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Short Communication Open Access

The Role of Educational Status in the Etiology of Maternal Absence of Respond to a Positive Screening Result of Their Infant

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Introduction

The Greek National Newborn Screening Program (GNNSP) follows the rules of WHO, initiated in 1974 and has been performed by the Institute of Child Health (ICH) until now [1,2]. The GNNSP is a public health tool for the early detection and pickup newborns with inherited chronic disorders [1]. This program includes the measurement of biomarkers related to four diseases, which play a very important role in the prevention of mental retardation, hemolysis etc. The GNNSP is taken place shortly after birth for a list of conditions that are treatable, but not clinically evident in the newborn period.

The GNNSP performs screening for the following disorders: Phenylketonuria, galaktosemia, congenital hypothyroidism and C6PD deficiency. The incidence of these disorders is as follows: phenylketonuria 1:18.000, galaktosemia (classical 1:51.000, galactokinaise (GALK) deficiency 1:101000 and udp-4-emiperase (GALE) deficiency 1:153.000), G6PD deficiency (males 5.5%, females 1.7%), continental hypothyroidism approximately 1:3.600 [3,4]. GNNSP is commonly run by national governing bodies with the goal of screening all infants born in the jurisdiction [5,6]. Most newborn screening tests are done by measuring of certain metabolites or enzyme activities, hormones etc in whole dried blood samples collected on special filter paper. Follow-up testing is typically coordinated between specialized and the infant's pediatrician or primary care physician if it is necessary. Both prenatal screening (screening before birth) and newborn screening (screening soon after birth, the latter is usually performed between 3-5 days of life) have improved health care. The first disorder detected by modern newborn screening programs was phenylketonuria, a metabolic condition in which the inability to degrade the essential amino acid phenylalanine can cause irreversible mental retardation unless it is detected early [1]. With early detection and dietary management, the negative effects of the disease can be largely eliminated [7]. Newborn screening around the world is still done using similar filter paper.

If a positive result is detected, employees of the agency, usually special doctors in cooperation with a psychologist and or social worker, begin to try to reach the parents or the doctor or the maternal physician, hospital were the suspected infant was born. They persist until they can arrange and reevaluate a new blood sample of the suspected infant by an appropriate depending on the disease. The specialist will attempt to confirm the diagnosis by repeating the tests by the same and or a different method. The confirmatory test varies depending on the positive results of the initial screen. Confirmatory testing can include analytic specific assays to confirm any elevations detected and functional studies to determine enzyme activity and genetic testing to identify disease-causing by a mutations. In some cases, a positive newborn screen can also trigger testing in other family members, such as sibling who did not undergo newborn screening for the same condition. Depending on the likelihood of the diagnosis and the risk of delay, the specialist will initiate treatment and provide information to the family. Performance of the program is reviewed regularly and strenuous efforts are made to maintain a system that catches every infant with these diagnoses. Guidelines for newborn screening and follow up have been published by the American Academy of Pediatrics [8] and the American College of Medical Genetics [9] and or the European Guidelines [10].

The aim of this study was to find out and classify the reasons because of witch a requested second Guthrie card with DBS was not posted to ICH for a repeated biomarker evaluation of a positive initial screening result.

The study was in accordance to Helsinki declaration (1980) and (1983) as revised in 2013, as well as by the local ethics committee and toke place from jan.01.06 to Dec.31.16. Two hundred fifty-one mothers (n=251), with average age 26.5 years old took part in this study. Maternal educational status as well as their age was taken out from the medical histories of Alexandra Public Maternity Hospital where the infants were born. The second DBS (Guthrie cart) was requested because of lack of uniformity or insufficient blood sample and or border line positive results of phenylalanine or total galactose blood levels. For these reasons we tried to communicate with the mothers with a telephone call.

As shown in Table 1 about half of the mothers had language difficulties. They cannot understand the reason of our telephone call and the letter they had already reserved. A number of mothers (n=42) had reserved a Guthrie card plus the attached information letter but they threw it away because they thought it was a letter of promotion. Roma mothers (n=38) did not accept that they had reserved our letter with Guthrie cart. A group of mothers (n=16) did not pay any attention to our report. A false medical consultation reserved (n=14) mothers. Family's problems such us divorce, accident, health problems of a family's member etc, affected (n=14). Perinatal health problems of the suspected infant obliged some mothers (n=13) to ignore our report. Maternal depression (n=10) was the reason because of which mothers did not react to our report.

With regards to the maternal educational status, most participants had ended Primary School 93/251 (37.0%), were as only 18/251 (7.2%) were graduated with a University degree. High school had finished 51/251 (20.3%). Unfortunately a great number of mothers had not received any education 89/251 (35.5%), they were Illiterates. Out of them 48/89 (53.9%) were immigrants, Roma 35/89 (39.3%) and the rest of them 6/89 (7.3%) were Greeks. It may be suggested that the absence

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Classification of maternal answers	Number	%	Educational status	Number	%
Language problem	104	41.9%	IL	48	46.2%
			PS	44	42.3%
			HS	11	10.6%
			UD	1	0.9%
Misunderstanding	42	16.9%	Il	10	9.6%
			PS	22	66.6%
			HS	10	23.8%
			UD	0	0%
Roma	38	15.3%	IL	35	92.1%
			PS	3	7.9%
			HS	0	0%
			UD	0	0%
Indifferent parents	16	6.5%	IL	5	31.2%
			PS	4	25.0%
			HS	7	43.8%
			UD	0	0%
False metical consultation	14	5.6%	IL	0	0%
			PS	4	28.6%
			HS	6	42.8%
			UD	4	28.6%
Family's problems	14	5.6%	IL	1	7.1%
			PS	2	14.2%
			HS	6	42.9%
			UD	5	35.8%
Perinatal health problems	13	5.4%	IL	0	0%
			PS	1	7.8%
			HS	6	46.1%
			UD	6	46.1%
Maternal Depression	10	4.0%	IL	0	0%
			PS	3	30%
			HS	5	50%
			UD	2	20%
Total	**251** **IL: 89 (35.5%)** **PS: 93 (37.0%)** **HS: 51 (20.3%)** **UD: 18 (7.2%)**	**100%**			

IL: Illiterate; PS: Primary school; HS: High school; UD: University degree.

Table 1: Maternal reaction versus educational status.

and or the low educational status in relation to their misunderstanding of the language may play the most important role in the lack to maternal response to our positive report. Other reasons such as family's problems, mother's depression etc may play a secondary role.

In conclusion, improvement of maternal educational status and learning the native language of the Country were mothers leave may help mothers for a better child care. Translation of the Information Newborn Screening Program Booklet into many foreign languages may be also useful.

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