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The Effect of Internet Information on Mothers with a Newborn Suspected for a Chronic Metabolic Disease

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To the Editor

The Internet is widely available (home, work, libraries), convenient (24h a day) and anonymous. A recent review highlighted the main reasons of using the Internet to search for health information: to gather additional information after a consultation, to access more analytical information about a symptom, a disease or a treatment, to look for information about healthy lifestyles or healthcare services, to participate in an online support group and to self-inform on other treatment alternatives [1].

Some might speculate that Internet usage represents just another channel for activated, information-seeking behavior, in which case the prediction might be for a positive relationship with primary care utilization. Results from studies about the impact of the Internet on health care utilization are heterogeneous, showing a positive relationship between Internet use and service utilization [2].

The National Newborn Screening Program in Greece (NNSPG) is a public health measure for the detection and pickup of newborns with chronic diseases [3]. Medical webpages give the opportunities to have information about the medical problems, therapeutic processes, psychomotor disturbances etc. of the diseases, perinatally. These medical web pages may intensify the psychological stress caused by the request of a second blood sample for the re-measurement of a biomarker.

Phenylketonuria (PKU) is an inborn error of metabolism characterized by the elevated levels of the amino acid phenylalanine in blood and brain. This amino acid is not metabolized to tyrosine because of the deficiency of the hepatic enzyme phenylalanine hydroxylase. The incidence of this disorder may vary from 1:14.000 to 1:18.000 [4].

High concentrations of blood Phenylalanine are toxic to the central nervous system and can cause severe neurological complications, intellectual disabilities, seizures, eczema, etc. [5] The new treatment guidelines of the American College of Medical Genetics and Genomics (ACMG) state that the clinical treatment goal for individuals with PKU is to maintain blood phenylalanine levels within the target range of 120–360 μmol/L for individuals of all ages and that treatment should be lifelong [5]. Dietary treatment, including the use of phenylalanine free medical food and the avoidance of high natural protein food, successfully lowers blood phenylalanine concentrations, in most individuals with PKU [6].

The aim of this study was to evaluate and classify the effect on parents of the medical information obtained from the web about the outcome of phenylketonuria of a suspected for this disease newborn.
The study was in accordance to Helsinki declaration (1980) and (1983) as revised in 2013, as well as by the local ethics committee. Forty eight mothers (48), with average age 27,6 years old took part in this study. These mothers were requested from the NNSPG service for a second blood sample collected from their newborn suspected for PKU.

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We aimed to enlist and classify the information about PKU taken by the mothers using medical web pages. Severe gynecological problems and chronic illnesses of the mother obligated us to exclude certain mothers from this study.

As presented in table I the most frequent information obtained by the mothers was on the mental development of the suspected for PKU infant. Social discrimination and quality of life were also frequent information obtained from the web by the mothers, at 70,8% and 58%, respectively. Surprisingly, severe symptoms and seizures counted only for 16,7%. Additionally, the possibility of dysmorphia and the presence of eczema were searched at 25% and 20,8%, respectively.

Table I: Information about PKU taken from the internet by the mothers (n=48)

Information	**Number of mothers**	**Percent %**
Mental retardations	48	100%
Social discrimination	34	70,8%
Quality of life	28	58%
Dysmorphia	12	25%
Eczema	10	20,8%
Seizures	8	16,7%

Phenylketonuria is characterized by severe mental retardation, seizures, eczema etc., in untreated patients, as mentioned above [7]. In this study, most of the mothers took into account that the most serious symptom of this disorder was mental retardation. Unfortunately, they were not able to differentiate the appearance of the symptoms in treated and untreated patients. This was the point for further explanation and psychological support, as mothers were very anxious to know about the mental outcome of their infant.

Lower quality of life and social discrimination have been reported in patients with diabetes mellitus [9], who are also on a restrictive diet. These patients are mainly treated with a carbohydrate restricted diet and it is reported that they feel a damage in their quality of life and feel social discrimination, especially when they take part in a social event [10]. Similarly, patients with PKU who are predominantly treated with a low protein special diet, including low natural protein intake, supplemented with amino acid medical food is the only therapy of classical phenylketonuria [6,8] are considered to be socially discriminated and also feel an impact on their quality of life, that seems to affect their mothers too.

Additionally, mothers were not interested in the future appearance of their suspected for PKU infant. On the other hand, seizures which is a severe symptom of untreated PKU, did not share much attention in mothers, probably due to the ignorance of the medical term 'seizures' and/or they confused this term with mental retardation.

In conclusion, most of the information obtained from web medical pages by the mothers of a suspected for PKU infant, is correct but not classified, according to the severity of the symptoms of the disease. Further explanation and differentiation of these symptoms between treated and untreated patients is necessary.

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