



# Views of Mothers about National Newborn Screening Tests Performed in Turkey

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## Abstract

**Background:** Newborn screening tests for detecting numerous congenital diseases that may cause disability or death were performed first in 2006 in Turkey. Newborn screenings for Phenylketonuria and congenital hypothyroidism have increased in recent years due to the emergence of new diseases. It is essential for healthcare personnel and families to carry out these screening programs in a timely, accurate, and efficient manner. Informing families, particularly mothers, about these screening tests will help more newborn babies benefit from these tests.

**Objectives:** This study aimed to explore mothers' views about newborn screening programs in Turkey.

**Methods:** This descriptive and cross-sectional study included 112 volunteer mothers and was conducted at Zekai Tahir Burak Hospital, Ankara, Turkey, from December 2018 to January 2019.

**Results:** Although mothers in Turkey were to some extent informed about the screening tests, they did not have sufficient information regarding the objective of these tests. Moreover, the majority of mothers expressed a positive opinion about the tests and stated that they would have these tests done even if they had to pay for them.

**Conclusion:** Based on the obtained results, although mothers in Turkey were not sufficiently knowledgeable about screening tests and their objectives, they expressed positive views about these tests. Therefore, it is recommended that families should be informed about newborn screening tests through mass media, educational environments (pregnancy schools), and screening test centers. Therefore, it is important to organize in-service training for midwives and nurses to raise their awareness in this regard.

**Keywords:** Mothers, Newborn, Screening test

## 1. Background

Newborn screening programs are important preventive health services under public health programs in both developed and developing countries around the world (1). National screening programs are conducted for treatable newborn diseases that are prevalent in the Turkey community. Newborn screening program includes tests that are conducted after birth and can detect numerous congenital diseases that may affect the whole life of the newborn and even cause death at an early age (1,2). Newborn screening programs in Turkey include the Turkish newborn screening program, Neonatal Screening Program (NSP), Newborn Hearing Screening Program (NHSP), and Screening for Developmental Dysplasia of the Hip (SDDH). Screening newborns for phenylketonuria and congenital hypothyroidism using heel lance procedure has been compulsory in Turkey since 2006 as part of the NSP. The scope of this program was expanded to include biotinidase deficiency in 2008 and cystic fibrosis in 2015. Congenital adrenal hyperplasia screenings were initiated in Konya, Adana, Kayseri, and Samsun Provinces, as pilot cities, in 2017. Moreover, NHSP and SDDH were

initiated in 2004 and 2010, respectively (3,4).

Consanguineous marriages increase the incidence and prevalence of congenital diseases. The rate of consanguineous marriages is high (23.2%) in Turkey (5). This high rate of consanguineous marriages increases the importance of newborn screenings. Therefore, due to the high rate of consanguineous marriages in Turkey, it is vital to detect congenital diseases and start treatments after birth at the earliest time possible (6,7).

The responsible health care personnel and newborns' families play a central role in conducting these screening programs in a timely, adequate, and efficient manner (8-10). Furthermore, knowledge and awareness of the families, especially mothers, about screening programs are essential factors in the successful implementation of screening programs. If mothers are not sufficiently knowledgeable about national screening programs and have negative opinions about these tests, they will refuse to have their infants tested in time to prevent their babies from getting hurt by invasive interventions (e.g. heel lance). The study conducted by Doğruel revealed that people did not bring their children to be screened for developmental dysplasia of the hip even though they were educated about developmental dysplasia of the

hip (DDH) (11).

## 2. Objectives

This study aimed to explore mothers' views regarding newborn screening programs.

## 3. Methods

The study population in this descriptive and cross-sectional study included the mothers of newborns admitted in the newborn clinics of Zekai Tahir Burak Woman's Health Training and Research Hospital, affiliated with the University of Health Sciences, Ankara, Turkey, between December 2018 and January 2019. The study objectives were explained to 112 mothers who agreed to participate in this study and sampling was conducted among mothers who gave verbal consent for participation in the study. The data obtained from the study literature were presented as a 43 items questionnaire regarding the sociodemographic characteristics of the participants and their knowledge of newborn screening programs (9,12-14). The necessary corrections were made on the sociodemographic characteristics forms and they took their final form after data collection was tried on five parents using the initial questionnaires. Research data were collected through face-to-face interviews with 112 mothers whose written and verbal consent were obtained previously. The time required for the completion of each questionnaire was approximately 10-15 minutes. Data were analyzed in SPSS software (version 24, 0) through percentage calculations and Fisher's chi-square test.

After questions were asked, mothers who took the survey were generally informed about the importance of neonatal screening programs.

## 4. Results

### 4.1. Mother's sociodemographic characteristics

Mothers' sociodemographic characteristics are presented in Table 1. Based on the data in Table 1, 42.9 %, 30.4%, and 74.3% of the mothers were in the age range of 26-35 years, secondary school graduates, and unemployed, respectively. Moreover, 75.9% and 42.9% of mothers had a nuclear family, and the income level between 1500 and 3000 Turkish Liras, respectively. Eventually, 81.3% of the mothers lived in the city center, and 85.7% did not have a blood relation with their spouses.

### 4.2. Knowledge status, information sources of mothers, and their views about newborn screening tests

Mothers' status of knowledge regarding neonatal screening tests according to mothers' sources of knowledge and their certain opinions about the screening tests is presented in Table 2. Based on the

**Table 1.** Mothers' socio-demographic characteristics

Characteristics (n=112)	N	Percentage (%)
<b>Age</b>		
18 years and younger	3	2.7
19-25	46	41.1
26-35	48	42.9
36 years and older	15	13.4
<b>Education</b>		
Primary school and below	16	14.3
Secondary School	34	30.4
High school	31	27.7
Undergraduate and higher	31	27.7
<b>Family Type</b>		
Nuclear family	85	75.9
Extended family	27	24.1
<b>Place of residence</b>		
City Center	91	81.3
Town / Village / Township	21	18.8
<b>Working Status</b>		
Employed	28	25.7
Unemployed	81	74.3
<b>Income Level</b>		
Less than 1500 ₺	37	33.0
Between 1500-3000 ₺	48	42.9
Over 3000 ₺	27	24.1
<b>Blood relation</b>		
Consanguine marriage	16	14.3
Not applied	96	85.7
<b>Regular Control</b>		
Yes	105	93.8
No	7	6.3

presented data, 73.2% of mothers were aware of the neonatal screening tests. The evaluation of mothers' sources of knowledge indicated that 81.1%, 86.1%, and 83.8% of mothers were informed about heel stick blood sampling, hearing test, and developmental dysplasia of hip screening from some health personnel, respectively. Moreover, 67.9% of the mothers stated that the tests shouldn't be performed without parents' consent and 75% emphasized that

**Table 2.** Knowledge status, information sources of mothers, and their views about newborn screening tests

Properties	N	%
<b>Status of Knowledge about Newborn Screening Programs (n = 112)</b>		
Yes	82	73.2
No	30	26.8
<b>Information Sources</b>		
<b>Heel blood screening o (no= 90)</b>		
Health personnel	73	81.1
Internet	17	18.9
<b>Hearing screening (n = 79)</b>		
Health personnel	68	86.1
Internet	11	13.9
<b>Hip dislocation screening (n = 68)</b>		
Health personnel	57	83.8
Internet	11	16.2
<b>Permission for Newborn screening tests (n=112)</b>		
Required	76	67.9
Not required	24	21.4
No idea	12	10.7
<b>If tests are done against payment, will you have the test done? (n=112)</b>		
Yes	84	75.0
No	20	17.9
No idea	8	7.1

**Table 3.** Mothers' statuses of knowledge about the objectives of newborn screening tests and their effectiveness (N = 112)

Properties	N	Percentage (%)
<b>Knowledge status</b>		
<b>Knowledge about Heel Blood Screening</b>		
Yes	41	36.6
No	71	63.4
<b>Knowledge about Hearing Screening</b>		
Yes	72	64.3
No	40	35.7
<b>Knowledge about Hip Dislocation Screening</b>		
Yes	57	50.9
No	55	49.1
<b>Heel Blood Screening</b>		
Beneficial	103	92
Not beneficial	9	8
<b>Hearing Screening</b>		
Beneficial	103	92
Not beneficial	9	8
<b>Hip Dislocation Screening</b>		
Beneficial	100	89.3
Not beneficial	12	10.7

they would get their babies screened even if they need to pay for that.

#### 4.3. Mothers' statuses of knowledge about the objectives of newborn screening tests and their effectiveness

Knowledge statuses of mothers about the objectives of newborn screening tests and their effectiveness are presented in Table 3. Based on the presented data, 63.4% of the mothers didn't know about the purpose of the heel prick test; however, 3% and 50.9% of mothers knew about the hearing test and the purpose of developmental dysplasia of hip screening, respectively. Evaluation of mothers' thoughts on benefits of neonatal screening tests revealed that 92% of mothers found heel prick and hearing tests useful, and 89.3% believed in the effectiveness of dysplasia of hip screening.

#### 4.4. Mothers' status of knowledge about neonatal screening tests based on their employment status

Based on the data in Table 4, working mothers had more knowledge about the tests, compared to non-working mothers and there was a statistically significant difference between them in this regard ( $P=0.028$ ). However, no statistically significant difference was observed between the mothers' status of knowledge about the screening tests and other demographic data. Therefore, a single table was created.

**Table 4.** Mothers' status of knowledge about neonatal screening tests based on their employment status

Working status	Mothers' knowledge of newborn screening tests			
	Yes		No	
	Number	%	Number	%
<b>Employed</b>	25	89,3	3	10,7
<b>Not employed</b>	57	67,9	27	32,1

Fisher Test: 4.873  $P=0.028$

## 5. Discussion

Today, several deadly congenital metabolic diseases can be diagnosed early thanks to the neonatal screening programs that are performed after the birth of the baby. Therefore, an early diagnosis of these diseases can be made in the early neonatal period and newborn infant morbidity and mortality rates have been reduced by appropriate treatment protocols, thanks to these tests (15,16). Accordingly, Neonatal Screening Programs are seen as an essential part of the public health system (16,17).

The improvement of mothers' knowledge about the purpose of these tests reduces their worry and makes them feel better (18). Based on the obtained results, mothers in this study were aware of neonatal screening programs; however, their knowledge was not complete, especially regarding the purpose of the heel prick test. Based on the results of another study, 42% of the parents believed that the heel prick test is performed only to identify phenylketonuria (19).

In this study, it was found that health personnel were the most significant source of knowledge for mothers to obtain information about neonatal screening programs. Internet, television, and brochures were other sources of access to information; however, they were less favored options, compared to health personnel. The results of another study indicated that 81.8% of the families get information about tests from the health personnel, which was in line with the results of the present study (19).

Consistent with the results of the present study, the data analysis of Turkey Population and Health Research (TPHR), dated 2013, revealed that mothers get 95% of their information about prenatal care from their doctors. It is worth mentioning that written materials, such as brochures were not much-preferred sources of knowledge. This can be attributed to the low education level of participant mothers.

The study findings indicated that most of the mothers would agree to have their infants screened by neonatal tests in the future even if they needed to pay for these tests. Based on the results of another study, 96.7% of parents defended the idea of free screening tests; however, 68.5% stated they would welcome these tests whether or not they required payment (19). Another study conducted in Finland indicated that parents were not concerned about test costs (20). The common point in all these studies is that although parents believe that these tests should be free, they will still take the tests even if they are charged for the tests.

More than half of the mothers in the present study asserted that they want their permission (whether or not they want their infants to be screened) to be taken in advance. In a similar study, 82.8% of the

participants mentioned this permission requirement (19). However, 46.0% of mothers in a different study believed that their consent for the performance of the routine screening tests is not required since they believed these tests to be simple and safe (21).

According to the results of the aforementioned studies, it can be concluded that families want to be informed about the content, benefits, and risks involved with the screening tests before deciding to have their newborns screened. On the contrary, research in the USA showed that health personnel believed that getting permission from parents would reduce the number of participants in neonatal screening tests (22).

Moreover, a statistically significant correlation was observed between the employment status of the mothers and their knowledge status about neonatal screening tests. This can be explained by the fact that working mothers' educational level is higher than that of the unemployed mothers, and that they have better access to information.

## 6. Conclusion

The high prevalence of congenital metabolic diseases in Turkey caused by the high rate of consanguineous marriages in this country indicates that today neonatal screening tests are more important than ever. It is essential to increase the parents' knowledge about the subject since having information about these tests increases the chance of their being performed on time and facilitates the early diagnosis and treatment process.

Based on the obtained results, mothers were not sufficiently knowledgeable about screening tests and their objectives; however, they expressed positive views about these tests. Therefore; it is recommended that families should be informed about screening tests through mass media, educational environments, such as pregnant women schools, and screening test centers.

Midwives and nurses are charged with the great responsibility to inform parents at every step of the newborn screening tests. Therefore, it is important to organize in-service training for midwives and nurses to raise their awareness on the subject.

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## Footnotes

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