KNOWLEDGE OF MOTHERS OF NEWBORNS ABOUT BIOLOGICAL NEWBORN SCREENING

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ABSTRACT

Objective: to evaluate the level of knowledge of mothers of newborns about biological neonatal screening. Method: a descriptive exploratory study with a quantitative approach, developed in the Rooming-in and Kangaroo Rooms of the Integrated University Health Center, located in the Sanitary District II of the city of Recife, PE, with reference to the State Health System in Pregnancy Care in Alto. Data were collected in interviews with 109 postpartum women, using a script with pre-defined variables, submitted to statistical analysis. Results: there was a predominance (84.40%) of participants who did not know the best time to perform the heel prick test; 55.04% reported having been instructed in the prenatal period and/or after delivery, 92.66% knew that the test was mandatory. 59.63% knew the purpose of the test. Conclusion: It is emphasized that mothers' knowledge about biological neonatal screening is essential for greater adherence to the test, highlighting the role of health professionals in educational actions to raise awareness of mothers in adhering to this procedure.

Keywords: Knowledge. Parent. Newborn. Neonatal Screening.

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INTRODUCTION

Biological neonatal screening (TNB), or "heel prick test", is a preventive action that allows the diagnosis of congenital diseases in the neonatal period. The test is performed from a blood sample, collected from the newborn's heel, ideally in the period between 48 hours after birth and the 5th day of the newborn's life [1,2]. Performing the collection in this period of time allows the initiation of specific early treatment and the reduction or elimination of sequelae associated with the diseases detected.

On May 26, 2021, Federal Law No. 14,154, which amends Law No. 8,069, of July 13, 1990 (Statute of the Child and Adolescent), was sanctioned to improve the National Neonatal Screening Program (PNTN). The Law establishes a minimum list of diseases to be screened by the heel prick test, expanding the number of diseases screened[3,4]. The heel prick test offered by the Brazilian Unified Health System is capable of detecting phenylketonuria (PKU), congenital hypothyroidism, sickle cell disease and other hemoglobinopathies, cystic fibrosis, congenital adrenal hyperplasia and biotinidase deficiency[1].

The National Neonatal Screening Program aims to investigate the presence of the aforementioned diseases in the pre-symptomatic phase in all Brazilian newborns and to reduce morbidity and mortality related to congenital pathologies in newborns[1]. It is necessary for parents of newborns to be aware of the program and biological neonatal screening — a right guaranteed by the Statute of the Child and Adolescent[1,4]. It is the responsibility of the health professional, especially the primary health care nurse, to guide the pregnant woman and other direct guardians of the child about the importance of the test[1]. Thus, the understanding of those responsible for the test is essential to ensure the total coverage of the National Neonatal Screening Program in Brazil[5].

In the country, between 2017 and 2019, the PNTN had an average of 82% of newborns screened[6]. In Pernambuco, in this same time range, the average number of newborns who underwent biological neonatal screening was 72.8%[7]. Thus, a drop of about 10% is noted when comparing the Pernambuco average with the national average.

After searching the literature on PNTN and TNB, it was noticed that there is a lack of studies that assess the population's knowledge about biological neonatal screening, especially in the state of Pernambuco. It is noteworthy that the lack of knowledge of the test results in low levels of adherence. Therefore, this study provides us with current data on the subject that may serve as support for health professionals who study the subject. In view of this, the understanding of mothers of newborns about the heel prick test is satisfactory.

Thus, the main objective of this study was to evaluate the level of knowledge of mothers of newborns about biological neonatal screening.

METHOD

This is a cross-sectional, exploratory study with a quantitative approach. The research was developed in the Rooming-in and Kangaroo Quarters of the Amaury de Medeiros Integrated University Health Center (CISAM), which belongs to the hospital complex of the University of Pernambuco (UPE). CISAM, located in the Sanitary District II of the city of Recife, has been a reference for the State Health System in the Care of High-Risk Pregnancy since 2004[8]. The use of the quantitative method aims to bring to light data with practical applicability, phenomena that can be enumerated, measured, and reproduced in a given historical, social and cultural context[9].

The study population was composed of mothers of newborns who were hospitalized in the Rooming-in and Kangaroo Quarters. The inclusion criteria addressed mothers of newborns over 18 years of age. The exclusion criteria ruled out mothers who were unable to answer the questionnaires due to cognitive limitations or difficulties arising from illiteracy.

The sample size calculation was random, determined by the number of participants who agreed to participate in the research between the months of May and July 2024, making a total of 109 participants. Data were collected from two self-administered instruments: a sociodemographic and obstetric questionnaire composed of 10 questions to identify the profile of the participants and a questionnaire composed of 08 questions about biological neonatal screening, which aim to identify the level of knowledge of the participants about biological neonatal screening. The two questionnaires were prepared by the authors.

The data were digitized in electronic spreadsheets, the statistical treatment was performed using *the Statistical Package for the Social Sciences* (SPSS) software, version 21.0, through the elaboration of simple tables and percentages. The existence of an association between two categorical variables was evaluated using the Chi-square statistical test (Fisher's exact test), adopting a margin of error of 5%, and the degree of association between two categorical variables was evaluated by the prevalence ratio and the respective confidence interval (95%).

In compliance with Resolution No. 466, of December 12, 2012 of the Ministry of Health, the study was submitted to the Research Ethics Committee (REC) of CISAM, where it was carried out [10]. Approval was obtained on May 13, 2024, with approval protocol

number 6,820,881. Before data collection, the participants were given the Informed Consent Form (ICF) in order to ensure the autonomy of the participants.

RESULTS

At the end of data collection, 109 postpartum women answered the two self-administered instruments. The sociodemographic characteristics of the participants are presented in Table 1. There was a predominance in the age group of 23-32 years (48.62%), 35.77% had more than two children and 43.11% had completed high school. 55.04% reported having been instructed about the heel prick test in the prenatal period and/or after delivery.

Table 1 - Sociodemographic characterization of the puerperal women participating in the study.

Variables	n	%
Age group		
18-22 years	27	24,77
23-32 years	53	48,62
Over 32 years old	29	26,60
Schooling		
Incomplete elementary school	28	25,68
Complete elementary school	26	23,85
Complete high school	47	43,11
Complete higher education	08	7,33
Number of children		
01 son	35	32,11
02 children	35	32,11
03 or more children	39	35,77
Received guidance on the test prenatally and/or after delivery		
Yes	60	55,04
No	49	44,95

Regarding the participants' knowledge about the biological neonatal screening test (Table 2), 97.24% reported having heard of it, 92.66% knew about the mandatory performance of the test. 59.63% knew the purpose of the test, however, a very significant percentage (40.36%) did not. Regarding the importance of performing the test, 61.46% answered correctly. The majority (84.40%) did not know the best time to perform the test.

Table 2 – Mothers' knowledge about the biological neonatal screening test.

Variables	n	%
Have you heard about the test		
Yes	106	97,24
No	03	2,75
Believes the test is mandatory by law		
Yes	101	92,66
No	08	7,33
Purpose of the test		
Answered correctly	65	59,63
Answered incorrectly	44	40,36

Importance of the test		
Answered correctly	67	61,46
Answered incorrectly	42	38,53
Best time to take the test		
Answered correctly	17	15,59
Answered incorrectly	92	84,40

A statistically significant association was found in (Table 3), with a P value of 0.005, between the education variables complete elementary school and complete high school and the purpose of the test, showing that knowledge was directly associated with the mother's level of education. Likewise, in relation to the importance of the test and the fact that the mothers received guidance about the test in the prenatal period and/or after delivery (Table 4).

Table 3 – Association between sociodemographic and obstetric variables according to the purpose of the biological neonatal screening test.

Variables	Purpose of the test		X^2	P value
	Answered correctly	Answered incorrectly		
Schooling				
Incomplete EF	18 (16,5%)	10 (9,2%)		
Full EF	9 (8,3%)	17 (15,6%)		
MS Complete	35 (32,1%)	12 (11,0%)	12,937	**0.005**[(a)]
Complete higher education	3 (2,8%)	5 (4,6%)		
Number of children				
1 child	22 (20,2%)	13 (11,9%)		
2 children	24 (22,0%)	11 (10,1%)	3,243	0,198
3 or more children	19 (17,4%)	20 (18,3%)		
Received guidance on the test				
Yes	38 (34,9%)	22 (20,2%)	0,759	0,384
No	27 (24,8%)	22 (20,2%)		

[(a)] p-value determined by Pearson's Chi-square test Significant difference less than 5.0%

Table 4 – Association between sociodemographic and obstetric variables according to the importance of the biological neonatal screening test.

Variables	Importance of the test		X^2	P value
	Answered correctly	Answered incorrectly		
Schooling				
Incomplete EF	12 (11,0%)	16 (14,7%)		
Full EF	14 (12,8%)	12 (11,0%)	14,128	**0.003**[(a)]
IN full	38 (34,9%)	9 (8,3%)		
Complete higher education	3 (2,8%)	5 (4,6%)		
Number of children				
1 child	25 (22,9%)	10 (9,2%)		
2 children	21 (19,3%)	14 (12,8%)	2,455	0,293
3 or more children	21 (19,3%)	18 (16,5%)		
Received guidance on the test				
Yes	42 (38,5%)	18 (16,5%)	4,102	**0.043**[(a)]
No	25 (22,9%)	24 (22,0%)		

[(a)] p-value determined by Pearson's Chi-square test. Significant difference less than 5.0%

In (Table 5), no statistically significant associations were found, with a P value of 0.005, between the variables of schooling, number of children and receiving guidance on screening and the best time to perform the test, however, it is worth noting that 45.0% of the mothers who received information about the test did not know when to perform it.

Table 5 – Association between sociodemographic and obstetric variables according to the best time to perform the biological neonatal screening test.

	Best time to take the test			
Variables	**Answered correctly**	**Answered incorrectly**	**X²**	**P value**
Schooling				
Incomplete EF	3 (2,8%)	25 (22,9%)		
Full EF	4 (3,7%)	22 (20,2%)	1,118	0,773
IN full	8 (7,3%)	39 (35,8%)		
Complete higher education	2 (1,8%)	6 (5,5%)		
Number of children				
1 child	5 (4,6%)	30 (27,5%)		
2 children	6 (5,5%)	29 (26,6%)	0,111	0,946
3 or more children	6 (5,5%)	33 (30,3%)		
Received guidance on the test				
Yes	11 (10,1%)	49 (45,0%)	0,760	0,383
No	6 (5,5%)	43 (39,4%)		

DISCUSSION

The results obtained from the answers of the puerperal women to the questionnaires allowed us to characterize the participants through sociodemographic and obstetric variables, in addition to identifying the mothers' knowledge about biological neonatal screening and correlating these two points.

The predominant age group (48.62%) in the study was participants between 23 and 35 years of age, similar to those found in a study conducted in Thailand, in which 61.2% of the participants were between 21 and 34 years of age [11].

Regarding education, most (43.11%) of the puerperal women have high school as their highest level of education; these data are consistent with a study published by the International Journal of Neonatal Screening on the knowledge of puerperal women about neonatal screening, in which most participants (33.7%) had completed high school[12].

Two statistically significant associations were found between schooling data and knowledge about the test. Among the results obtained (Table 3), it was expected that more people with complete primary education would be aware of the purpose of biological neonatal screening and it was expected that fewer people with complete secondary education would be aware of the purpose of the test. Similarly (Table 4), it was expected that more people with complete primary education would be aware of the importance of

biological neonatal screening and it was expected that fewer people with complete secondary education would be aware of the importance of the test.

The results suggest that the higher the level of education, the greater the knowledge about the test. However, it was observed that mothers with complete higher education had insufficient knowledge about the test compared to mothers with lower levels of education. However, another study published by the International Journal of Neonatal Screening identified that an educational level higher than a bachelor's degree is associated with a better knowledge about the biological neonatal screening test[13].

Of the study participants, most (35.77%) have three or more children. Although this variable did not present a statistically significant association with knowledge about TNB, it is noted that this group of mothers presented a precarious knowledge about the purpose, importance and best time to perform the test, when compared to the groups of primiparous women and mothers with up to two children. On the other hand, a study carried out in the Czech Republic observed better knowledge about biological neonatal screening in mothers with multiple children[13].

In this study, 97.24% of the puerperal women stated that they had heard about the heel prick test before data collection. The results found are similar to those of a study that evaluated the knowledge of pregnant women, puerperal women and health professionals about the heel prick test, where it was found that 97.06% of the puerperal women found that they had already heard of the procedure[15].

It was observed that more than half (55.04%) of the mothers stated that they had received guidance on biological neonatal screening during prenatal care and/or after delivery. By associating these data (Table 4) with knowledge about the importance of the test, it was expected that fewer participants who received guidance would be aware of the importance of screening and it was expected that more participants who stated that they had not received guidance would be aware of the importance of the test. Although this variable did not present a statistically significant association with knowledge about the purpose and the best time to perform biological neonatal screening, it is noted that this group had a greater understanding of the subject when compared to the group of mothers who had not previously received guidance.

These results indicate that receiving previous guidance positively influences the mothers' knowledge about the test. A European study that analyzed the way information about neonatal screening is passed on to parents observed that, if parents receive inadequate information, there is a greater chance that the tests performed will deliver false

positive results, as well as there is a greater chance that parents will not perform the heel prick test on their children[15].

Knowledge about neonatal screening is of paramount importance for mothers' adherence to the test on their children. Thus, the role of the nurse who has direct contact with the pregnant woman during the prenatal period is highlighted in emphasizing the guidance on the importance of performing the heel prick test, which aims to identify pathologies early, thus promoting the reduction of morbidity and mortality and, consequently, ensuring a better quality of life for the children[16].

The heel prick test offered in the public health network is free and mandatory for all live births in Brazil[1]. The obligation is justified by the importance of the pre-symptomatic diagnosis of the 06 diseases detected by the test offered by the Brazilian Unified Health System. Most puerperal women recognize the legal obligation to perform the test. These data are consistent with a study published by Franková et al., when they found that 80.65% of the postpartum women interviewed were aware of the mandatory nature of the procedure[14].

The purpose of performing TNB is that, when performed in a timely and appropriate manner, it indicates the possibility of a newborn being a carrier of one or more diseases that can significantly affect their quality of life[1]. Most participants (59.63%) answered correctly regarding the purpose of the test. Similar results were found in a study on the knowledge and attitude of mothers about neonatal screening in Jordan[18].

TNB has its importance ensured by being included in the National Neonatal Screening Program, defined as a set of preventive actions that includes: presumptive diagnosis, interpretation of TNB results, indicating suspicion of specific disorders or diseases; diagnosis of certainty, verification of the presence of the disorder or disease through confirmatory tests and/or clinical evaluation; treatment; improvement of the effectiveness of access to treatment; and follow-up of the diagnosed cases and the incorporation and use of technologies aimed at promotion, prevention and comprehensive care([1]). In this study, a little less than two-thirds (61.46%) of the puerperal women correctly answered the importance of the test.

Most of the study participants (84.40%) did not know the best time to perform the test. In other studies, most participants believe that TNB should be performed between the 3rd and 7th day of the baby's life [12,17]. These data show that incorrect knowledge about the best time to perform screening is common among puerperal women, a fact that can compromise the efficacy of PNTN and TNB, if it is performed at a different time than opportune.

IMPLICATIONS FOR HEALTH AND NURSING PRACTICE

The findings of this study may provide nurses, especially those who work in primary health care, with an opportunity to improve the role of health educators. By exposing gaps in mothers' knowledge about TNB, the study provides topics about the test that can be emphasized by professionals in consultations and activities aimed at pregnant and postpartum women.

CONCLUSION

The results of the research revealed that it was possible to observe a good understanding of the mothers about the legal obligation, purpose and importance of the test. However, the participants showed a deficit in knowledge about the best time to perform the TNB.

It is also noted that postpartum women who received information about TNB during the prenatal period and/or after delivery had greater knowledge about the test.

The possible causes for the gaps in knowledge would be the non-receipt of guidance from health professionals about the heel prick test, as well as the receipt of incorrect guidance about the test. Thus, it is necessary for health professionals to constantly seek updates on the subject, in order to ensure that parents have access to adequate information about neonatal screening. This knowledge is essential to promote educational actions to raise awareness among mothers and guardians of newborns about TNB and its importance, encouraging the population to adhere to the procedure.

Regarding the limitations of this study, the small number of participants with low adherence is highlighted and, consequently, it is imperative to carry out new investigations on the subject, as they make it possible to advance in the understanding of the social and cultural determinants that interfere with this knowledge.

In view of this, it is hoped that this study will be useful for the reflection of health professionals who study the subject and foster new strategies to improve the coverage of the National Neonatal Screening Program, ensuring a better quality of life for future generations.

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