

Triagem neonatal: o panorama atual no estado do Amapá

Newborn screening: current situation in the state of Amapá

ABSTRACT

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Newborn screening comprises a set of tests that aim to detect pathologies in newborns and should be performed preferably between the 3rd and 7th month of life. The screening detects six congenital anomalies: phenylketonuria, congenital hypothyroidism, sickle cell anemia, cystic fibrosis, biotinidase deficiency, and congenital adrenal hyperplasia. According to the Ministry of Health, in 2007 the state of Amapá had the lowest population coverage for the screening tests in Brazil. Through a qualitative methodology, institutional data were collected in the reference laboratory of the State at the Institute of Hematology and Hemotherapy of Amapá (Hemoap), and a questionnaire was applied to the mothers or guardians of neonates at the moment of the test. Only 5 of the 16 municipalities investigated carried out the newborn screening, providing a coverage of 31.2%. Regarding the questionnaires, the majority of the individuals did not have knowledge about the importance of the screening test; in contrast, 100.0% of the interviewed people said they had an interest in getting the results. Nevertheless, the study raised neglected data from 2013 to 2015, showing that there is a great disinterest by mothers or guardians and that the National Newborn Screening Program in Amapá is far from having a complete coverage and that databases are scarce regarding the information about this state.

KEYWORDS: Neonatal Screening; Newborn Screening; Databases

RESUMO

A triagem neonatal conhecida como teste do pezinho é um conjunto de exames que tem como finalidade detectar patologias em recém-nascidos e que deve ser realizado preferencialmente entre o 3º e o 7º mês de vida do neonato. O teste detecta seis anomalias congênitas: fenilcetonúria, hipotireoidismo congênito, anemia falciforme, fibrose cística, deficiência de biotinidase e hiperplasia adrenal congênita. Para o Ministério da Saúde, em 2007, a menor cobertura populacional de teste do pezinho no Brasil ocorreu no Amapá. Através de uma metodologia qualitativa, foram coletados dados institucionais no laboratório de referência do estado, Instituto de Hematologia e Hemoterapia do Amapá (Hemoap), usando também como instrumento de pesquisa um questionário dirigido às mães e/ou responsáveis dos neonatos no momento de realização do exame. Dos resultados obtidos somente cinco municípios dos 16 realizam a coleta do teste do pezinho, dando uma cobertura de 31,2%. Quanto aos questionários, mostrou-se majoritário o número de indivíduos que não têm conhecimentos sobre a importância do exame. Em contrapartida, 100,0% dos entrevistados responderam que tinham interesse em retornar para buscar o resultado do exame, contudo o estudo levantou dados negligenciados dos anos de 2013 a 2015, demonstrando ser grande o desinteresse das mães e/ou responsáveis que levam o neonato para realizar o teste. Tais dados mostram que o Programa Nacional de Triagem Neonatal no Amapá está longe de obter uma cobertura completa e que os bancos de dados são escassos quanto a informações sobre o estado.

PALAVRAS-CHAVE: Triagem Neonatal; Teste do Pezinho; Banco de Dados

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INTRODUCTION

Newborn screening (NS), created and implemented by Ministerial Act GM/MS n. 822, of June 6, 2001, is a set of tests aimed at detecting diseases in newborns aged zero to 30 days of life. Since this is a preventive examination that identifies congenital anomalies, early diagnosis may decrease sequelae. Therefore, the examination should be performed in the first week of the baby's life, after the first protein feeds. This shows the importance of every Brazilian state joining the National Newborn Screening Program (NNSP)¹.

The method proposed by Dr. Robert Guthrie in 1963 and then widely adopted throughout the world consisted of a bacterial inhibition test performed on dried blood samples collected on filter paper for the detection of phenylalanine concentrations. Guthrie aimed to identify subjects with pre-symptomatic phenylketonuria to perform the treatment earlier¹. The tests are screenings and separate the population of newborns into two groups: one consisting of those who may have a disease and another formed by those who should not have it¹.

Early and appropriate diagnosis is the philosophical basis of global NS programs. Therefore, the definition of normality values that are adequate to differentiate individuals who need treatment or not, as well as the speed of the procedures, is fundamental to achieve these objectives and avoid unnecessary stress to the families².

Tracking newborns means identifying children who are at risk of developing a metabolic disease within a population considered "normal", so as to enable effective search for preventive or therapeutic intervention in a timely manner³. A good newborn screening program should meet some goals, such as broad population coverage, ideally reaching 100% of live births, low recall or false positives, and finally the possibility of initiating early treatment and follow-up⁴.

NS is also popularly called the "heel prick test". The term was created to inform mothers and the population in general about the collection of blood from a capillary puncture of the newborn's heel³. However, the outcome of NS should not be considered definitive. The correct diagnosis through laboratory confirmation of the result⁵ is essential for proper treatment and counseling.

Like in other developing countries, the introduction of screening programs in Brazil occurred in a disorganized manner, with no quality control structure. It also preceded any ethical discussion about the subject. The first disease to be screened was PKU, based on the pioneering work done by the APAE of São Paulo, Brazil. NS currently can be done either in private laboratories (whose programs can diagnose approximately 30 metabolic diseases) or by the public system (depending on the state, up to four groups of diseases can be diagnosed)⁶.

The heel prick test can detect several diseases, but only six are addressed in the Brazilian Unified Health System (SUS), namely: phenylketonuria (PKU), congenital hypothyroidism (CH), sickle

cell anemia, cystic fibrosis (CF), biotinidase deficiency and congenital adrenal hyperplasia (CAH). The two latter were licensed recently, in May 2014.

In 2001, aware of the need to enforce the law properly, the Ministry of Health (MS) issued a ministerial act (n. 822/01) aimed at organizing a NS network in Brazil, with an increase in the number of exams covered by SUS⁶. Thus, the NNSP was created. However, the demographic, economic, political, cultural and logistic heterogeneity of a country like Brazil means that all stages of this broad process represent a great challenge⁷.

Every child born in the Brazilian territory is entitled to NS. All Brazilian states have at least one reference service in NS and several collection points for the heel prick test scattered about different cities of the state⁸, but many cities do not perform the heel prick test yet. It is not easy to implement an NS program, but the publication of the challenges faced in the first programs and the solutions that were applied may help those who intend to implement a program of this type. Once the program is implemented, it is important to make sure it is effective⁹.

For the purpose of disease panel selection, the NNSP was organized into three phases of implementation, for which each state was accredited based on the preexisting coverage and infrastructure: phase I - congenital hypothyroidism and PKU; phase II - congenital hypothyroidism, PKU and hemoglobinopathies; phase III - congenital hypothyroidism, PKU, hemoglobinopathies and cystic fibrosis⁷.

Studies conducted in Brazil assessed the coverage of heel prick tests. Considering previously published data from some states, we found that Bahia is the Northeastern state with the highest coverage. And according to data from the Ministry of Health, in 2007 the lowest coverage in Brazil was found in the state of Amapá¹⁰. Another problem is that diagnostic tests are not performed in the state. The NS test does not cover all phases, so there is a lack of databases¹¹. Despite their relevance, diagnostic tests for sickle cell anemia are not performed in the state of Amapá, nor is there adequate hospital infrastructure to treat such condition. Therefore, it is necessary to implement the testing structure in the state, so that these people can be identified and receive the appropriate treatment, with improvement of their quality of life¹².

The early detection of these diseases is extremely important for Brazilian healthcare services because it rationalizes expenses with high-complexity services. Therefore, this study proposes to describe the status of the NS program in the state of Amapá in relation to the coverage of its 16 municipalities. This will show the diversity of the state's public healthcare network, where we found NNSP access in the municipalities of Amapá, the implementation phase of the tests and structuring of the services in the state of Amapá and the flow of the patient follow-up program, from test to treatment, and the number of neglected heel prick tests by mothers and/or guardians from 2013 to the first half of 2015.



METHOD

It is an observational, cross-sectional, analytical research project, that is, it is an epidemiological study in which the factor and the effect are observed during the same time.

It consists of a qualitative institutional data survey that is representative of NS in the state of Amapá over the past few years.

Institutional data was provided by the Institute of Hematology and Hemotherapy of Amapá (Hemoap), located on Avenida Raimundo Álvares da Costa and classified as a reference center for heel prick test results in the state. The questionnaires were applied at the Hemoap complex located on Avenida FAB, inside the capital's maternity hospital.

For the study, a questionnaire with 15 close-ended questions was used as a research tool. It was given to mothers and/or guardians of newborns from zero to 30 days of age, from August to September 2015, duly authorized by the responsible sector coordination. The questionnaire has the purpose of evaluating the opinion of the mothers and/or guardians on the importance of the heel prick test. The identity of the respondents was kept confidential to avoid constraints or any form of intimidation. First the individuals authorized the application signing the Free and Informed Consent Form (ICF) and then answered the questionnaire.

Institutional data was collected from October to December 2015 at the Hemoap and the collection was duly authorized by the Institute's coordination.

Data from this research was analyzed according to the Bardin content analysis method¹².

Qualitative data from the answers was categorized and analyzed in light of the pertinent bibliography. The data was also tabulated in Excel spreadsheets and represented graphically.

Based on the theoretical framework on the quality of the services offered to newborns, we carried out a survey of the technical team in charge of doing the test in the state capital. We also investigated the screening workflow, from the test to the treatment (whenever necessary) of the newborn.

The study was submitted to approval of the Research Ethics Committee (REC) of the Federal University of Amapá under number 1.094.592/2015. The number of the Certificate of Presentation for Ethical Appreciation (CPEA) is 45134115.7.0000.0003. All study participants signed the Free and Informed Consent Term (ICF) in accordance with Resolution n. 466 of December 12, 2012 of the National Health Council.

RESULTS AND DISCUSSION

The NS program, heel prick test/biological phase, began in Amapá in 2002. To date, the Institute of Hematology and Hemotherapy, located in the state capital, is the only specialized laboratory to screen the results. The screening program was performed according to the Diagnostic Support Center of the Medical School

of the Federal University of Minas Gerais (Nupad/UFMG), Brazil. The state of Minas Gerais is the pioneer in this examination, with coverage of 100% of its cities. This means that 100% of its 853 municipalities perform the heel prick test. The service is a result of the partnership between the Ministry of Health and the state department of health. Over 5.4 million newborns have been screened by the Newborn Screening Program of Minas Gerais and more than 5,000 children are in follow-up and treatment of the diagnosed diseases (January 2016 data)¹.

Regarding access to NNSP exams, according to institutional data, five cities in the state of Amapá collect the test and are classified as active: Macapá, Santana, Porto Grande, Laranjal do Jari and Oiapoque. This means that, 31.2% of the state's 16 municipalities are covered by the test. Four cities are classified as inactive (due to shortcomings in governmental and institutional management, since they received the training, but do not collect the test): Mazagão, Serra do Navio, Tartarugalzinho and Amapá. Roughly 69% of the cities do not make any kind of collaboration to the NNSP and their respective citizens do not have NS collection. The coverage of the target population is one of the main indicators of a program's effectiveness¹³. An example of that is the Newborn Screening Program of Rio Grande do Sul: it proved to be effective, with 80.9% coverage of the newborns who use the public healthcare system to perform the heel prick test.

In the state of Paraná, the Fundação Ecumênica de Proteção ao Excepcional is the reference center. This center extends free and compulsory service to 432 hospitals and 580 state health units participating in the program, with approximately 14,500 newborns screened per month³. This type of program comprises very complex structures, involving a wide network of collection units, specialized laboratory, an active search system and the infrastructure for diagnostic confirmation, multidisciplinary treatment and long-term follow-up⁷.

Currently all Brazilian states are qualified in the NNSP with at least one reference service accredited by the Ministry of Health. According to the Ministry, Hemoap is qualified to perform phases I, II and III of the NNSP (Table). Since 2002, the institute has been screening for PKU and CH, thus fulfilling phase I. The specialized laboratory has been approved for phase II, but it does not process exams for sickle cell anemia and other hemoglobinopathies due to lack of material and logistical support. Therefore, it is not considered qualified for phase II. After eight years releasing results

Table 1. Percentage distribution of the awareness of mothers and/or guardians who performed the test in the reference unit on congenital anomalies screened by the heel prick test from September to October 2015.

Question	Yes (%)	No (%)	I've heard of it
Do you know what Phenylketonuria is?	0	100.0	0
Do you know what Sickle Cell Anemia is?	20.0	0	80.0
Do you know what Congenital Hypothyroidism is?	2.0	50.0	45.0
Do you know what Cystic Fibrosis is?	5.0	55.0	40.0

Source: Own author.



for two congenital diseases, in the first half of 2015 results for PKU/CF began to be processed without confirmatory test (sweat test), characterizing phase III. In a survey of the death records for sickle cell anemia in Brazil, from 1979 to 1995, Alves warned of the inability of the healthcare system to detect this anomaly, since 88% of the people died as a result of the disease and did not have the correct record of their death. This study was carried out 20 years ago, but the state of Amapá does not yet screen for sickle cell anemia and other hemoglobinopathies. This reveals the state's deficiencies in NS, as well as the lack of information about the disease on the part of the population and healthcare professionals responsible for the examination¹⁴.

The good prognosis of the pathologies identified by NS depends on early identification, treatment and follow-up from the first months of life. Another factor that warrants the importance of NS is that most of these pathologies only present symptoms during the first years of the child's life, already compromising the quality and even the life of individuals who were not properly diagnosed¹⁵.

The professionals involved in the test should inform and speak to the families, providing integral and continuous care, materializing referrals and safe interventions. Patient identification and diagnostic confirmation should be facilitated. The patient should receive a complete evaluation by a team of professionals, following guidelines on the evolution and treatment of the respective disease(s). The clinical and therapeutic follow-up of the patients will always be carried out by the multidisciplinary team, with physicians, psychologists, social workers and dietitians¹⁶.

In view of the above, the family is the first to undergo some changes. This implies the restructuring of the members' roles, often leading to a decrease in family income. For the family, the onset of a disease raises questions and uncertainty. It is up to the multiprofessional team to promote social and educational initiatives to provide all the information necessary for the treatment, with the main objective of maintaining the patient's social routine.

Based on the theoretical framework on the quality of the services offered to newborns, we carried out a survey of the technical team in charge of doing the test in the state capital. We also investigated the screening workflow, from the test to the treatment (whenever necessary) of the newborn, as seen in Figure 1.

Chart. Scheme of the phases of the heel prick test in the state of Amapá.

Variables	Phase I	Phase II	Phase III
	PKU and CH	PKU, CH and Hemoglobinopathies	PKU, CH, Hemoglobinopathies and CF
Ministry of Health/AP	Enabled	Enabled	Enabled
Institutional data*/AP	Implemented	Not implemented	Partially implemented

PKU: Phenylketonuria; CH: Congenital hypothyroidism; CF: Cystic fibrosis. *Source: Institute of Hemotherapy and Hematology of Amapá.

The city of Macapá has a single collection point, located in the maternity hospital. It has a team of 18 professionals, including two nurses, one endocrinologist, 13 nursing technicians and administrative personnel. The Ministry of Health advocates that the staff should be trained to properly collect and store material, complying with the required standards. The staff should also be responsible for providing guidance to parents about the procedure to be performed. The government of the state of Amapá, in partnership with the Department of Health, provides educational materials and request for examinations for the collection points so that they can be delivered to the mothers and/or guardians immediately after the first appointment with the pediatrician. This reminds the physicians of the need to perform the test at the right time and strengthens their commitment to checking the results.

These activities are carried out by several healthcare professional categories, in different places. They are usually subordinated to different managers. Nevertheless, they must be well articulated in order to ensure that the program is fully successful in its objectives⁷.

Hemoap does not have the numbers of heel prick tests processed in the years 2013 and 2015 because of operational reasons. In the year 2014, about 9,865 heel prick tests were done in the institution, according to Figure 2. This gives us a monthly average of approximately 822 exams. Based on data from the Live Birth Information System (Sinasc), provided by Datasus, in its last system update until the year 2013, the state of Amapá obtained a number of 16,840 live births in 2013. Using data on live births in 2013 as the basis for the 2014 program coverage, we obtain 58.5%. This means that the state has achieved half of the goal set by the Ministry of Health. Even if we consider that this other half of newborns may have undergone examinations in the private network, there is still a large possible number of babies not included in the Newborn Screening Program.

Surveillance is critical to the success of these programs. Worse than not having NS programs is to have them ineffective, as they generate a false sense of security, consume public resources and

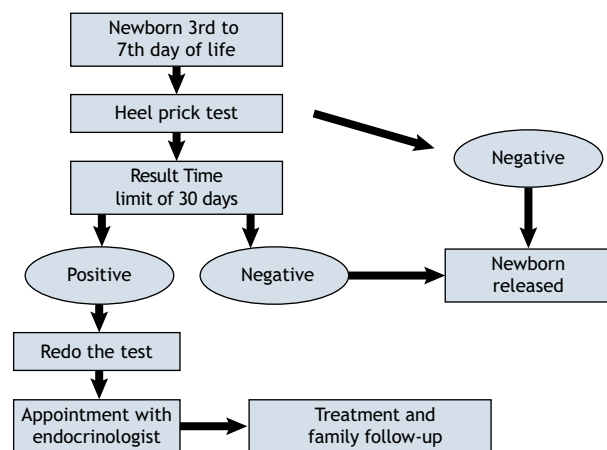


Figure 1. Screening flow of collection and patient follow-up services during the treatment.

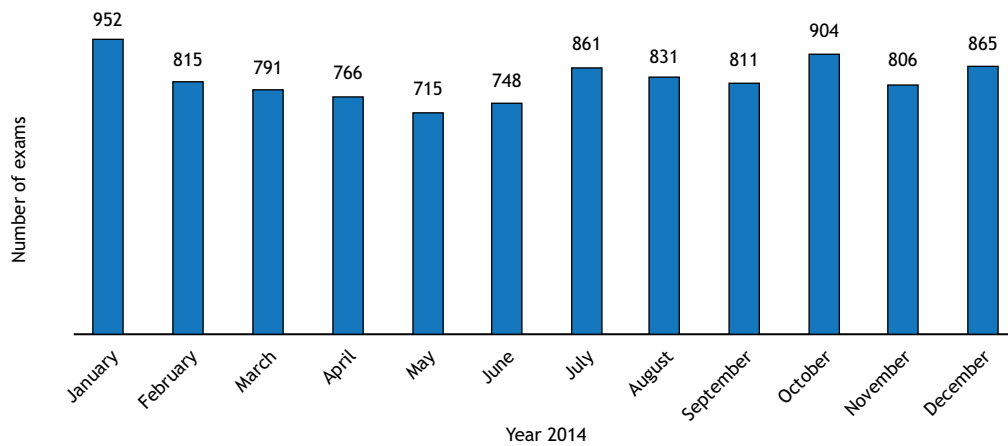


Figure 2. Heel prick tests processed by the Hematology and Hemotherapy Institute of Amapá in the year 2014.

do nothing to minimize the serious consequences of the diseases that are allegedly tracked⁹.

Regarding the questionnaires to check the knowledge about the heel prick test, these were applied in the Hemoap complex located inside the maternity hospital of the capital, where the mothers and/or guardians would perform the collection for the test.

A hundred questionnaires were applied from August to September 2015, consisting of 12 close-ended questions (yes/no) and three open-ended questions. We verified that the age of the mothers and/or guardians was between 18 and 38 years old and that the monthly income of the participants indicated that the population assisted in the unit where the study was performed is characterized by not having a fixed income (75%). Only 10% said they earned more than three minimum wages a month.

There was a predominance of guardians from the capital (50%, n = 50), from other municipalities (20%, n = 20) and from other states. There is therefore a significant number of mothers who come to have their children in Macapá, especially from the state of Pará (30%, n = 30). The government finances virtually the entire healthcare system. All citizens and immigrants are entitled to public health insurance⁷. The data shows that it is often easier to perform the test and treatment of some children from the state of Pará in the state capital of Amapá (Macapá) than to take them to their own state capital (Belém), perhaps due to costs or problems generated in the NS system of the state of Pará. This consequently makes it more difficult to track, monitor and treat these newborns, since they actually live in neighboring states.

In terms of education (Figure 4), half of the respondents had high school level only, while 20% (n = 20) had higher education and a smaller portion were illiterate (5%, n = 5). The results showed that education is a variable that probably does not interfere with the understanding of what the test is for, that is, the majority of the individuals had no knowledge about NS regardless of their level of education. In line with Garcia, who also came to the conclusion that the professions of the guardians, as well as their family income, did not seem to be variables that would interfere in the results¹⁷.

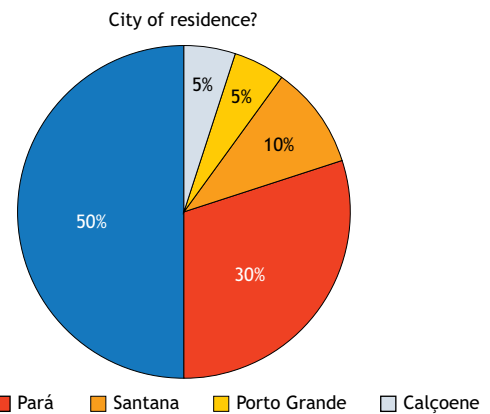


Figure 3. Percentage distribution of the city of residence reported by mothers and/or guardians who performed the heel prick test in the reference unit from August to September 2015, in the city of Macapá.

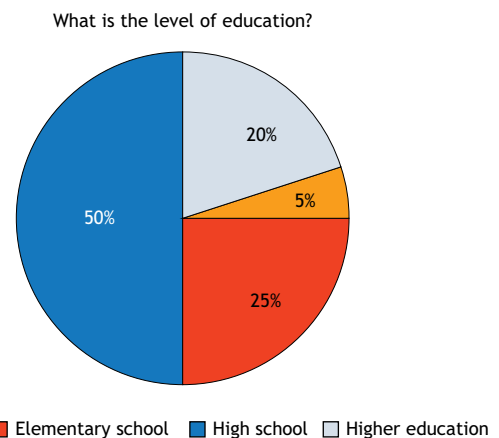


Figure 4. Percentage distribution of the level of education reported by mothers and/or guardians who performed the heel prick test in the reference unit from September to October 2015.

Most participants (45%, n = 45) had two to three children, and a smaller proportion (20%, n = 20) had more than three children. We found that in the capital there is no relation of multiparous women with the fact that some children do not do the test.



When asked about “*how many children did the heel prick test?*”, roughly 80% (n = 80) said that all their children had done it, 15% (n = 15) said that only some had done it, and only 5% (n = 5) said that none of their children had done the test.

Regarding the need to perform the test, 95% (n = 95) of the individuals said that they knew the importance of performing the test, even though 5% (n = 5) did not find the test important as a resource for the promotion of children’s health. In contrast, even though the vast majority said that the heel prick test is an important test, when asked “*what is the test for?*” (Figure 5), 60% (n = 60) said they had no idea or had only heard of its purpose. A total of 40% answered yes. The results obtained in this research are in line with Garcia’s¹⁷ study, in which 90% described NS as important for their children’s health, even though most respondents did not know why.

Goldback explains that the user-healthcare professional communication must happen in two stages. The first is during the collection, when the mother of the newborn should be informed about the importance of the test and its objectives, as well as about the diseases that the program proposes to track. The second stage of the process is when it is necessary to communicate an altered result to the family, prioritizing the retrieval of the information given to the family member at the time of the collection of the¹³ test.

Despite all the campaigns of the Ministry of Health and in the media aimed at raising awareness among mothers, 70% (n = 70) of them said they learned about the test during prenatal examinations, 15% (n = 15) learned about it in the media and 15% (n = 15) learned about it from third parties (including family and friends). A total of 56% (n = 56) obtained information from nurses, 39% (n = 39) from physicians and 5% (n = 5) from pharmacists. With that, we compared our data with Reichert’s research, whose results showed that 97% of the mothers who performed the tests on their children heard of the test through the media, showing the success of the dissemination of the test through vehicles associated with the written, spoken media and television¹⁸.

Figure 5 shows that 60% (n = 60) of the mothers and/or guardians of the newborns do not know what the test is for. They say they

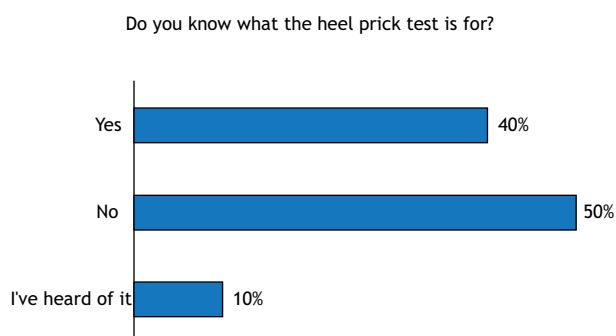


Figure 5. Percentage distribution of the question “*Do you know what the heel prick test is for?*” reported by mothers and/or guardians who performed the test in the reference unit from September to October 2015.

have only heard of it and are unable to explain its purpose. This is in line with Silva, who explains that the path to 100% of children screened is arduous and tortuous, despite all programs of education and awareness of professionals and parents and/or guardians⁸.

Mothers and/or guardians of newborns were asked about their knowledge of the four diseases selected from the heel prick test (Table 2). The percentage corresponded to the data obtained in the whole questionnaire on the lack of knowledge about the exam. A minority of the individuals said they were familiar with one or more diseases we mentioned, and the greater percentage of the respondents answered not knowing or that they have never heard of one or more diseases. Considering that 50% (n = 50) of the mothers and/or guardians lived in the capital, we can assume that they have more access to information than those living upstate. Nevertheless, according to Table 1, it becomes evident that, regardless of location or educational level, mothers and/or guardians of newborns did not know or had never heard of diseases screened by the heel prick test. This is different from Stranieri’s survey⁹, which highlights that total population coverage is often hampered by socioeconomic and cultural problems, lack of information about the importance of NS testing and difficulty of parents - especially those living in rural areas - to access the collection points for the examinations. Stranieri’s research brings data different from that shown in Table 1.

Regarding the intention to search NS results, all respondents (100%) answered that they intended to return to collect the results. These indices could reflect an efficient service, if it were not for the contradiction. According to Goldback, the idea of “accountability” of the exams might generate guilt, if the results happen to be positive¹³.

The Hemoap complex also provided institutional data, that is, heel prick test results neglected by the guardians. For the two halves of the year 2013, 2,334 results were forsaken. In the

Table 2. Number of tests neglected by mothers and/or guardians of newborns from 2013 to 2015.

Months	2013	2014	2015
January	234	325	375
February	142	320	235
March	175	295	276
April	217	405	251
May	137	347	255
June	241	221	274
1st half - Total	1,146	1,913	1,666
July	-	315	-
August	-	289	-
September	297	329	-
October	303	301	-
November	356	226	-
December	227	419	-
2nd half - Total	1,188	1,564	-
Annual value	2,334	3,477	1,666

Source: Hemoap, 2015.



year 2014 the values were higher, with the two halves accounting for 3,477 results. In the first half of 2015, 1,666 heel prick test results were forsaken by mothers and/or guardians (Table 2). The neglected results show the deficiency in the heel prick test tracking system, since the guardians are often not located.

This data could be further explored, since we assume that it is directly related to the operational cost or scarce computerization in the collection units. This demonstrates that information obtained through the internet is not yet a preference at the base of the health system, although this medium is the most recalled option today¹³.

According to data from Figure 2, in which there were about 9,865 exams processed by Hemoap in the year 2014, compared to the neglected data of the same year, one-third of the results that Hemoap releases are forsaken in the archives. Guardians do not have motivational stimuli to return or do not understand that the test is important for the health of newborns, whether positive or not. This causes an additional expense for the reference laboratory in materials and kits for the exams. Additionally, it covers up forsaken results in institutional files and conceals the need to fix the errors of the NNSP in the state of Amapá.

Disclosure is important so that they are aware of the seriousness of the diseases detected and the economic and social impact on families and society. Knowing the reality and prevalence of diseases that affect the newborn population favors the elaboration and improvement of public policies aimed at children's health. More than that, it minimizes unnecessary spending on high-complexity services and contributes to the reduction of the infant mortality rate³.

CONCLUSIONS

Institutional data shows that access to NNSP tests does not cover half of the municipalities of Amapá. This is worrying, especially

if we consider the state's small population compared to other states in Brazil that reach 100% coverage.

According to the Ministry of Health, the state is able to perform the three phases of the NNSP. But this is not in accordance with reality, since only phase I was implemented. Improvement is necessary in the communication between the results obtained by the reference laboratory with the collection points and with the state department of health, so that there are positive changes in the reality that we see today.

The established collection flow is standard and meets the needs of the state, however, the technical team should have other healthcare professionals, like pharmacists, who are versatile and can work more incisively in the laboratory diagnosis and also in socio-educational measures related to NS, since this is increasingly required in many segments of healthcare and related areas. The results show that tracking services are still flawed. To confirm this, the study showed numerous results of neglected examinations.

The little understanding mothers and/or guardians have of the heel prick test and its importance for the health of the newborns. These individuals should be assisted by a well-prepared multiprofessional team and media that sensitize the target population about the fact that NS detects congenital anomalies and, if identified early, decreases sequelae. Raising awareness is not an easy task, but it needs to be done.

We also emphasize that the deployment and good structuring of more reference laboratories with qualified professionals, trained teams for the collection of the material, quality control of the results and orientation to the parents are steps for an efficient service. However, the provision of data for the literature is essential for the improvement of the Newborn Screening Program and its update in the state of Amapá.

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Conflict of Interest

Authors have no potential conflict of interest to declare, related to this study's political or financial peers and institutions.



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