine in the blood.

Aim of the study:

The study aimed to determine the effect of online education on mothers' knowledge and practice regarding caring for children with phenylketonuria through:

- Assessing mothers' knowledge level regarding phenylketonuria pre and post-online education.
- Assessing mothers' practices level regarding phenylketonuria pre and post-online education.
- Designing and implementing online education based on the mother's and their children's needs.
- Evaluating the effect of online education on mothers' knowledge and practice regarding caring for their children with phenylketonuria.

Research hypothesis:

Online education regarding phenylketonuria will have a positive effect on improving mothers' knowledge and practices regarding caring for children with phenylketonuria.

Subjects and Method:

Research design:

A quasi-experimental research design was used in this study (pre/post-test).

Setting:

The research was carried out in a genetic counselling clinic in a basic health care facility affiliated with the Ministry of Health in Sohag City (MOH), Egypt. This setting was selected because of the high prevalence of children with phenylketonuria in this setting, as well as the fact that it serves the most populated region of the country.

Subjects:

A non-probability purposive sampling technique included 50 mothers and their children with Phenylketonuria for six months.

Sample size

This sample was selected by using the following equation according to **(Steven and Thompson, 2012):**

$$n = \frac{N \times p(1-p)}{\left[N-1\times\left(d^2 \div z^2\right)\right] + p(1-p)}$$

N = total patient population size who attended the previously selected settings

Z = confidence levels is 0.95 and is equal to 1.96D = the error ratio is = 0.05

P = the property availability ratio and neutral = 0.50

Inclusion criteria

- Mothers aged from18 to 40 years' old
- Able to use the internet.
- Mothers can read & write
- Agree to participate with the researchers.
- Have a smartphone or computer with internet access.

Data collection tools:

Two tools were used to collect data and carry out the present study.

Tool (I): Self-administering questionnaire: It was designed by the researcher after reviewing related literature and translated into the Arabic language it consisted of three parts as the following:

Part (1): Included demographic data of the mothers and their children:

- Demographic data of the child, such as age, gender, and child ranking.
- Demographic data of mothers regarding age, relative degree, educational level, and occupation.

Part (2): Children's medical history:

It included items related medical history of children with PKU. It included items related to

the medical history of children with PKU, such as the effect of the disease on general health, the presence of complications of the disease, and the number of investigating Phenylalanine levels in the blood.

Part (3): Mothers' knowledge about phenylketonuria:

It consisted of 15 questions divided into two sections: The first section asked six questions concerning the mothers' knowledge of PKU condition, including meaning, risk factors, causes, early symptoms, latent signs, and complications. The second section included five questions about their role in caring for children with PKU: Prevention of complications, adequate nutrition, prevention of growth retardation, management of emergencies like fever, prevention of infection, follow-up, practicing exercise, and maintenance of the child's safety **(Fouad & Abd Elmoneem, 2016; Roberts et al., 2017**; **Abd-Elkodoos et al., 2018; Cazzorla et al., 2018).**

Scoring system of knowledge:

The overall score for knowledge was 15 points; questions were either correct or incorrect, with one point awarded for correct answers and zero for incorrect answers and I don't know. Mothers' knowledge was divided into three categories: poor knowledge (> 50% of total score), fair knowledge (50 % to 70% of total score), and good knowledge (greater than 70%) (**Abd-Elkodoos et al., 2018**).

Tool (II): Mothers' reported practice about phenylketonuria:

It was developed by the researcher after reviewing the recent literature to collect the required data. As the measurement of diet balance, allowed and forbidden food, physical activity, dental care, check of phenylalanine level, follow up of weight at home, and follow up of height at home, and calculation of body mass index (**Abd-Elkodoos, et al., 2018 & Elsayed et al., 2020).**

Scoring system of reported practice:

The total score was 25 points, with one point for each statement. The checklist's answers were either done or not done, with one mark for done and zero for not done. Each component was added together and converted to a percentage. The total scores of mother's reported practices were calculated and classified as either satisfactory practices from 60 % -100% or unsatisfactory practices for less than 60 % **(Fouad and Elmoneem 2016; Abd-Elkodoos et al., 2018 & Khdair et al., 2020).**

Validity of the tools:

The content of the tools was reviewed for clarity, thoroughness, appropriateness, and relevancy. To ensure that the questionnaire was clear and relevant to PKU, five expert professors with more than ten years of experience, two professors in Pediatric Nursing, one professor in Community Health Nursing, and two professors in Medical Biochemistry from Sohag University examined and revised the content validity of the tools. No changes were made in response to the panel's suggestion. Examination of the content validity index (CVI) showed that CVI = 89%.

Reliability of the tools:

The reliability of the tools was tested using Cronbach's Alpha for the tool (I) was 0.899 and tool (II) was 0.815.

Fieldwork:

Data collection was carried out in three phases:

Preparatory phase:

Create the study questionnaire for data collection, which includes examining the available literature in various sections of the review using textbooks, publications, various studies, the internet, and journals. The health directors were granted permission to conduct the study by the Dean of the Faculty of Nursing at Sohag University.

Pilot study:

Before beginning data collection, a pilot study was conducted on 10% of the total sample (5 mothers and their children) in the study. The pilot research data was collected around the middle of April 2021. This pilot study aimed to evaluate the tools' clarity and determine how long it would take to complete the questionnaire. Based on the findings of the pilot study; no modifications to the tools were done.

Ethical consideration:

Approval was obtained from ethical committee of the faculty of nursing, at Sohag University to conduct this study before starting the study. The mothers were assured that there would be no danger to them during the study, that they could decline or join at any time, and

that they had the right to refuse or participate. The privacy of study participants was respected during data collection. The researcher also met with the mothers to explain the purpose of the study and obtain their permission to participate. They were assured that the information gathered would be kept private and secret and that it would only be utilized for scientific research. Subjects were given the option to leave the study at any time.

Implementation phase:

Data were collected from April to September 2021, three days per week for the mothers who were being investigated, and typically 5-6 questionnaires were collected every day. The questionnaire took between 30 and 35 minutes to complete. Before enrolling the mothers in the study, verbal consent was obtained from each of them, and the study objectives were thoroughly done.

The researchers created an educational package based on the pre-test results for determining the mothers' actual needs. An online link was created and given to the mothers of the study via social media web pages (Facebook and WhatsApp). Online education aimed to provide knowledge for mothers caring for children with PKU. It focused on knowledge and practice issues that should be improved.

The subject contents have been sequenced through 6 sessions (4 sessions for the theoretical part and 2 sessions for the practical part). Four theoretical online lectures were part of online education. **The first online lecture** covered an overview of PKU including meaning, risk factors, causes, early symptoms, latent signs, and complications. **The second and third lectures** focused on the role of the mothers in caring for children with PKU: Prevention of complications, adequate nutrition, prevention of growth retardation, management of emergencies like fever, and prevention of infection. The follow-up, practicing exercise, and maintenance of the child's safety was covered in **the fourth online lecture**. **The fifth online lecture** focused on the measurement of diet balance, allowed and forbidden food, physical activity, dental care, and check of phenylalanine levels. **The sixth online lecture** focused on follow-up of weight at home and follows up of height at home, and calculation of body mass index

A simplified booklet was used as a supportive resource and delivered to the mothers in the Arabic language to cover all elements of the information and practice of PKU. This online education was delivered to mothers using a live broadcast Zoom meeting. Each lecture lasted one hour, and the researchers began the session by giving a review of the prior one in 5 minutes. And 10 minutes were included at the end of each presentation for questions and clarification. For attracting the studied mothers, PowerPoint presentations, brainstorming, questioning, and responses were employed as teaching methods during each online lectures.

Evaluation phase:

After two months of completing the online education, a post-test was administered. The mothers were reassessed using the same pre-test tools. The post-test was prepared online using the same questionnaires (tools one and two) as the pretest through Google Forms. The mothers were invited to respond to it and submit it via an internet link. The online link was distributed to all of the mothers who participated in the study via the previously mentioned online social media web domains.

Administrative Design:

An official letter requesting permission to conduct the study was directed from the dean of the faculty of nursing at Sohag University to the directors of the previously selected setting to obtain their approval to carry out this study.

Statistical Design:

The collected data were coded and entered into a social science statistical package (SPSS Version.23.00). At the coding and data entry stages, quality control was performed. For categorical variables, descriptive statistics were used in the form of frequencies and percentages, whereas for continuous quantitative variables, means and standard deviations were used. The Chi-square (X2) test was used to compare qualitative category data, with the hypothesis that the row and column variables are independent, but without revealing the degree or direction of the link. The chi-square test, T-test, and F-test were used to compare qualitative variables. When the P-value was less than 0.05 and the difference was ($P<0.001$), statistical significance was evaluated.

Results:

Table (1): Shows the children's demographic data. Regarding age, 40% of them were between the ages of 2 - < and 5, with a Mean ± SD of 4.43 ± 1.54, and 54% of them were boys. Concerning child ranking, 38 % of the children were ranked second.

Table (2): Illustrates that PKU disease affected 54% of the general health of children. Concerning complications, 20% of children had complications from the disease. Half of the children made Phenylalanine levels in the blood once every two months.

Table (3): Reveals that 70% of the studied mother's ages between 18 < and 30 years with a mean ± SD of 23.35 ± 4.39 and 42% of them had secondary education. Meanwhile, it is pointed out that 60% of the mothers that were analyzed were housewives and 32% were consanguineous.

Figure (1): Shows the study's percentage distribution of the mothers' sources of PKU knowledge, it can be seen that the main source of knowledge of the studied mothers was doctors, followed by media, and friends.

Table (4): Illustrates the distribution of the studied mother's knowledge regarding phenylketonuria pre and post-online education intervention. Mothers' knowledge has improved significantly regarding phenylketonuria after online education (P<0.001).

Figure 2: Presents that 86% of the studied mothers had poor knowledge levels regarding PKU pre-online education while all of them (100%) had good knowledge post-online education with significant improvement at P <0.001.

Table (5): Portrays that the phenylketonuria practices of mothers improved with a highly statistically significant difference before and after online education (P<0.001).

Figure (3): Presents 85% of the studied mothers had unsatisfactory practices pre-online education while the majority of them 87% had satisfactory practices post-online education with significant improvement at P<0.001.

Table (6): Shows a significant correlation between the mothers' knowledge and practices post- online education at a P. value of 0.018.

Table (1): Frequency and percentage distribution of the studied children regarding their demographic data (n=50)

Demographic data	No	%
Age: (years)		
<2	13	26.0%
2 - < 5	20	40.0%
> 5 years	17	34.0%
Mean ± SD	4.43 ± 1.54	
Gender:		
Boys	27	54.0%
Girls	23	46.0%
Child ranking:		
First	14	28.0
Second	19	38.0
Third or more	17	34.0

Table (2): Frequency and percentage distribution of the children with PKU regarding the medical history (n=50)

Medical history	No.	%
Effect of the disease on general health		
Yes	27	54.0
No	23	46.0
Presence of complications of the disease		
Yes	10	20.0
No	40	80.0
Number of investigating Phenylalanine levels in the blood		
Once monthly	20	40.0
Once every two months	25	50.0
Once every three months	5	10.0

Table (3): Frequency and percentage distribution of the studied mothers regarding their demographic data (n=50)

Demographic data	No.	%
Age in years		
18 < 30	35	70.0
30 – 40	15	30.0
Mean ±Stander deviation	23.35 ± 4.39	
Educational level		
- Read and write	10	20.0
-Secondary education	21	42.0
-University education	19	38.0
Occupation		
- Working	20	40.0
- Housewives	30	60.0
Consanguineous degree		
- Yes	16	32.0
- No	34	68.0

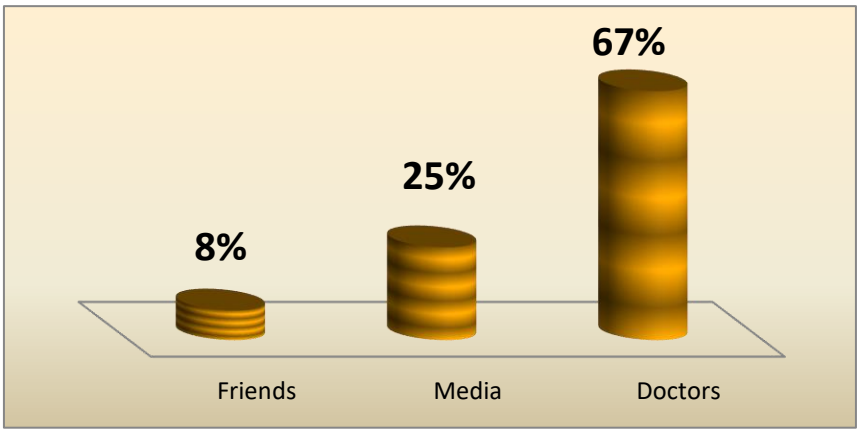

Figure (1): Percentage distribution of the studied mothers regarding their source of knowledge about PKU (n=50)

Table (4): Frequency and percentage distribution of the studied mother's knowledge regarding phenylketonuria pre and post-online education intervention (n=50)

Mother's knowledge	No =(50)				P-value
	Pre-online education intervention		Post-online education intervention		
	No	(%)	No	(%)	
PKU meaning	10	20%	47	94%	<0.001*
PKU risk factor	15	30%	43	86%	<0.001*
PKU causes	8	16%	41	82%	<0.001*
PKU symptoms	16	32%	40	80%	<0.001*
PKU latent symptoms	9	18%	46	92%	<0.001*
PKU complications	14	28%	43	86%	<0.001*
Role in caring for children with PKU	12	24%	45	90%	<0.001*
Prevention of complications	18	36%	44	88%	<0.001*
Adequate nutrition	19	38%	44	88%	<0.001*
Prevention of growth retardation	18	36%	43	86%	<0.001*
Management of emergencies	21	42%	47	94%	<0.001*
Follow up	15	30%	39	78%	<0.001*
Practicing exercise maintenance of the child's safety	11	22%	44	88%	<0.001*

** Highly Statistical significant (P ≤ 0.001) P value a: McNemar test1063

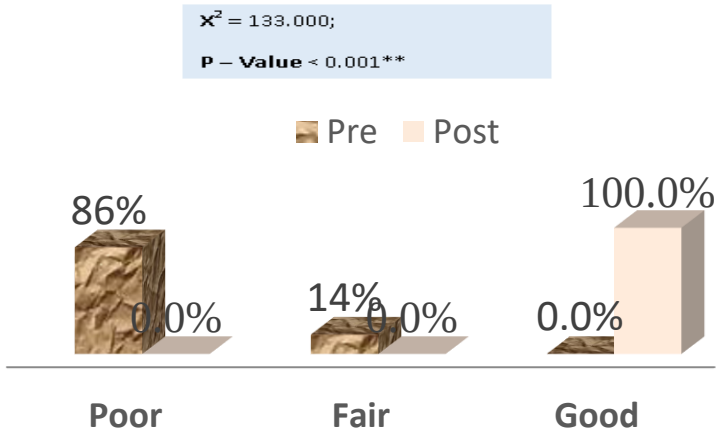

Figure (1): Percentage distribution of total knowledge level regarding PKU among the studied mothers pre/ post online education (n= 50).

Table (5): Frequency and percentage distribution of the studied mother's practices regarding phenylketonuria pre and post-online education intervention (n=50)

Mother's practices	No =(50)				P-value
	Pre-online education intervention		Post-online education intervention		
	No	(%)	No	(%)	
Measurement of diet balance	15	30%	48	96%	<0.001*
Allowed and forbidden food	20	40%	48	96%	<0.001*
Physical activity	13	26%	46	92%	<0.001*
Dental care	15	30%	45	90%	<0.001*
Check of phenylalanine level	24	48%	49	98%	<0.001*
Follow up of weight and height at home	19	38%	40	80%	<0.001*
Calculation of body mass index	17	34%	40	80%	<0.001*

** Highly Statistical significant (P ≤ 0.001) P value a: McNemar test1064

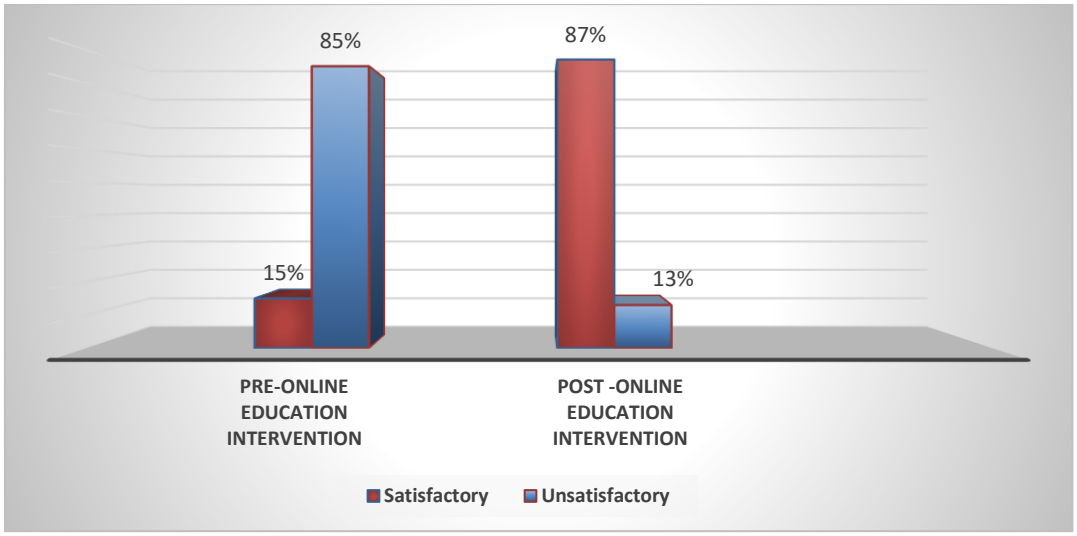

Figure (2): The total practices level of the studied mothers regarding PKU pre and post-online education

Table (6): Correlation between total knowledge score and total practices score of the studied mothers' pre and post- online education

Correlation	Pearson correlation coefficient			
	Total practice score			
	Pre-online education		Post-online education	
	R	P	r	P
Total knowledge score	.055	.607**	825	.018*

**** Correlation is significant at the 0.0001 level**

Discussion:

Phenylketonuria disease is a prevalent chronic genetic disorder that necessitates daily mother's effort to maintain a particular food program and deal with the child's limitations. Furthermore, the care of the child and the workload of the hospital are mostly on the mother´s shoulders Therefore, mothers play a crucial role in the treatment and providing care for their children with phenylketonuria. Due to the chronic nature of PKU, everyday efforts on the part of family caregivers are required to manage the condition of the child and to uphold a special rehabilitation and diet plan **Mortazavi et al., (2020).**

The current study discovered that two-fifths of children were between the ages of 2 - < and 5, with a Mean ± SD of 4.43 ± 1.5. This finding is consistent with the findings of **MacDonald et al. (2016**), who studied "The personal burden for parents of children with phenylketonuria" and that the median age of children with the condition was 4.43 ± 0.4. Also, this finding was in the same line as **Al-Zyoud et al. (2019),** who conducted a study about " The absence of cultural gut microbes Children with phenylketonuria get Escherichia coli infections" and found that the children ages were between 4-6 years old.

Concerning the effect of the disease on studied children's general health, the current study revealed that the disease affected more than half of children's general health and one-fifth of children had complications from the disease. This result may be related to the disease's effect on the normal growth and development of children. This result was supported by **Abd-Elkodoos, et al., (2018**) who found that less than one-fifth of PKU children showed signs of cognitive impairment, according to a study titled "Family Caregivers' Knowledge and Practices Among Children With Phenylketonuria.", according to the findings. These findings also was agree with those of **Gad et al. (2019**), who researched "Pediatric Phenylketonuria in Fayoum Governorate" and discovered that the children had a history of motor developmental delay, seizures, and autism as a complication of PKU.

This result is in line with **Tiele et al. (2019**), who concluded in a study titled "Investigation of pediatric PKU breath malodor, comparing glycol macro peptide with phenylalanine free L-amino acid supplements" that the majority of children had general health problems, including convulsions, delayed weight and length growth, delayed social and intellectual skills, and bad body odor." The results of **Walkowiak et al. (2019),** who conducted a study on "General health in classical phenylketonuria children: A retrospective cohort study," are similarly consistent with this finding.

The current study found that the main source of knowledge of the studied mothers was doctors, followed by media, and friends. These findings were similar to those of **Abd Elkodoos et al., (2018**) who studied "Family Caregiver's Knowledge and Practices of Children with Phenylketonuria at Abo El Reesh Hospital," **Elsayed et al., 2020**, who investigated "Assessment of Mothers' Care toward their Children Having Phenylketonuria". From the researchers' point of view, these findings reflect the mothers' need for effective online education about proper PKU children management.

Findings of a considerable improvement were discovered in the present study in mothers' knowledge of phenylketonuria after online education. Also, the results showed that most of the studied mothers had poor level of knowledge of PKU prior to online education, but all of them had good knowledge after online education with a significant improvement of P<0.001. The findings of **Elsayed et al., (2020**) study, "Assessment of Mothers Care toward their Children with Phenylketonuria," which revealed that more than

half of mothers were unaware of PKU, are consistent with the findings of the current study. Also, according to **Abd-Elkodoos et al., (2018**), slightly less than two-thirds had poor knowledge of PKU, more than one-fifth had acceptable knowledge, and less than one-fifth had good knowledge of PKU. From the researchers' point of view, these results reflect the need of those mothers for these online education about the proper knowledge and practices of their children with PKU and this proved the positive impact of online education, as evidenced by an increase in knowledge of the research issue.

Regarding the mothers' practices with their children having phenylketonuria, the study illustrated that 85% of the studied mothers had unsatisfactory practices pre-online education while the majority of them (87%) had satisfactory practices post-online education with significant improvement. These findings could be due to the nature of the disease PKU, which is one of the most challenging chronic diseases. It places a significant burden on mothers and needs a system of care that addresses the medical, social, and psychological elements of the illness. To limit the risk of significant consequences, mothers of these children must adhere to a complicated and coordinated treatment regimen as well as daily maintenance that include several health practices that provided through this online education in the current study (**Durham et al. 2018**). This result supported by **(Fouad et al., 2016)** who found that there were highly statistically significant differences in the total knowledge for family caregivers and their practices post program implementation

The results of this study showed that there was a strong correlation between the mother's knowledge and practices after receiving online education. These results suggest that mother's knowledge affected their practices, according to the researchers. Mothers' methods for caring for their children with PKU and the extent of their parental responsibilities improve when they are adequately informed on the conditions of their children. This explanation was in line with what **Ozel et al. (2018**) wrote in their study titled "Does maternal knowledge impact blood phenylalanine concentration in Turkish children with phenylketonuria?" They claimed that giving caregivers some basic information about their children's condition, developmental outlook, and available treatment options will help them adopt new, healthy behaviors or give up bad ones.

Additionally, these results support those of **Olsson and Montgomery (2017),** who investigated "Family conditions and dietary control in Phenylketonuria" and **Sharman et al., (2019),** who investigated "Qualitative analysis of factors affecting adherence to the phenylketonuria diet in adolescents" and discovered that dietary knowledge is a crucial factor in dietary compliance.

The results of the current convey the success of the online education implementation for mothers of children with PKU which met their needs regarding improving their knowledge and their practices, resulting in acceptance of the research hypothesis and aim.

Conclusion:

It is clear from the findings of the present study that mothers' knowledge and practice regarding caring for children with phenylketonuria was enhanced by their participation in online education. Between the mothers' knowledge and practices after receiving an online education, there was a strong correlation.

Recommendations:

The following recommendations were made in light of the study's findings:

- Dissemination of educational programs for mothers or family caring for children with phenylketonuria is recommended to increase their knowledge and practices about the disease and to prevent its complications
- The need to establish support groups and family therapy programs to overcome deficient knowledge and practices toward the children with PKU
- Further studies and replicating the present research with sample in different settings are required for generalizing the results.

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