International Journal of Advanced Engineering Research and Science (IJAERS)
Peer-Reviewed Journal
ISSN: 2349-6495(P) | 2456-1908(O)
Vol-9, Issue-9; Sep, 2022
Journal Home Page Available: https://ijaers.com/
Article DOI: https://dx.doi.org/10.22161/ijaers.99.48

Administration of the Reference Service in Newborn Screening in Pará: Experience Report

João Victor Moura Rosa[1], Tamilis Feitosa Leal[1], Lidineusa Machado Araujo[1], Ilma Pastana Ferreira[1], Ana Lúcia da Silva Ferreira[1], Claudia Ozela El-Husny[1], Felipe Valino dos Santos[1], Elizabeth Ferreira de Miranda[2], Michelle da Silva Pereira[3], Fernanda Rafaela de Souza Rebelo da Costa[4]

[1]State University of Pará, Brazil.
[2]Evandro Chagas Institute, Brazil.
[3]Federal Institute of Pará, Brazil.
[4]Censupeg College, Brazil.

Received: 22 Aug 2022,
Received in revised form: 14 Sep 2022,
Accepted: 23 Sep 2022,
Available online: 30 Sep 2022

***Keywords*— Neonatal screening; Health services; neonatal deaths; Metabolic diseases.**

***Abstract*—** *Objective: To present an experience report regarding the administration of the neonatal screening referral service in Pará. Based on the implementation of the National Neonatal Screening Program through Ordinance nº 822, of June 6, 2001. Method: This is a descriptive study, with a qualitative approach, of the experience report type, experienced by four nurses who work at the Reference Service in Neonatal Screening at the University of the State of Pará, through systematic, structured or controlled observation. Results: An approach to the work process was carried out based on forwarding through postage to the Research and Diagnostic Support Laboratory responsible for the development of the following steps: 1) sample screening, which is a process of evaluating the quality of the material collected; 2) entering the child's information in the VEGA triage system and 3) processing the biological samples to obtain the results. These procedures are in accordance with the provisions of the Neonatal Screening Technical Manual. Conclusion: In this process, the importance of the multidisciplinary team, especially the nurse, is highlighted in the search for empowerment on the importance of neonatal screening for the early diagnosis of metabolic diseases and the prevention of irreversible sequelae, complications and deaths.*

I. INTRODUCTION

In 2001, the Brazilian Ministry of Health implemented the National Newborn Screening Program through Ordinance no. 822, of June 6, 2001, which establishes that every child born in the national territory must undergo the heel prick test, which is free and mandatory with a goal of universal coverage and guarantee of completion of all stages [1].

Newborn screening is a tool used by public health, which seeks to track some diseases in newborns. Through this screening, it is possible to make an early diagnosis of metabolic, genetic and infectious diseases and offer the best available treatment, essential to reduce morbidity and mortality, as well as minimize the damage or sequelae left by these health problems [2].

The newborn screening test, popularly known as the foot test, consists of collecting a small blood sample from

the newborn's heel, which must be collected until the baby's fifth day of life. The test makes the preventive diagnosis for several congenital diseases and, currently, in public health services, it performs the specific diagnosis of six pathologies, among them: phenylketonuria, congenital hypothyroidism, cystic fibrosis, sickle cell disease, congenital adrenal hyperplasia and biotinidase deficiency [3].

The National Newborn Screening Program is developed in the Brazilian states in four stages, according to the diseases evaluated: Stage I: phenylketonuria and congenital hypothyroidism; Stage II: sickle cell anemia and other hemoglobinopathies; Stage III: cystic fibrosis; Stage IV: Biotinidase deficiency and congenital adrenal hyperplasia [2]. In December 2009, the State University of Pará, located in northern Brazil, was accredited by the Ministry of Health as a Reference Service in Newborn Screening in the State, which guarantees screening, confirmation of diagnosis, treatment and free follow-up at the outpatient clinic of the service. In addition, the state of Pará carries out biological screening of stages I, II and III, although the state is already qualified to carry out stage IV, it has not yet been possible to start this practice due to operational and financial complications [4].

According to Ordinance no. 822 of June 2001, the Newborn Screening Reference Service is responsible for operationalizing, executing and controlling the National Newborn Screening Program in its area of operation, from collection, exams, active search, diagnostic confirmation, monitoring and treatment of cases positives detected, as defined in the National Newborn Screening Program. The Reference Service in Newborn Screening, in the State of Pará, was implemented at the Marco School Health Center, linked to the University of the State of Pará since 2009, through Ordinance no. 428 of May 2009. approximately ten thousand test samples of the foot for newborn screening.

The Newborn Screening Reference Service is formed by a multidisciplinary team to develop the activities required in the National Newborn Screening Program. With this, the nurse stands out, who has a relevant role for being close to the user, being able to clarify doubts about the possible diagnoses and follow-up of the children, through the nursing consultation, in addition to acting in the management of the service. In this sense, the objective of this article is to report the experience of nurses in the administration of the reference service in newborn screening in Pará in a higher education institution [5].

II. METHODOLOGY

Descriptive study with a qualitative approach, of the experience report type, experienced by 04 nurses who work at the Reference Service in Newborn Screening at the State University of Pará, through systematic, structured or controlled observation. The experience occurs in the development of work activities, with the identification of the main problems and correlating the observed findings with the scientific bases [6].

The State University of Pará is a higher education institution that encompasses teaching, research and extension. We also assume assistance activities, including newborn screening. Since February 2010, this institution has assumed the role of newborn screening, in addition to performing diagnoses, the institution responsible for monitoring and treating children tested with newborn screening tests presented changes.

The Reference Service in Newborn Screening of the State of Pará carries out medium complexity activities with the 856 collection points distributed in the basic health units of the 144 municipalities of the state of Pará, it is responsible for the diagnosis through the processing of samples of the foot test, performed at the Research and Support Laboratory Diagnosis and monitoring of children with altered results for phases I, II and III (outpatient clinic) [5].

III. RESULTS AND DISCUSSION

During the work activities of nurses from the Newborn Screening Reference Service, these professionals worked in the administration of the newborn screening service and experienced the main routines established in the work process of the National Newborn Screening Program. Program that begins at the time of collection of the heel prick test, carried out in the Health Services affiliated to the Unified Health System.

After carrying out the collection in the municipalities and adequate storage, the sample is sent by mail SEDEX to the Laboratory for Research and Support for Diagnosis, which performs the following steps: 1) sample screening, which is a process of evaluating the quality of the material collected; 2) enter the child's information into the VEGA triage system and; 3) process the biological samples to obtain the results. These procedures are in accordance with the provisions of the Newborn Screening Technical Manual [7]. With the results in hand, the report is issued, those that do not show alterations are sent online to the collection points, on the other hand, for those with altered parameters, the children are summoned for a new collection or immediate consultation at the outpatient clinic of the Reference Service in Newborn screening.

After the altered result, the clinic scheduled an appointment with a multidisciplinary team composed of a nurse, psychologist, social worker, nutritionist, pediatrician, endocrinologist and geneticist. Once the diagnosis is confirmed, if the change is due to sickle cell disease or cystic fibrosis, the children are followed up at the Newborn Screening Reference Service or referred to specialized services, as shown in the flowchart in Figure 1.

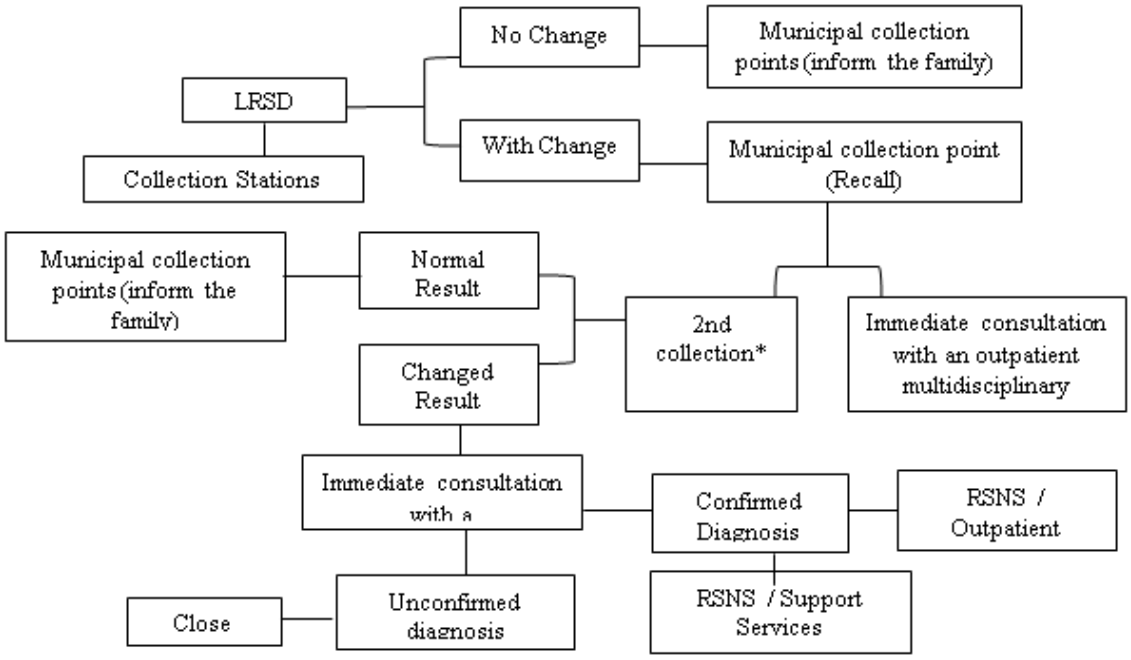


Fig.1 – Flowchart of the Reference Service in Newborn Screening at the University of the State of Pará, 2015-2017.

Source: Authors, 2018.

LRSD: Laboratory for Research and Support for Diagnosis.

RSNS: Reference Service in Newborn Screening.

*****It depends on the evaluation of the outcome parameters for each disease and age of the child in the collection of the foot.

In this work process, the multidisciplinary team, especially the nurse, develops actions to coordinate care, being responsible for quality care, promoting integration between different professionals [8]. With this, use management as seeking tools directed as nursing practices.

Thus, nurses identify the need to assess the quality of newborn screening, seeking to develop the process of management and performance of health services. The number of children screened in the state presents a good result considering the national coverage of collection [9], according to figure 2. It is worth mentioning that not all children undergo their exams through the Unified Health System, additional coverage is obtained through exams carried out in the private network of services.

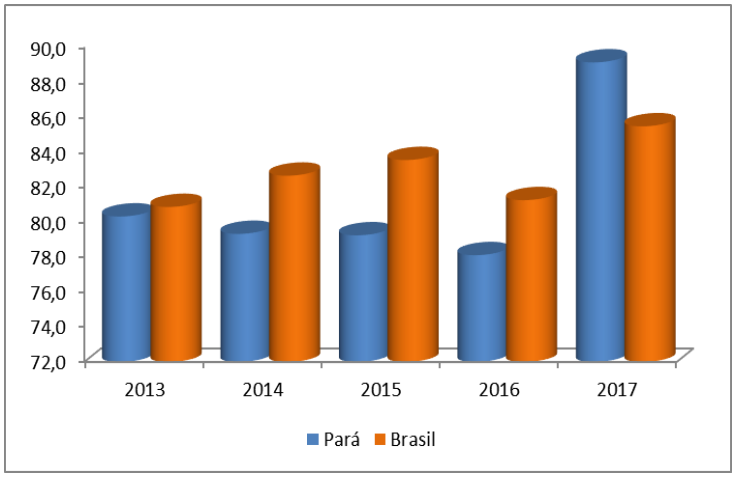


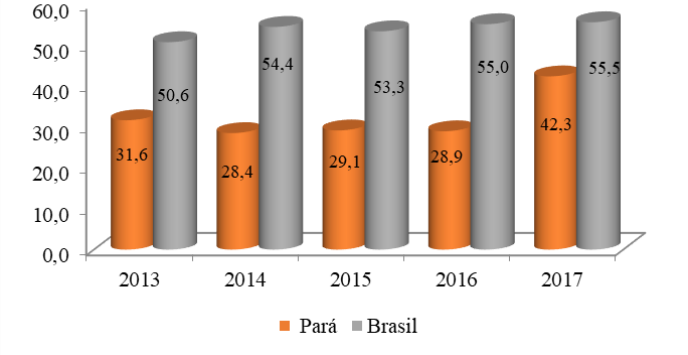
Fig.2 - Coverage of the heel prick test in Brazil and the State of Pará, 2013-2017.

Fonte: National Newborn Screening Program / VEGA Screening / SINASC.

From these data, it was evidenced that the state, despite having a good coverage of the collection of the heel prick test, in the evaluation of the collection at the timely date, the results are not in accordance with the parameters established by the Ministry of Health, as shown in Figure 3.

This may occur due to the difficulties encountered in the state of Pará, which has a territorial extension of 1,248,000 km², is the second largest state in the country, formed by 144 municipalities and has more than 20 thousand kilometers of rivers that cross the state, being the main ones: Amazonas, Tapajós, Tocantins, Xingu, Jari and Pará. It is the most populous state in the northern region with a population of 7,321,493 [10].

This territorial extension and the rivers that cross the state, associated with the poor conservation of the roads, make it difficult for children and their guardians to access the collection points in the opportune period, and the flow of samples within the municipality itself and mainly until the arrival at the Laboratory of Research and Diagnostic Support. Thus, it is highlighted that some samples can take around four weeks to reach the laboratory, harming the main objective of the program, which is to provide an early diagnosis of diseases.



Fonte: National Newborn Screening Program / VEGA Screening / SINASC.

Fig.3 – Proportion of collection of the heel prick test at the ideal date, Brazil and the State of Pará, 2013-2017.

This difficulty in access also interferes with the median age at which the child with an altered result in the heel prick test goes to the outpatient clinic of the Reference Service in Newborn Screening for diagnostic confirmation and follow-up. On average, children arrive at the service between 90 and 180 days of age. The Ministry of Health defines the ideal period for the first consultation for diseases phenylketonuria up to 15 days of life, congenital hypothyroidism, up to 10 days of life, sickle cell anemia and cystic fibrosis up to 30 days of life.

In addition to the difficulty of transporting the samples, there is the difficulty of actively searching for children with altered results in the heel prick test and who need to undergo confirmatory tests in the state capital.

After confirming the diagnosis, periodic and definitive follow-up at the Newborn Screening Reference Service is difficult and costly for families, who often cannot afford these financial costs and municipalities, on the other hand, do not assume the expenses through the Out-of-Home Treatment program, as provided for in the guidelines of the Unified Health System.

According to Ordinance No. 648, of March 28, 2006, in item 2, item IV, it is the responsibility of the Municipal Health Departments to organize the "flow of users, aiming at guaranteeing referrals to health services and actions outside the scope of Primary Care".

It is also noteworthy that the financial transfer from the Unified Health System for the maintenance of the program is not compatible with the expenses, especially for the acquisition of kits that allow the processing of samples. This situation is corroborated by Lorenzetti et al. [11] when stating that weaknesses in health management are contributing to serious public health problems.

IV. CONCLUSION

The study demonstrates how the Newborn Screening Reference Service has been developing in the state of Pará. Despite the financial difficulties and access to services, it has indicators of satisfactory coverage in the performance of newborn screening with collection, screening and analysis of samples, as well as in the search and follow-up of children.

The experience of nurses who perform the managerial role is a commitment of the profession, especially the knowledge about the elements that surround the work process becomes important for the professional to be sensitized with the awareness that when performing it effectively, it can improve assistance at work.

It is worth mentioning the importance of the nurse in the foot test, as both qualification and professional practice strengthen the practices of the multidisciplinary team, since care and management go hand in hand in the activities of the National Newborn Screening Program.

In this process, the importance of the multidisciplinary team, especially the nurse, is highlighted, seeking empowerment on the importance of newborn screening for the early diagnosis of metabolic diseases and the

prevention of irreversible sequelae, complications and deaths.

In addition, this research aims to ensure that the program has quality, meeting the expectations of the Ministry of Health's proposals and the needs of the population, ensuring universal coverage, in addition to health promotion, protection and recovery actions.

REFERENCES

[1] Rodrigues, L. P., Tanaka, S. C. S. V., Haas, V. J., Cunali, V. C. A., & Marqui, A. B. T. (2019). Teste do pezinho: condições materno-fetais que podem interferir no exame em recém-nascidos atendidos na unidade de terapia intensiva. Rev Bras Ter Intensiva, 31 (2): 186-192.

[2] Carvalho, B. M., Tavares, W. R., Vicente, J. B., Sanguino, G. Z., Leite; A. M., & Furtado, M. C. (2020). Acesso precoce à triagem neonatal biológica: coordenação entre programas de ação de assistência à infância. Rev. Latino-Am. Enfermagem, 28.

[3] Silva, F. W. T., Paiva, E. C. C., Santos, M. S., Oliveira, F. B. M., & Almeida, M. M. (2015). Anemia falciforme: cuidados realizados por enfermeiros na Estratégia Saúde da Família. Rev. Pre. Infec e Saúde, 1(4):18-26.

[4] Universidade do Estado do Pará (2014). Site notícias: Pará é habilitado para a Fase IV do Teste do Pezinho.

[5] Brasil. (2001). Portaria nº 822, de 06 de junho de 2001. Estabelece a obrigatoriedade de que os hospitais e demais estabelecimentos de atenção à saúde de gestantes. Ministério da Saúde.

[6] Pope C., & Mays N. (2009). Pesquisa qualitativa na atenção à saúde. Porto Alegre: Artmed.

[7] Brasil. (2016). Ministério da saúde. Manual de norma técnica: triagem neonatal biológica. Brasília, DF.

[8] Souza, E. A., Teixeira, C. F., & Souza, M. K. B. (2017). Análise da produção científica nacional sobre o trabalho da enfermeira (1988-2014). Saúde Debate, 41(113):630-646.

[9] Brasil. (2019). Ministério da saúde. Indicadores de triagem neonatal. Brasília, DF.

[10] Governado do Estado do Pará. (2019). Mensagem do Governo do Pará à Assembleia Legislativa. Secretaria de Estado de Planejamento e Administração.

[11] Lorenzetti J., Lanzoni, G. M. M., Assuiti, L. F.C., Pires, D. E. P., & Ramos, F.R.S. (2014). Gestão em saúde no Brasil: diálogo com gestores públicos e privados. Texto Contexto Enferm, 23(2):417-25.