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Original Research

Information Acquisition and Avoiding Behavior among Parents of Children with Phenylketonuria: A Cross-Sectional Study

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Abstract

Information has a crucial role in the management of Phenylketonuria (PKU). This study aimed to investigate information acquisition and avoidance behavior among parents of children with PKU and determine the associated factors. This cross-sectional survey was conducted on 144 parents of children with PKU at a teaching hospital in Tehran, Iran. Information acquisition behavior and information avoidance were evaluated using the questionnaire. Information-seeking and scanning about PKU were reported by 132 (91.7%) and 45 (31.3%) parents, respectively. The primary sources for seeking information about PKU were physicians (99/132, 75%), informative websites (77/132, 58.3%), scientific websites (21/132, 15.9%), and friends and family (20/132, 15.2%). There was a significant relationship between information-seeking behavior and parents' educational level (P=0.03), which remained significant in multivariable analysis after controlling for confounding variables (95% CI: 0.05-0.90, P=0.03). Also, parents' online information-seeking behavior was associated with their age (P=0.03) and educational degree (P=0.008). Thirty parents (20.9%) avoided PKU information at least occasionally. Physicians and the Internet were the primary sources of information among parents of children with PKU. Although PKU is a non-acute disease, information avoidance was reported by the parents. Considering that avoiding information can lead to misunderstanding and disrupt the treatment process, physicians must pay attention

to this issue.

Keywords: Information Seeking Behavior, Information Scanning Behavior, Information Avoidance, Phenylketonuria, Pediatrics.

Introduction

Phenylketonuria (PKU) is an inherited metabolic disorder characterized by an enzyme deficiency that results in elevated phenylalanine levels (Hillert et al., 2020). It can lead to intellectual disability, seizures, behavioral problems, and other neurological symptoms if left untreated (van Spronsen et al., 2021). The primary treatment is a lifelong, phenylalanine-restricted diet, requiring careful monitoring of food intake (Lichter-Konecki & Vockley, 2019). As PKU is a chronic condition, parents play a critical role in managing their children's dietary therapy from infancy through adolescence (de Almeida et al., 2020).

Parents' level of PKU knowledge significantly influences the child's metabolic control and neurocognitive outcomes (Medford, Hare, & Wittkowski, 2018). However, prior qualitative research indicates that parents often feel uncertainty about diet management (Akkus et al., 2020). To make informed decisions and adapt the diet effectively, parents need access to reliable information about the disease. Therefore, understanding parents' information behavior is essential.

Information behavior refers to human behaviors concerning sources and channels of information. It describes how individuals handle information and is generally divided into acquisition and avoidance (Agarwal, 2022). According to the literature, there are two types of information acquisition behaviors: information seeking and information scanning (Lewis, 2017). Information seeking is an active, systematic way of searching for specific information (Zimmerman & Shaw, 2020). Information scanning is a passive act defined as the incidental encounter with information about a particular topic (Lee, Ocepek, & Makri, 2022). Information avoidance entails intentionally avoiding information (Golman, Hagmann, & Loewenstein, 2017).

Studies show many patients with acute diseases like cancer actively seek information but also commonly avoid information (Consedine, Morgenstern, Kudadjie-Gyamfi, Magai, & Neugut, 2006; Javadi, Kamfar, Zeinali, Rahmani, & Moghaddamemami, 2023; Miles, Voorwinden, Chapman, & Wardle, 2008; Nelissen, Beullens, Lemal, & Van den Bulck, 2015). However, little is known about how parents of children with non-acute conditions like PKU navigate health information. Identifying their behaviors and needs is crucial for healthcare providers to educate better and provide resources. This study aimed to fill this knowledge gap by investigating the following questions among parents of children with PKU: (1) What are their patterns of actively seeking and passively scanning PKU information?; (2) What sources do they utilize?; and (3) How prevalent is deliberate information avoidance? Findings will provide insights to inform health communication strategies and education for parents managing a complex lifelong disease like PKU.

Materials and Methods

Study design

In this cross-sectional study, parents of at least one child with PKU who were referred for routine controls to the pediatric endocrinology clinic at Mofid Children's Hospital from 1

November 2022 to 10 May 2023 were enrolled. A consecutive sampling method was used, in which all eligible parents of children with PKU who were referred to the clinic during the study period were approached for participation. Similar studies on psychosocial impacts of PKU in parents used sample sizes ranging from 59 to 207 (Becsei et al., 2021; Elsayed, AlRafay, Khalifa, & Mohamed, 2020; Ramos-Álvarez et al., 2023). Our minimum target sample size of 130 was selected based on these prior works to ensure sufficient statistical power. Parents were asked to complete a paper questionnaire before their visit to the physician. The questionnaire was developed based on the literature review of previous studies that have examined information behavior in different populations (Kimiafar, Sarbaz, Shahid Sales, Esmaeili, & Javame Ghazvini, 2016; Mengiste, Ahmed, Bogale, & Yilma, 2021; Nelissen et al., 2015; Perumal, Prasad, Surapaneni, & Joshi, 2015). The questionnaire included four sections: (1) socio-demographics, (2) information-seeking behavior, (3) information scanning behavior, and (4) information avoidance. Socio-demographic variables included gender, age, educational attainment, and income. Also, participants were asked about their perceived health, with answers ranging from poor (0) to excellent (4). Information seeking and scanning sections included 14 different sources in 4 main categories that parents could use for information acquisition: (1) Face to face information sources (physicians, friends, and family), (2) Written information sources (newspapers, magazines, books), (3) Online information sources (forums, blogs, social networks, informative and scientific websites), and (4) Mass media (informative and entertainment TV programs, medical drama, and radio programs). Answers were coded on a 5-point Likert scale ranging from never (0) to always (4). Information avoidance was assessed with a single question. How often do you deliberately avoid information about PKU? The answers ranged from never (0) to always (4). The validity and reliability of the study questionnaire were rigorously evaluated. Content validity was established through expert review by two pediatric endocrinologists, two information scientists, and two psychologists, who examined the questionnaire items for relevance to the research aims and constructs. This expert panel confirmed the questionnaire's validity. Reliability was assessed by administering the questionnaire to 20 parents of children with PKU who were not part of the study sample. Cronbach's alpha coefficients were calculated, resulting in a total alpha of 0.78 for the full questionnaire. This alpha level indicates acceptable internal consistency reliability for the questionnaire.

Statistical analysis

Quantitative and qualitative variables were expressed as mean ± standard deviation and as numbers (percentages), respectively. Pearson's correlation was computed to examine the relationships among quantitative variables and information-seeking, information-scanning, and information-avoidance scores. To analyze the relationship between information acquisition and avoidance behaviors, t-tests and One-way ANOVAs were performed using categorical independent variables. Multivariable analysis to adjust for confounding variables was performed using multiple regression. A two-tailed P-value less than 0.05 was considered significant. All analyses were conducted with IBM SPSS Statistics (version 23.0; IBM Corp, Armonk, NY, USA).

Ethical considerations

The aim of the study was explained to all parents, and informed consent was obtained from

parents included in the study. The Research Ethics Committee of Shahid Beheshti University of Medical Sciences approved the study [IR.SBMU.RETECH.REC.1402.365].

Results

One hundred forty-four parents participated in this study. Ages ranged from 19 to 66 years, and 71.5% were female. Most parents had a diploma or university degree, and over half reported a monthly income of less than 70,000,000 Rials. Details of participants' demographic and health-related characteristics are presented in Table 1.

Table 1
Socio-demographic and health-related characteristics of parents participating in the study

Variables	Frequency	Percent
Gender		
Male	41	28.5
Female	103	71.5
Age (years)		
≤ 30	25	17
31–40	58	40
41–50	40	28
≥ 51	21	15
Degree		
Primary school	16	11
Secondary school	37	26
High school	12	8
Diploma	49	34
University	30	22
Income (Rial)		
<70,000,000	84	58
70,000,000-100,000,000	48	33
>100,000,000	12	9
Health perception		
Poor	4	2.8
Fair	3	2.1
Good	24	16.7
Very good	79	54.9
Excellent	34	23.6
Having another child with PKU		
Yes	6	4.2
No	138	95.8

One hundred thirty-two parents (91.7%) had sought information about PKU, and 8.3% had never searched for PKU in any channel. The experience of information scanning about PKU (at least in one information source) was reported by 45 parents (31.3%). The frequencies of PKU information seeking and scanning across the different channels are shown in Table 2.

Table 2
Frequencies of PKU information-seeking and scanning in different channels n (n%)

Information-seeking (n=132)	Never	Rarely	Sometimes	Often	Always
Physician	13 (9.8)	4 (3)	9 (6.8)	7 (5.3)	99 (75)
Friends and family	103 (78)	3 (2.3)	3 (2.3)	3 (2.3)	20 (15.2)
Newspapers	121 (91.7)	6 (4.5)	2 (1.5)	0	3 (2.3)
Magazines	115 (87.1)	6 (4.5)	2 (1.5)	1 (0.8)	8 (6.1)
Books	115 (87.1)	9 (6.8)	4 (3)	1 (0.8)	3 (2.3)
Informative websites	35 (26.5)	8 (6.1)	5 (3.8)	7 (5.3)	77 (58.3)
Scientific websites	91 (68.9)	9 (6.8)	9 (6.8)	2 (1.5)	21 (15.9)
Forums	106 (80.3)	4 (3)	2 (1.5)	5 (3.8)	15 (11.4)
Blogs	113 (85.6)	6 (4.5)	3 (2.3)	3 (2.3)	7 (5.3)
Social networks	107 (81.1)	5 (3.8)	13 (9.8)	3 (2.3)	4 (3)
Informative TV shows	111 (84.1)	8 (6.1)	5 (3.8)	3 (2.3)	5 (3.8)
Entertainment TV programs	115 (87.1)	8 (6.1)	5 (3.8)	1 (0.8)	3 (2.3)
Medical drama	115 (87.1)	9 (6.8)	3 (2.3)	2 (1.5)	3 (2.3)
Radio Programs	116 (87.9)	10 (7.6)	4 (3)	2 (1.5)	0
Information-scanning (n=144)					
Physician	116 (80.6)	9 (6.3)	7 (4.9)	2 (1.4)	10 (6.9)
Friends and family	125 (86.8)	1 (0.7)	7 (4.9)	2 (1.4)	9 (6.3)
Newspapers	140 (97.2)	2 (1.4)	1 (0.7)	1 (0.7)	0
Magazines	138 (95.8)	4 (2.8)	1 (0.7)	1 (0.7)	0
Books	138 (95.8)	2 (1.4)	4 (2.8)	0	0
Informative websites	127 (88.2)	1 (0.7)	6 (4.2)	3 (2.1)	7 (4.9)
Scientific websites	135 (93.8)	0	4 (2.8)	2 (1.4)	3 (2.1)
Forums	132 (91.7)	3 (2.1)	5 (3.5)	1 (0.7)	3 (2.1)
Blogs	133 (92.4)	1 (0.7)	3 (2.1)	4 (2.8)	3 (2.1)
Social networks	135 (93.8)	4 (2.8)	4 (2.8)	1 (0.7)	0
Informative TV shows	131 (91.0)	4 (2.8)	5 (3.5)	2 (1.4)	2 (1.4)
Entertainment TV programs	129 (89.6)	6 (4.2)	4 (2.8)	1 (0.7)	4 (2.8)
Medical drama	131 (91)	5 (3.5)	5 (3.5)	0	3 (2.1)
Radio Programs	140 (97.2)	4 (2.8)	0	0	0

We analyzed the characteristics of information seekers in four types of information sources. There was a negative, significant association between the age of seekers and their search for PKU information on online sources (r = -0.17, P = 0.03). There was no significant association between the seekers' age and other information sources: face-to-face (r=0.17, P=0.88), written (r=0.01, P=0.88), and mass media (r=0.84, P=0.31). Table 3 presents the socio-demographic characteristics of seekers in four types of information sources.

Table 3
The relationships between the independent variables and parents' scores of information seeking in four types of information sources

Variables	Face-to-face information sources		Written information sources		Online information sources		Mass media	
	Mean± SD	P-value	Mean± SD	P-value	Mean± SD	P-value	Mean± SD	P-value
Gender								
Male	3.19±1.93	0.05	0.31±1.23	0.07	4.39±4.72	0.95	0.63±1.66	0.35
Female	3.93±2.13		0.83±2.23		4.43±4.45		1.01±2.42	
Degree								
Primary school	4.50±2.36	0.34	0.25±1.00	0.26	3.50±5.39	**0.008**	1.81±3.54	0.07
Secondary school	3.29±2.47		0.78±2.10		2.48±3.38		0.32±0.66	
High school	3.63±1.68		0		3.54±2.58		1.90±3.59	
Diploma	3.61±2.17		1.12±2.64		5.57±4.97		0.65±2.07	
University	4.03±1.30		0.35±1.22		5.70±4.25		1.19±2.08	
Income (Rial)								
<70,000,000	3.86±2.02	0.57	0.66±2.04	0.34	3.95±4.35	0.34	1.20±2.68	0.14
70,000,000-100,000,000	3.58±2.35		0.91±2.18		5.06±4.76		0.60±1.45	
>100,000,000	3.30±1.49		0		5.07±4.59		0.15±0.55	
Health perception								
Poor	4.00±0	0.82	1.25±2.50	0.41	1.25±2.50	0.26	1.50±1.91	0.70
Fair	2.66±2.30		2.66±4.61		0.33±0.57		0	
Good	3.79±2.66		0.62±1.84		4.00±5.03		0.50±1.10	
Very good	3.62±2.02		0.53±1.81		4.69±4.61		0.91±2.32	
Excellent	3.97±1.99		0.85±2.25		4.82±4.07		1.20±2.71	
Having another child with PKU								
Yes	4.00±0	0.11	0	0.39	1.66±3.20	0.12	1.00±1.67	0.92
No	3.71±2.14		0.71±2.04		4.54±4.53		0.90±2.26	

Twenty-four parents (16.7%) reported deliberately avoiding PKU information. The data show that three parents (2.1%) did it sometimes, and three parents (2.1%) rarely did. 114 parents (79.1%) never avoided PKU information. There was no significant correlation between parents' age and their information-seeking (r = -0.06; P-value = 0.44), information-scanning (r = 0.03; P-value = 0.66), and information-avoidance scores (r = -0.10; P-value = 0.20). According to univariate analysis, there was no statistical relationship between the independent variables and information scanning and avoidance behaviors. However, there was a significant difference between the information-seeking scores of parents with different educational degrees (Table 4).

Table 4

Univariate analysis between the independent variables and information-seeking, information-scanning, and information-avoidance scores.

Variables	Information-seeking score		Information-scanning score		Information avoidance score	
	Mean± SD	P-value	Mean± SD	P-value	Mean± SD	P-value
Gender						
Male	8.00± 5.38	0.15	2.63± 5.82	0.91	0.43± 1.22	0.07
Female	9.48± 5.79		2.51± 6.17		0.88± 1.61	
Degree						
Primary school	9.81± 7.25	0.03	2.31± 6.48	0.33	0.75± 1.61	0.22
Secondary school	6.59± 4.43		1.21± 2.64		0.59± 1.40	
High school	8.63± 5.69		4.00± 8.01		1.63± 1.96	
Diploma	10.02± 6.16		2.30± 6.64		0.87± 1.62	
University	10.25± 4.73		4.12± 6.91		0.45± 1.20	
Income (Rial)						
<70,000,000	9.09± 6.05	0.57	2.40± 6.24	0.94	0.79± 1.55	0.79
70,000,000-100,000,000	9.41± 5.51		2.77± 5.57		0.64± 1.43	
>100,000,000	7.53± 3.86		2.61± 6.99		0.92± 1.75	
Health perception						
Poor	6.75± 3.40	0.34	7.00± 11.48	0.47	1.00± 2.00	0.79
Fair	4.33± 0.57		1.33± 2.30		1.33± 2.30	
Good	8.50± 5.84		1.29± 2.64		1.00± 1.76	
Very good	9.01± 5.81		2.54± 6.48		0.63± 1.40	
Excellent	10.26± 5.61		3.02± 6.22		0.79± 1.55	
Having another child with PKU						
Yes	7.83± 5.07	0.59	0	0.29	0.16± 0.40	0.33
No	9.11± 5.73		2.65± 6.16		0.78± 1.55	

Additionally, multivariable analysis showed that the relationship was significant after adjusting for confounding variables (Table 5).

Table 5

Multivariable analysis between the independent variables and information-seeking, information-scanning, and information-avoidance scores

Information-seeking behavior				
Independent variables	B	P-value	95% Confidence Interval for B	
			Lower Bound	Upper Bound
Age (Year)	0.01	0.81	- 0.09	1.25
Gender	1.53	0.16	- 0.61	3.68
Degree	0.79	**0.03**	0.05	0.90
Income (Rial)	- 0.88	0.25	- 2.41	0.64
Health perception	1.02	0.06	- 0.08	2.13
Having another child with PKU	- 1.16	0.63	- 6.02	3.70
Information-scanning behavior				
Age (Year)	0.05	0.36	- 0.06	1.11
Gender	0.03	0.97	- 2.30	2.38

Degree	0.62	0.12	- 0.17	1.42
Income (Rial)	- 0.33	0.69	- 2.00	1.33
Health perception	- 0.06	0.91	- 1.27	1.14
Having another child with PKU	- 3.34	0.21	- 8.64	1.95
Information avoidance behavior				
Age (Year)	- 0.01	0.40	- 0.04	1.01
Gender	0.37	0.20	- 0.21	1.96
Degree	- 0.03	0.72	- 0.23	1.16
Income (Rial)	0.05	0.78	- 0.36	1.47
Health perception	- 0.11	0.47	- 0.41	1.19
Having another child with PKU	- 0.44	0.50	- 1.78	1.88

Discussion

According to our results, physicians were the most highly utilized source of information for parents of children with PKU. Informative and scientific websites were ranked as a preferred source of information after Physicians. It highlights the ongoing importance of face-to-face doctor-patient interactions and the increasing role of online health information. Results have been relatively similar in previous studies. Soong and colleagues reported that the most preferred source of information for patients with dementia and their caregivers was the Internet (websites and forums), followed by healthcare professionals and family and friends (Soong, Au, Kyaw, Theng, & Tudor Car, 2020). Another study of 259 patients with colorectal cancer found that 1 in 3 patients searched for information online and 1 in 4 consulted a healthcare provider for more details (Wieldraaijer, Duineveld, Bemelman, van Weert, & Wind, 2019).

Physicians and nurses are often the first to inform patients and caregivers about the disease. They provide necessary information during the patient education process. However, in hospitals, especially teaching hospitals with large patient volumes, it is difficult for physicians and nurses to provide individualized training for each patient. Providing complementary services, such as the health information prescription (HIP) service, parallel to routine treatment, can improve patient education. HIP is defined as providing the correct information to the right person at the right time (Diggins, 2023), and all these steps are done under the supervision of a physician. It can be provided in various formats, such as brochures, pamphlets, videos, and online resources. Also, it can be tailored to the patient's level of understanding and preferred learning style (Sonika, Sharma, & Singh, 2014).

The Internet was the second most utilized information source among parents of children with PKU. Unsurprisingly, there was a negative and significant association between age and online information-seeking scores. It means young parents use the Internet to search for PKU more than the elderly. Age is one of the main characteristics that significantly affect online information-seeking behavior, as reported in previous studies (Alkhatlan, Rahman, & Aljazzaf, 2018; Jamal et al., 2015; Kyriacou & Sherratt, 2019; Nangsangna & Vroom, 2019). Young parents are more familiar with the elderly. They use the Internet in almost all aspects of daily life, such as entertainment, education, and shopping. However, the quality of health information on the Internet is always challenging (Daraz et al., 2019).

While our findings highlight the frequency with which parents use the internet as an information source, particularly among younger and more educated individuals, this study did not evaluate the quality or credibility of the information accessed. Prior evidence suggests that

online health information varies widely in accuracy, completeness, and readability. In our previous research assessing the quality and readability of health content published by the Iranian Ministry of Health and its affiliates, the overall quality was found to be moderate (mean DISCERN score: 41.1) and the readability level was low (mean Flesch-Dayani score: 35.2), indicating that much of the content was difficult for the general public to understand (Zeinali, Haghparast, Damerchilou, & Vazifehshenas, 2019). These findings emphasize the importance not only of identifying which sources parents use but also of ensuring that these sources meet recognized standards of quality and accessibility. Healthcare providers should proactively guide parents to reliable, readable resources and consider incorporating information prescription practices to support informed decision-making and reduce the potential harms of misinformation.

Out-of-date, incomplete, or incorrect information could mislead the patients and their caregivers. Providing verified and credible content about PKU on hospitals' websites could help parents access accurate information. This finding also highlights the importance of increasing digital literacy among older adults. They may need more hands-on training and support to use technology. Providing classes or workshops specially designed for older adults can be helpful. In line with our findings, a study on COVID-19 in Indonesia found that social media was the most frequently used source of information, while still highlighting the government and healthcare authorities as crucial providers of accurate pandemic information (Linardi, Syakurah, & Moudy, 2021). Another study on COVID-19 in Indonesia reported that although most participants were satisfied with the overall amount of information available online, over half felt there was insufficient detail on screening/testing and treatment (Iskandarsyah, Yudiana, Shabrina, & Passchier, 2022).

In our study, information-seeking behavior, primarily through online sources, was common among highly educated parents. Similar findings were reported in previous studies (Kyriacou & Sherratt, 2019; Nangsangna & Vroom, 2019). The probable explanation is that educated people may have better health literacy, enabling them to understand better and interpret health information. Additionally, they have more information about the availability of online information. When they are not satisfied with the information given by the health practitioners, they search the internet. In some studies, other socio-demographic characteristics such as gender (female) and high income significantly correlated with online health information-seeking (Nangsangna & Vroom, 2019; Tenbult - Van Limpt et al., 2022). Our study could not confirm similar relationships, probably because of the abnormal distribution of gender and income in the sample (more than 71% of participants were female, and only 9% were high-income).

In our study, almost 20 percent of parents avoided PKU information at least occasionally. It was significantly lower than the information avoidance rate reported in cancer studies (50-65%) (Consedine et al., 2006; Miles et al., 2008; Nelissen et al., 2015). A possible explanation could be that fear can affect a person's information behaviors (Sultana, Dhillon, & Oliveira, 2023). In non-acute diseases such as PKU, with available treatments and a good prognosis, patients and their caregivers experience less fear and information avoidance. Our findings show no significant relationship between information avoidance and sociodemographic variables such as age, gender, education level, income, health perception, and having another child with PKU. Similar to our findings, Nelissen et al. reported no significant relationships between information avoidance and age, gender, educational level, or income. However, they claimed

that personal health perception, direct cancer experience, and fear of cancer were predictors of information avoidance (Nelissen et al., 2015).

Avoiding information about a disease can have negative consequences. It can lead to misunderstandings about the disease and its treatment (Soroya, Farooq, Mahmood, Isoaho, & Zara, 2021). Therefore, healthcare providers should be aware of the possibility of information avoidance and provide appropriate support and education to patients and their families. It is recommended that future studies focus on the reasons for information avoidance in parents of children with PKU by qualitative methods. Healthcare providers can help ensure patients receive the best possible care for their condition by addressing the root causes of information avoidance.

This study had some limitations. First, our study was a cross-sectional survey. Therefore, no causal conclusions could be drawn. Also, we used a convenience sample in one teaching hospital in Tehran. Therefore, the results cannot be generalized to the entire population. Finally, the study relied on the parents' self-reported information behavior, which may not accurately reflect their actual behavior.

Conclusion

According to our findings, physicians remained the predominant source of PKU information for parents, highlighting the ongoing importance of doctor-patient communication and education. However, online sources, especially informative websites, were also heavily utilized. Younger, more educated parents were significantly more likely to seek online information about PKU. This underscores the need to increase digital literacy and eHealth skills among older adults. Despite PKU being a chronic, non-acute condition, information avoidance was reported by 20% of parents. While lower than avoidance rates for diseases like cancer, this finding suggests some parents still avoid potentially threatening information. Because avoidance can negatively impact disease management, physicians should be mindful of this possibility. The results can help physicians and public health professionals better meet the informational needs of parents of PKU patients. Future qualitative research could further explore the reasons behind avoidance behaviors. With optimal education and support, parents can gain the knowledge needed to best manage their child's PKU.

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