Original Article

Neonatal Screening Program coverage in Maringá (PR), 2001 to 2006

Cobertura do Programa de Triagem Neonatal em Maringá (PR), 2001 a 2006

Cobertura del Programa de Triaje Neonatal en Maringá (PR), 2001 a 2006

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ABSTRACT

Objective: To evaluate the National Newborn Screening Program (NNSP) coverage in the city of Maringá, from 2001 to 2006. **Methods:** This is a cross-sectional research design, which verified the number of live newborns as well as the number of screened children. The study considered the children born in Maringá as well as those born in other cities but living in Maringá. **Results:** The NNSP did not reach the expected coverage of 100% in Maringá during the first five years of evaluation. There is a need to consider certain particularities when performing data analysis, such as the period and the place of material collection. **Conclusion:** Changes should be made so as to improve NNSP coverage. Furthermore, the period when the blood sample was drawn should be reconsidered and decentralized with a view to improve health care delivery.

Keywords: Evaluation; Neonatal screening; Child health; Primary prevention

RESUMO

Objetivo: Avaliar a cobertura do Programa nacional de Triagem Neonatal (PNTN) do município de Maringá, no período de 2001 a 2006. **Métodos:** É um estudo observacional transversal retrospectivo. Foram verificados o número de nascidos vivos e o número de crianças rastreadas, considerando os nascidos vivos em Maringá e os nascidos vivos residentes em Maringá. **Resultados:** A cobertura do PNTN em Maringá nos cinco primeiros anos avaliados, não conseguiu o objetivo almejado pelo programa, ou seja, 100% dos nascidos vivos. Algumas considerações são necessárias na análise dos dados, uma delas é a época e o local em que o material é coletado. **Conclusão:** Sugerem-se mudanças que possam vir a melhorar a cobertura do Programa de Triagem Neonatal, rever a época da coleta do sangue e descentralizá-la para ampliar o horizonte de atendimento.

Descritores: Avaliação; Triagem neonatal; Saúde da criança; Prevenção primária

RESUMEN

Objetivo: Evaluar la cobertura del Programa Nacional de Triaje Neonatal (PNTN) del municipio de Maringá, en el período 2001 a 2006. **Métodos:** Se trata de un estudio observacional transversal retrospectivo. Fueron verificados el número de nacidos vivos y el número de niños rastreados, considerando los nacidos vivos en Maringá y los nacidos vivos residentes en Maringá. **Resultados:** La cobertura del PNTN en Maringá en los cinco primeros años evaluados, no alcanzó el objetivo deseado por el programa, o sea, el 100% de los nacidos vivos. Algunas consideraciones son necesarias en el análisis de los datos, una de ellas es la época y el local en que el material es recolectado. **Conclusión:** Se sugieren cambios que puedan ayudar a mejorar la cobertura del Programa de Triaje Neonatal, revisar la época de la recolección de la sangre y descentralizarla para ampliar el horizonte de atención.

Descriptores: Evaluación; Triaje neonatal; Salud del niño; Prevención primaria.

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INTRODUCTION

Three decades ago, children with metabolic diseases were born without any life expectancy(1). As of the 1960s, the World Health Organization has promoted the development of neonatal screening programmes in developing countries. The WHO created criteria for the insertion of diseases; including high specificity and sensitivity of the disease in the population. Hence, laws have been passed to support the detection of genetic diseases with irreversible sequelae by means of Neonatal Screening Programmes(2).

In Brazil, the Ministerial Regulation number 822/01(3) regulates the early detection of genetic diseases included in the National Neonatal Screening Programme (NNSP) – Phenylketonuria, Congenital Hypothyroidism, Hemoglobinopathy, and Cystic Fibrosis. To legitimate this law has been a challenge for the Single Health System (Sistema Unico de Saude), since it makes good results possible in health care delivery and management. The damages, with chronic characteristics, resulting from a late diagnosis determine the need for efficiency and precision of secondary prevention actions.

Neonatal screening was become compulsory in the State of São Paulo by Federal Law number 3914, on November 14, 1983. Since then, all children born in the State Public Hospitals and Maternities were screened only for Congenital Hypothyroidism and Phenylketonuria (PKU). On July 13, 1990, the Federal Law number 8069 instituted this programme compulsory for all Brazilian children(3). Diseases are identified through a blood exam collected by heel puncture in the newborn. To facilitate the dissemination of this exam among the population, it was referred to as the “Heel Prick Test” (in Portuguese: Teste do Pezinho – Little Foot test)(4).

The NNSP has as objectives to increase the coverage of live newborn (LN) screening, aiming at 100%; the active search for screened patients; diagnosis confirmation and proper attendance(2). In this sense, the NNSP tracks, diagnoses, and forwards the patients to the reference services to which they are connected, for example, The Brazilian Association of Mucoviscidosis (Associação Brasileira de Mucoviscidose) providing more quality and efficiency to the treatment(5).

In view of the different levels of organization of health care units in the many Brazilian States, the variation in screened LN coverage rates and the different population characteristics, the government established stages for administering the NNSP in each state. Stage I regards the detection of PKU and congenital hypothyroidism; Stage II, PKU, congenital hypothyroidism + falciform diseases and other hemoglobinopathies; stage III, PKU, congenital hypothyroidism, falciform diseases and other hemoglobinopathies + cystic fibrosis(5). The criteria for stage evolution are based on the coverage rate of each state; for instance: a 50% coverage implies there is screening for Hemoglobinopathies; coverage up to 70% allows screening for Cystic Fibrosis(6).

The State of Paraná is in Stage III of the NNSP, but the government has included Biotinidase Deficiency (BIOT) in the screening, at their own cost. The municipal districts perform the blood collection after the first forty-eight hours of the newborn’s life and send it to the reference service, the Ecumenical Foundation of Protection to Exceptional Individuals (Fundação Ecumênica de Proteção ao Excepcional - FEPE), located in Curitiba(5).

In Maringá, the material is collected in maternities and in the laboratory of the Municipal Health Bureau.

There is no doubt about the utility of neonatal screening for population health. Nevertheless, it is always necessary to evaluate the programme, which can result in objective arrangements to correct the any flaws(7).

OBJECTIVE

To evaluate the coverage of the Neonatal Screening Programme in Maringá from 2001 to 2006.

METHODS

This study is a cross-sectional, observational retrospective study. The research complied with Resolutions numbers 196/96 and 251/97 of the National Health Counsel and was approved by the Maringá State University Ethics Committee.

The studied population included all LN in the Maringá municipal district, in the State of Paraná, from 2001 to 2006. The data were collected from the computerized records of the Health Bureau and FEPE. The numbers of LNs, screened LNs, and the number of LN in Maringá but not resident in the district were verified. The number of LN was taken from the Live Newborns System (SINASC), Health Ministry (SIM/MS/DATASUS), using the TABX programme provided by DATASUS. The FEPE provided the number of LN screened in each year.

The FEPE was established in 1961, as a Ecumenical School of Special Education and since 1974, it operates as a Research Centre in the detection of Innate Metabolism Errors. This philanthropic entity has the responsibility to investigate the screening tests for the early neonatal diagnosis and the prevention of sequelae by diseases(5). It is a reference service for neonatal screening in Paraná, and, thus, is responsible for receiving the collected materials, doing research on the diseases, and providing the services with the exam results. When positive, they are committed to searching for the patient and family to provide diagnosis tests. On this everlasting journey, it has prevented 500 children from developing mental deficiency.

The study comprised 28,247 LN, born or living in the city, and 20.529 LN screened in health services in Maringá in the referred period.

The data collected were organized and analysed using Excel (Microsoft).

RESULTS

Tables 1 and 2 display the number of LNs, born and living in the city,screened LNs, and the NNSP coverage rate in Maringá from 2001 to 2006.

Table 1 – Distribution of the live newborns according to the coverage by the National Neonatal Screening Programme

Years	Live Newborns	Screened Children	NNSP Coverage %
2001	1,434	1,127	78,6
2002	4,824	3,958	82,0
2003	5,136	3,810	74,2
2004	5,623	3,937	70,0
2005	5,634	3,701	65,7
2006	5,596	3,996	71,4
Total	**28,247**	**20,529**	**72,7**

NNSP – National Neonatal Sreening Programme

Table 2 – Distribution of the live newborns, residents, according to the coverage by the NNSP – National Neonatal Sreening Programme

Years	Live Newborns	Screened Children	NNSP Coverage %
2001	1,284	1,127	87,8
2002	4,203	3,958	94,2
2003	4,060	3,810	93,8
2004	4,246	3,937	94,2
2005	4,181	3,701	88,5
2006	4,063	3,996	98,4
Total	**22,037**	**20,529**	**93,2**

NNSP – National Neonatal Sreening Programme

DISCUSSION

The Neonatal Screening Programme of Paraná was one of the first programmes related to the evolution of the stages for establishing the screened diseases. Therefore, making the NNSP effective is considered a strategy to reduce infant mortality and improve the quality of life of the patient and family. Moreover, it also contributes to obtaining information about epidemiology, physiopathology, diagnosis, and treatment(1).

From 2001 to 2006, the number of LN not living in Maringá was 150, 621, 1076, 1377, 1433, and 1533, respectively. These data demonstrate that Maringá is the reference for health services in the region, with hospitals equipped with technology and adult, child and neonatal ICU beds. The increase in more than 1000% of the LN screened in Maringá, but not living in the city, justifies the change in the percentage of NNSP coverage if all LNs in Maringá are considered.

In the period evaluated, the NNSP coverage considering the LN in Maringá was 72.7%. However, when considering only the LNs living in Maringá, variation difference is observed, i.e., NNSP coverage reaches 93.2%. This data difference can be explained by the fact that LNs registered in Maringá but not living in the district were screened in their district of origin or by performing the exam in private laboratories. Going through the tables year by year, it was observed that, in 2001, the percentage went from 78.6% to 87.8%; in 2002, from 82% to 94.2%; in 2003, from 74.2% to 93.8%; in 2004, from 70% to 94.2%; in 2005, from 65.7% to 88.5%; and in 2006, from 71.4% to 98.4%.

Any neonatal screening programme should target 100% coverage of LNs; i.e., the blood samples must be collected from every newborn(8). A factor that can explain the results of the partial coverage of the NNSP is that the tests are performed by private laboratories, in which the data are not added to the official registers in the state. According to the records of the Health Ministry, in 2000, from the 3.000.000 LN, between a third and a half did not performs the test through the Programme(6).

It is observed that NNSP coverage in Maringá remained within the average of 92.5% in the first four years, with an expressive reduction in 2005, 88.5%, and an increase to 98.4% in 2006. The alteration pointed out in the last two years can be justified by the number of LN in the end of 2005, that is, they were born in the last week of December, but the material collection was recorded under the following year, thus increasing the rate in about 10%. The prevalence of 98.4% in 2006 reflects the improvement of the Programme and the quality in health care delivered by the collection units (maternities and Health Bureaus) and the reduction in the number of collections done by private laboratories. Even though the prevalence found is below the targets established by the Programme, i.e., to reach 100% coverage. A study performed in 1995, in the State of Sergipe, showed a neonatal screening coverage of 15%(9). In Campina Grande, Paraiba, a coverage of 32.2% was found(10). In a research performed in the State of Santa Catarina, neonatal screening coverage was evaluated from

1994 to 1998, revealing a rate of 81%, which reached 91.4% in 1997(8). The latter are very close to the figures found in this study, and are substantially different from the previous ones. These differences among Brazilian regions can reflect the country's social economic and cultural panorama.

Another study performed in Recôncavo Baiano from 2001 to 2003 showed the differences of coverage rates among municipal districts: in the city of Cachoeira, there was a reduction from 82.6% to 46.6% from 2001 to 2003; in Maragogipe, coverage was 56.2% in 2003; only in São Felix was the coverage 100% in 2002 and 2003. The success in São Felix was due to a better service structure; number of Family Health Programmes suitable to the size of the population; options of material collection units: Association of Parents and Friends of the Exceptional, Health Bureaus and vaccination centres (in the moment of the first vaccine)(11).

However, it is necessary to consider the possibility that these figures might not reveal the real screening situation in Maringá, since the fact that these tests were performed by the private system makes it unfeasible to consider the official data.

In Maringá, the material is collected in maternities after the first 48 hours of the infant's life. In a natural delivery, it is common for mother and newborn to be discharged before the 48 hours are completed. This behaviour makes material collection in the maternity unfeasible. After this period, the collection is a responsibility of the Municipal Health Bureau, located in the city centre, which is of difficult access to the population with lower income and living in the city's outskirts.

According to the Brazilian Society of Neonatal Screening(12), the ideal period for blood collection is between the third and the seventh day of life, however, never before completing 48 hours of life.

In Paraná State, it is demanded that material collection for the neonatal screening be performed after the first 48 hours of life (ideal between 48 and 120 hours) and before completing one month(13). Some Neonatal Screening Programmes, as the one in Minas Gerais, for example, collect the material on the seventh day after the delivery. It has been shown that this is appropriate for a successful diagnosis, avoiding losses like post-delivery discharges(14). Therefore, material collection is performed at basic health units and not in the maternities, as in Maringá.

CONCLUSION

The prevalence of the Neonatal Screening Programme coverage in Maringá, from 2001 to 2006, reached rates above 90%. Despite reaching an expressive coverage, it did not reach the target established by the screening Programme, although these data did not consider the tests performed in private laboratories.

The fact that Maringá is the reference for health services in the region implies that people born in the city, despite not living there, can be discharged before completing 48 hours, and, therefore, may not be reached by the screening.

However, this situation should not be considered exclusively responsible for the failure in reaching the target. A situation that could have contributed for not reaching the objective is the period and place where the collection was accomplished.

The fact that other collection centres, such as Basic Health Units (BHU), are responsible for collecting the material for the Neonatal Screening tends to increase coverage rates. This occurs because it is more feasible for the family to take their child to a BHU, since care delivery is not centralised, and thus makes the access easier to the population. In addition, the presence of the BHU is decisive to follow the child's health, more specifically by the Family Health Programme.

In Maringá, only the maternities or the Health Bureau collects blood samples for the "heel prick test". In some ways, this behaviour exempts every health institution from the responsibility of not collecting the blood or collecting it late. If a child is discharged from the hospital before completing 48 hours of life, the child can miss the exam and the services cannot be accounted for that, since maternities could not collect the material and the Health Bureau does not perform an active search, only waits for newborns to attend the service for the collection. This wearisome situation should be reconsidered with a view to maximise neonatal screening coverage.

This study led to conclusions that can could improve neonatal screening programme coverage, which are: to review the period when blood collection is performed, thus contributing to the access of live newborns, and decentralise services with a view to expand the delivery of health care.

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