ORIGINAL ARTICLE

Eastern Journal of Medicine
East J Med 25(1): 77-83, 2020
DOI: 10.5505/ejm.2020.36693

Investigation of Knowledge Levels of Neonatal Screening Programs in Medical Faculty Staff

Fatma Ay[1], Hüseyin Elbi[2], Fatih Özcan[2*]

[1]Göloba District State Hospital, Sivas
[2]Manisa Celal Bayar University Faculty of Medicine Department of Family Medicine

ABSTRACT

Newborn screening tests are an important preventive public health program that provides early detection of the treatable diseases of infants. This study was carried out to investigate the knowledge levels of health workers and administrative staff on neonatal screening programs.

Our research is a descriptive study. The sample wasn't selected, and a questionnaire was conducted to 365 people in a period of about 2 months. The questionnaire used in the research consists of 20 questions prepared by searching the literature to measure the information of participants about neonatal screening programs.

89.04% and 10.95% of the employees participating in our study are health staff and administrative staff, respectively. 69% of the participants were female, and the average age was 33,13. 66% of the participants in the study had service years of 10 years or less while 44% had service years of 11 years and longer. The largest group of the participants in the study is research assistants (28.4%) and the second largest group is nurses (22.1%). The total of General Administrative services, technical services and auxiliary services is 10,94%. It was seen that 98.4% of the participants were aware of the newborn screening tests.

It can be concluded that both physicians and assistant health staff have high knowledge about subjects and applications related to newborn screening tests. However, it is noteworthy that some non-health staff members have inaccurate knowledge and thoughts about some applications related to newborn screening tests.

Key Words: Newborn, screening tests, knowledge level

Introduction

Neonatal screening is an important public health program that enables the early detection of curable diseases by testing them genetically, endocrinological, metabolically and hematological, thus it prevents the mortality and morbidity that may develop (1). Most of these diseases occur in the first two weeks of life and lead to metabolic acidosis, seizures, coma, neurological disorder or even death if not diagnosed and treated early. However, if the children are diagnosed early in the first two weeks of life with screening programs, they have a chance for a better quality of life by starting diet, hormone and other medical treatments (2).

Metabolic diseases effect about 1: 3000–4000 of cumulative live births, although they are rare diseases when evaluated alone. (3-5). Because metabolic diseases are genetically carried, it is a great importance for health care staff to improve the quality of life by taking care of screening programs (6,7).

The first example of neonatal screening is Phenylketonuria. Phenylketonuria was first described by Folling in Norway about 80 years ago (8). Phenylketonuria, Biotinidase Deficiency and Congenital Hypothyroidism are three diseases that have been accepted in almost every country for the screening of newborns without exception (9). In our country, newborn screening started in 1983 for the first time. The National Newborn Screening Program was launched in Turkey on December 25, 2006 with the screening of all newborns for congenital hypothyroidism and phenylketonuria. In October 2009, biotinidase deficiency was added to the screening program (10). In January 2015, Cystic Fibrosis disease was included in the screening program too. In our country, there are also Neonatal Screening Program, Neonatal Hearing Screening Program, Developmental Hip Dysplasia (DDH) Screening Program and Vision Screening Programs in newborn period (11).

Parents and relatives as well as health care staff are responsible for the correct and reliable screening tests of newborns. Information about the risk factors, symptoms and treatment processes associated with congenital diseases is of utmost importance in making early diagnosis and initiating the treatment process. The aim of this study is to investigate the knowledge levels of the medical staff and administrative staff of the

***Corresponding Author:** Dr. Fatih Özcan, Manisa Celal Bayar University School of Medicine, Department of Family Medicine
E-mail: fatihozcan41@gmail.com, Phone: 0 (533) 695 23 04
Received: 11.09.2019, **Accepted:** 10.12.2019

Faculty of Medicine and University Hospital about neonatal screening programs.

Material and Methods

This study is a descriptive study aimed to investigate the knowledge levels of health care and administrative staffs of the Faculty of Medicine and university hospital about neonatal screening programs. The population of our study consists of faculty members, specialist physician, research assistant, general practitioner, intern physician, nurse, midwife, other health care staff, general administrative services, technical services and auxiliary services working in the Medical Faculty and Hospital.

The study was conducted between March 2017 and May 2017 at Faculty of Medicine and university hospital. Criteria for inclusion in the study were determined to be older than 18 years, corporate employee and volunteer. The sample was not selected and approximately 375 people were reached in a two-month period. Ten people in this group refused to participate in the study. In the study, a questionnaire with 20 questions was used to measure the knowledge level about neonatal screening programs and socio-demographic information. In order to conduct this study, the approval was obtained from Medical Faculty Health Sciences Ethics Committee. Written and verbal consents were obtained from the volunteers who agreed to participate in the study.

Descriptive statistics for the continuous variables were presented as Mean, Standard deviation, minimum and maximum values while count and percentages for categorical variables. Chi-square test was performed to determine the relationship between categorical variables. Statistical significance level was considered as 5% and SPSS (ver: 15) statistical program was used for all statistical computations.

Results

365 people participated in our study. The average age of the participants was 33,13 (± 8,59 maxes: 60.00, min: 19.00). 69.00% of the participants were women and 45.10% of them had at least one child (Table 1). It was determined that most of the faculty members who participated in our study had a working period of more than 20 years (81.30%), specialist physicians (73.00%) had a working 10 years or less, and 41.20% of the ones working in general administrative services had more than 20 years of working period.

All faculty members, specialist physicians, research assistants, general practitioners, interns, nurses, midwives and technical services employees (100%), other health care staff (95.70%), the most of general administrative services employees (94%), most ancillary service workers (60.00%) were found to be aware of newborn screening tests. 1.60% of the occupational groups, who were not aware of the newborn screening tests, were other health care staff, general administrative services and auxiliary services.

In the study, the participants having children had significantly higher knowledge of screening tests about Phenylketonuria ($p = 0.008$), Congenital Hypothyroidism ($p < 0.001$), Biotinidase Deficiency ($p < 0.001$), Cystic Fibrosis Disease ($p < 0.001$), hearing ($p = 0.034$) and vision ($p = 0.041$) (Table 2). It was noted that physicians had a significantly higher awareness of the status of having information about neonatal screening tests compared to occupational groups (Table 3).

The ideal screening method and periods for neonatals were less known by the administrative and technical staff. The ideal screening for Congenital Hypothyroidism, Phenylketonuria, Biotinidase Deficiency, Cystic Fibrosis diseases was answered correctly by 50.80% of physicians, 39.2% of assistant health care staff, and 19.40% of administrative and technical staff. Health care staff were significantly better at screening for Congenital Hypothyroidism, Phenylketonuria, Biotinidase Deficiency and Cystic Fibrosis diseases ($p < 0.001$).

The ideal screening method for Congenital Hypothyroidism, Phenylketonuria, Biotinidase Deficiency and Cystic Fibrosis diseases was correctly answered by 91.70% of physicians, 89.20% of auxiliary health care staff, and 58.30% of administrative and technical staff. According to occupational groups, knowing the ideal screening time of congenital hypothyroidism, phenylketonuria, biotinidase deficiency, cystic fibrosis diseases, was extremely important for health care staff ($p < 0.001$).

The ideal period of hearing screening test and developmental hip disorders were generally less well known by all participants than other methods. 52.80% of physicians, 63.80% of assistant health care staff and 44.40% of administrative and technical staff answered the ideal period of hearing screening test correctly. In terms of developmental hip disorders, 47.70% of

Table 1. Distribution of sociodemographic characteristics of the participants

Features		n	%
Age (Mean ± SD, Min, Max)	33.13±8.59 (19-60)	365	100.0
Gender	Female	252	69.0
	Male	113	31,0
Education	Primary education	2	0.5
	Secondary education	28	7.7
	Associate degree	28	7.7
	University	140	38.4
	PhD / Specialist	167	45.8
Marital status	Married	201	55.1
	Single	153	41.9
	Divorced	11	3.0
Having child	Yes	164	45.1
	No	200	54.9
Occupation	Faculty member	16	4.4
	Specialist	15	4.1
	Research Assistant	104	28.5
	General practitioner	1	0.3
	Intern Doctor	57	15.6
	Other medical staff	132	36.1
	Administrative personnel	40	11.0

physicians, 46.20% of assistant health care staff and 36.10% of administrative and technical staff answered the ideal screening period correctly. 49.20% of physicians, 50.00% of auxiliary health care staff and 55.60% of administrative and technical staff answered the ideal period of neonatal vision screening. According to the occupational groups, no statistically significant difference was found between knowing the ideal period of these three screening methods.

The status of knowing the reasons for the neonatal screening programs according to occupational groups were shown at Table 4. 47.20% of physicians, 68.50% of auxiliary health care staff and 58.30% of administrative and technical staff answered ensuring early diagnosis of rare diseases correctly. 60.10% of physicians, 48.50% of auxiliary health care staff, and 33.30% of administrative and technical staff answered ensuring normal physical and mental development correctly. 92.70% of physicians, 82.30% of auxiliary health care staff and 86.10% of administrative and technical staff accurately answered the option of preventing or minimizing sequelae with early treatment. There was a statistically significant difference between the occupational groups in terms of being a health care staff for all three questions.

Discussion

It is aimed to start treatment in the first twenty days of life in diseases determined by neonatal screening. It is recommended that the first blood sample must take on the 3-5th day after birth for newborn screening. Therefore, in order to reach as many infants as possible, health institutions should take screening samples from newborns as a priority, and they should state that the families should get a new blood sample by applying the nearest health center in the first week (12).

In a study conducted to determine the knowledge level of families about the Guthrie test, most of the families (66.00%) had knowledge about the heel blood, but they did not know enough information about the disease with which can be

detected with heel blood (54.70%). It was found that 62.3%, 66.00% and 79.20% of the families did not know the phenylketonuria test, the Congenital Hypothyroidism test and the Biotinidase test, respectively. 94.30% of the families known that taking blood from the heel was an important test and provided useful information, and 92.50% of them known that the heel blood test was an identified health problem. However, 50.90% of the families thought that the heel blood test was a painful procedure for the child (13). While the awareness rate on screening tests was higher than 90% among the health care staff participating in our study, this rate was found to be 60% among the other participants. The awareness of participants who are not health care staff can be considered like other studies based on community.

In 2014, according to the study of Evcili et al, 60.60% of the mothers did not know that phenylketonuria caused an irreversible brain damage for the infant, however 55.00% of them known that the disease findings were exacerbated if early treatment was not started (14). In another study conducted by Evcili et al. about newborn screening tests, 51.30% of the mothers known that hereditary diseases could cause mental retardation in the infant, and 42.00% of them knew that hereditary diseases might cause growth and developmental delay in the baby. Moreover, 44.50% of the mothers knew that hereditary diseases could be detected through some tests and 34.20% of them were uncertain (15). The incidence of knowledge about screening tests was found to be significantly higher in the participants having children in our study. This significant difference can be attributed to the fact that a significant majority of the participants was health workers. When the data of the study were examined, it can be stated that physicians gave good answers at first to recognize the ideal screening method of heel blood diseases and the ideal times of hearing-vision-DDH scans, however administrative and technical staff did not have any enough information about this issue. The lack of enough knowledge of the administrative and technical staff can be attributed to the fact that they are not adequately informed about the diseases. In a study conducted for nursing and midwifery students, it was found that there was not enough information about DDH risk factor and prevention methods (16). If hearing loss is not diagnosed early in the newborn period, speech-language development and communication as well as adaptation of the child to the environment are negatively affected (17,18). According to the study on this subject, 39.90% of the mothers known that a newborn baby should be tested for hearing screening within the first month, however 43.50% of them were doubtful about it (15). When the findings of our study were evaluated, it can be noted that the ideal screening time of hearing, DDH and visual screening test were not enough for the participants who did not give active health service in accordance with the results of literature.

In a study conducted to measure the knowledge of pediatricians about DDH, 86.70% of the participants stated that the treatment should be started at the earliest age because DDH treatment will become difficult when the baby grows (19). In our study, it was found that health care staff had more knowledge about the reason for screening programs in general. In conclusion, when we evaluate the results of our study, it can be conluded that both physicians and assistant health care staff have a high level of knowledge about the subjects and practices related to neonatal screening tests. However, some administrative and technical staff who participated in our study have incorrect information and thoughts about some practices such as “strict arson practice is the right procedure” and “may not be aware of the necessity of premarital education”, so this study reveals the importance of the education for non-health care staff.

Table 2. Having information about newborn screening tests according to having a child

Having a child	Phenylketonuria		Congenital hypothyroidism		Biotidinase deficiency		Cystic fibrosis		DHD		Hearing		Seeing	
	True Reply n/%	False Reply n/%	True Reply n/%	False Reply n /%	True Reply n/%	False Reply n /%	True Reply n/%	False Reply n /%	True Reply n/%	False Reply n/%	True Reply n/%	False Reply n/%	True Reply n/%	False Reply n/%
Yes	117/78,50	32/21,50	90/60,80	58/39,20	50/33,60	99/66,40	44/29,50	105/70,50	109/73,20	40/26,80	132/88,60	17/11,40	97/65,10	52/34,90
No	165/89,20	20/10,80	148/80,00	37/20,00	121/65,40	64/34,60	115/62,20	70/37,80	125/67,60	60/32,40	148/80,00	37/20,00	100/54,10	85/45,90
Total	282/84,40	52/15,60	238/71,50	95/28,50	171/51,20	163/48,80	159/47,60	175/52,40	234/70,10	100/29,90	280/83,80	54/16,20	197/59,00	137/41,00
P	0,008		0,001		0,001		0,001		0,268		0,034		0,041	

DHD: developmental dysplasia of hip

Table 3. Having knowledge about newborn screening tests according to occupational groups

Occupation	Phenylketonuria		Congenital hypothyroidism		Biotidinase deficiency		Cystic fibrosis		DHD		Hearing		Seeing	
	True Reply n/%	False Reply n/%	True Reply n/%	False Reply n/%	True Reply n/%	False Reply n/%	True Reply n/%	False Reply n/%	True Reply n/%	False Reply n/%	True Reply n/%	False Reply n/%	True Reply n/%	False Reply n/%
Doctor	169/91,40	16/8,60	159/86,40	25/13,60	132/71,40	53/28,60	118/63,80	67/36,20	132/71,40	53/28,60	147/79,50	38/10,50	96/51,90	89/48,10
Other health staff	107/86,30	17/13,70	72/58,10	52/41,90	38/30,60	86/69,40	39/31,50	85/68,50	87/70,20	37/29,80	111/89,50	13/10,50	83/66,90	41/33,10
Administrative personnel	6/23,10	20/76,90	7/26,90	19/73,10	1/3,80	25/96,20	2/7,70	24/92,30	16/61,50	10/38,50	23/88,50	3/11,50	19/73,10	7/26,90
Total	282/84,20	53/15,80	238/71,30	96/28,70	171/51,00	164/49,00	159/47,50	176/52,50	235/70,10	100/29,90	281/83,90	54/16,10	198/59,10	137/40,90
p	0,001		0,001		0,001		0,001		0,592		0,050		0,010	

DHD: developmental dysplasia of hip

Table 4. Knowing the reason of the newborn screening programs

	Doctor		Other health staff		Administrative personnel		Total	p
	True Reply n/%	False Reply n/%	True Reply n/%	False Reply n/%	True Reply n/%	False Reply n/%		
4a	91/47,20	102/52,80	89/68,50	41/31,50	21/58,30	15/41,70	359/100,00	0,001
4b	116/60,10	77/39,90	63/48,50	67/51,50	12/33,30	24/66,70	359/100,00	0,005
4c	179/92,70	14/7,30	107/82,30	23/17,70	31/86,10	5/13,90	359/100,00	0,015
4d	71/36,60	122/63,20	47/36,20	83/63,80	11/30,60	25/69,40	359/100,00	0,773

4a. Ensuring early diagnosis of rare diseases
4b. To ensure normal physical and mental development
4c. Prevent or minimize sequelae with early treatment
4d. Getting the chance of prenatal diagnosis for subsequent pregnancies

References

1. Fingerhut R, Olgemöller B. Newborn screening for inborn errors of metabolism and endocrinopathies: an update. Anal Bioanal Chem 2009; 393: 1481-1497.
2. Levy PA. An overview of newborn screening. J Dev Behav Pediatr 2010; 31: 622-631.
3. R.A.F Bell. A Clinical Guide to Inherited Metabolic Diseases. Arch Dis Child 2003; 88: 945-947.
4. Madhava M.A. clinical guide to inherited metabolic diseases. Arch Dis Child 2006; 91: 875.
5. Wilcken B, Rinaldo P, Matern D. Newborn Screening for Inborn Errors of Metabolism. Inborn Metabolic Diseases Diagnosis and Treatment. Fifth Ed. New York 2012: 75-86.
6. Hacettepe Üniversitesi [İnternet]. Türkiye Nüfus ve Sağlık Araştırması, 2008. http://www.hips.hacettepe.edu.tr/TNSA2008-AnaRapor.pdf (Erişim Tarihi: 01.07.2019).
7. Tuncbilek E.Akraba evlilikleri. Gorunum 2011. file:///C:/Users/ASUS/Downloads/GOcak2011.pdf (Erişim Tarihi: 01.07.2019).
8. Zeybek ÇA. Fenilketonüri Tarama Programı. İ.Ü. Cerrahpaşa Tıp Fakültesi Sürekli Tıp E¤itimi Etkinlikleri, Sempozyum Dizisi 2003; 35: 65-71.
9. Wilcken B. Recent advances in newborn screening. J Inherit Metab Dis 2007; 30: 129-133.
10. Bakar Tiker F. Genişletilmiş yenidoğan taraması, Türkiye Klinikleri Pediatri Dergisi 2012; 21: 212-223.
11. Sağlık Bakanlığı [İnternet]. İzleme ve Değerlendirme Eğitimi Rehberi. http://cocukergen.thsk.saglik.gov.tr/bilgi-dokumanlar/raporlar.html# (Erişim Tarihi: 01.07.2019).
12. Türkiye Anne, Çocuk ve Ergen Sağlığı Enstitüsü [İnternet]. https://www.tuseb.gov.tr/enstitu/tacese/tarama-programlar (Erişim Tarihi: 01.07.2019).
13. Arıkan D, Sağlık S, Bakar P. Yenidoğan bebek sahibi ailelerde Guthri tanımla testi hakkında bilgi düzeyinin belirlenmesi. Sted 2017; 26: 89-95.
14. Evcili F, Demirel G, Yurtsal ZB, Yıllmaz EA. Yenidoğan tarama testleri eğitiminin annelerin bilgi düzeyine etkisi. GÜSBD 2017; 6: 80-86.
15. Evcili F, Cesur B, Yurtsal B, Kaya N. Annelerin yenidoğan tarama testlerine ilişkin görüşlerinin ve tarama programlarına katılma durumlarının belirlenmesi. Mersin Univ Sağlık Bilim Derg 2017; 10: 25-35.
16. Uzel M, Ergün UG, Celik M, Ekerbiçer H, Cetinus E, Karaoğuz A. Knowledge and attitude of nursing and midwifery college students on developmental dysplasia of the hip. Acta Orthop Traumatol Turc 2006; 40: 377-383.
17. Hahn M, Lamprecht-Dinnesen A, Heinecke A, et al. Hearing screening in healthy newborns: feasibility of different methods with regard to test time. İnt J Pediatr Otorhinolaryngol 1999; 51: 83-89.
18. Thompson DC, McPhillips H, Davis RL, Lieu TL, Homer CJ, Helfand M. Universal newborn hearing screening: summary of evidence. JAMA 2001; 286: 2000-2010.
19. Külcü NU, Orak MM, Gerenli N, Sarı E, Say A. Bir Eğitim Hastanesinde Çocuk Hekimlerinin Gelişimsel Kalça Displazisi ile İlgili Bilgi Düzeyleri. J Curr Pediatr 2015; 13: 89-96.