

KNOWLEDGE OF NEONATAL SCREENING AND ITS OPERATIONALIZATION*

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ABSTRACT: This exploratory-descriptive study, with a qualitative approach, aimed to describe nurses' knowledge relating to neonatal screening and its operationalization. The study participants were 13 nurses working in seven Family Health Strategy Centers in a city in the south of the State of Rio Grande do Sul, in May – July 2010. The data were collected in semi-structured interviews and were analysed using the technique of the Discourse of the Collective Subject. The interviewees showed knowledge concerning the neonatal screening test regarding its aim, the ideal period for blood collection, the collection technique, the diseases tracked, and which of them the State is equipped to diagnose. During the study, the importance was emphasized of the nursing professional continuously seeking technical-scientific training. Concomitantly, the need was perceived for public managers to provide more training opportunities to the health professionals.

DESCRIPTORS: Nursing; Neonatal screening; Knowledge, attitudes and practices in health.

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INTRODUCTION

The Neonatal Screening (NS) test, popularly known as the heel-prick test, is undertaken through collecting a blood sample from the newborn's heel⁽¹⁾. It is a simple laboratory examination which detects metabolic, genetic and/or infectious illnesses, before the symptoms become evident, facilitating the newborn's inclusion in specific treatment so as to reduce or eliminate sequelae associated with each illness, allowing the child better quality of life⁽²⁾.

The World Health Organization has been calling for newborn population screening programs for the prevention of mental handicaps and threats to the health of the newborn since the 1960s. In Brazil, this test began to be used in the 1970s, and was considered a pioneering initiative in Latin America⁽³⁾.

In the 1990s, NS was incorporated into the Unified Health System (SUS) and was expanded nationwide, tracking illnesses such as phenylketonuria and congenital hypothyroidism, included under Decree GM/MS n. 22/92⁽²⁾. In 2001, the Ministry of Health launched the National Neonatal Screening Program (PNTN) under Decree GM/MS n. 822/01 which, in addition to adding the tracking of sickle cell anemia and cystic fibrosis, aimed to extend coverage to 100% of live newborns, including the undertaking of laboratory examinations, the active search for suspected cases, and diagnostic confirmation, treatment and specialized multidisciplinary monitoring of patients with any of the diseases screened for⁽¹⁾.

Considering the process of decentralization of the management of the health system, currently underway in Brazil, and with the aim of covering the whole variety of the contexts experienced, the PNTN involved the public structures at the three levels of government – municipal, state and federal – allowing a broad mobilization concerning the actions related to NS^(1,3).

In this way, it was established that the PNTN would be undertaken in an articulated way by the Ministry of Health and by the Health Departments of the different states and Federal District, through the creation of a State Network for Neonatal Screening, which would have as its central unit the Neonatal Screening Reference Services (SRTN)⁽¹⁾. Considering the different levels of organization of the care networks in the different states, and the variation in the percentage of the NS's coverage which was being undertaken with live newborns, and also the diversity of the populational characteristics existing in Brazil, it was decided to implant the PNTN in phases⁽³⁾.

Phase I detects phenylketonuria and congenital hypothyroidism; phase II adds the investigation of sickle cell anemia and other hemoglobinopathies; and phase III includes, in addition to those previously cited, the diagnosis of cystic fibrosis⁽²⁾. The accreditation of each phase depends on a populational coverage of at least 70% and on the organization of the SRTN; the State of Rio Grande do Sul is accredited for phase II of the PNTN⁽³⁾.

Regarding the collection of the blood sample, this must be undertaken not less than 48 hours after the newborn's ingestion of protein. After that, the collection must be made as quickly as possible, as – as the illnesses tracked are asymptomatic – the earlier they are diagnosed, the earlier the respective treatments may be initiated, preventing irreversible damage to the child's physical and mental development⁽¹⁻⁴⁾.

In the light of the above, it is believed that preventive actions form one of the best strategies for avoiding child morbidity and mortality⁽⁵⁾. The NS test is a preventive measure to be undertaken by the nurse, whose participation in the process of implementing the PNTN is fundamental, and who has to clarify to the caregivers the test's importance and aim, who has to explain the procedure in itself, and the need to collect the results⁽⁵⁻⁶⁾.

As a result it is believed that the time of collection is an opportune occasion for the nurse to interact with the parents and reinforce guidance which “allows the family the feeling of security, offering it knowledge which consolidates responsibility for the promotion of the well-being, and support for the health, of their child”^(6:600). In addition to the need to guide the family, the nurse also has an important role as a multiplier of knowledge in the health team with which she works⁽⁵⁾.

Nevertheless, in spite of the subject's relevance, there is a scarcity of scientific productions focusing on the nurse's work in the NS program⁽³⁾. In one study undertaken with the SRTN in the State of Paraná, a high rate of technical errors was identified in the collection of blood samples, caused by incompetence and requiring the test to be repeated⁽⁶⁾. Further, through an integrative review undertaken, it was ascertained that various studies had considered parents' knowledge regarding the NS⁽⁵⁻⁹⁾, it being possible to verify that the parents have superficial information about the test's importance and purpose⁽⁷⁾.

Such gaps may be related to a lack of technical-scientific knowledge and/or undervaluing of the test by the health professionals who collect the samples^(2,4), which shows the importance of the nurses being trai-

ned, as much to guide the caregivers, as to instruct the person responsible for the collection of the blood sample satisfactorily⁽⁹⁾. Undertaken satisfactorily and within the required time, the test is one of the important stages for the success of the objectives proposed for the PNTN⁽³⁻⁴⁾.

In this way, evidence being presented regarding the nurse's importance as a propagating agent of information and guidance at the various times of contact with the parents in conjunction with the health team, the production of this article, which aims to describe nurses' knowledge regarding neonatal screening and its operationalization, was justified.

METHOD

This is an exploratory-descriptive study with a qualitative approach, undertaken in May and June 2010. The study participants were 13 nurses working in seven of the eight Family Health Strategy (ESF) teams in the urban zone of a city in the south of Rio Grande do Sul (RS), who managed and/or collected blood samples for the diagnosis of the diseases tracked by the PNTN.

The criteria adopted for inclusion in this study were: to be a nurse; with the procedure to be undertaken by the ESF team; and to be available for, and interested in, participating in the study. Following clarification about the study's aim, and signing of the Terms of Free and Informed Consent, semi-structured interviews were held in a place previously arranged between the researcher and the interviewee.

The data collection questionnaire had the following questions: What is Neonatal Screening for you? What is the technique like, used in collecting the blood for the heel-prick test? Which diseases are detected in Neonatal Screening? The interviews were recorded and later transcribed so as to maintain the reliability of the information.

The information was interpreted based in the method of the Discourse of the Collective Subject (DCS)⁽¹⁰⁾, which made it possible to construct, using excerpts from the various individual discourses, synthesis-discourses which expressed the collective thinking of the nurses who participated in the study regarding the problem investigated.

The data were presented in groups of Central Ideas (CI). The precepts of National Health Council Resolution n. 466/12 were respected, authorization was obtained from the Municipal Health Department, and approval was received from the Ethics in Health Research Committee, under Decree N. 53/2009.

RESULTS

All the participants in the research mentioned having undertaken a postgraduate qualification in some area of health, although not necessarily in collective health or family health. In addition to this, all had worked as nurses for about 10 years; however, regarding the area of work, some mentioned having worked previously in hospital institutions. Regarding age range, this varied from 42 to 47 years old.

Regarding the interviewees' understanding in relation to what the NS test is, in spite of the importance of the nurse knowing about the issue in order to undertake the procedure efficaciously and be able to advise appropriately, the need was noticed for the interviewees to increase their knowledge, as in the discourses described in CI: the purpose of neonatal screening according to the nurses:

Neonatal screening is those tests which are done as soon as the baby is born, when the child arrives here in the Primary Care Center (UBS), they can also be done in hospital, for analyzing the newborn's blood, tracking, seeing if there is some problem, some malformation. It is possible to diagnose a mental problem which can be treated and avoid a cognitive defect. Imagine being able to treat the person, and they become normal. Also to know which diseases that the Unified Health System covers, and to detect some of the traces of the metabolic or congenital diseases possible, which can be discovered early, in time. They can be treated, avoiding greater harm to the child in the future. (N2, N3, N4, N7, N10, N11)

Regarding the appropriate period for undertaking the collection of the blood sample, although the nurses mentioned that the collection must be made in the neonate's first days of life, they demonstrated some weak points regarding the guidance of the appropriate period for this collection. Hence CI: the ideal period for collection of the blood sample for the Neonatal Screening test:

NS is done from the 3rd to the 7th day. It is done on the newborn of, at the most, 10 days. After the tenth day, there has to be a reason, such as the child being hospitalized or premature, something like that, in which case the test has to be done within 30 days. Nowadays we no longer have that urgency to take the blood sample in the first seven days of life, as there are studies

which say that the test made in 30 days doesn't harm the child in any way. The best age for the collection is up to one month old, let's say from four days old onward, in the first four days we can't collect it, only in sporadic cases if the child was hospitalized and you couldn't do it, there are these exceptions, because we can't identify the type of pathology which the child will have. (N1, N3, N4, N5, N13)

All of the nurses interviewed mentioned having had contact with the guidance regarding the correct technique for collecting the blood sample. When questioned, in addition to indicating the steps made in the collection, one can observe their emphasis on the interaction with the family member during the procedure:

We follow the protocol. We have already received various circulars about the technique for the heel-prick test, on how to do the collection. I, in particular, prepare the information card. I fill out all the data identifying the child and the mother. I explain to the mother what is going to happen, and I ask the mother, the father or the carer to place the baby on their lap, it is best if they are chest to chest, I massage the foot a little, especially if it is winter, because it is more difficult for it to fill with blood. After that we collect the blood from the foot. I put on the glove, perform asepsis with dry cotton wool, then I do the "V" on the left heel in order not to puncture it in the middle, as according to what they told us on the course which we did in the Municipal Health Department, there is the correct place for doing the collection. Using a disposable lancet or an HGT needle I prick the foot adequately, and give a little twist, as the point of this lancet is kind of triangular. Sometimes I need to make a second prick in the same little hole because we know that we cannot squeeze so that the drop of blood is reasonable, neither less, nor a gush of blood, these are medium-size drops. Sometimes the foot is really cold and they have to go to the other foot in order to finish the procedure. Next, I do a milking movement on the baby's foot, like you milk a cow, I milk it so that the drops of blood fall without the foot touching the paper, I reject the first drop of blood and try to fill all the fields necessary for the sample, generally these are three to five little spaces on the filter paper available in the center. Once the collection is finished, I put a bit of cotton on and press a little, and lie the child down with her foot upward to impede bleeding, I put the sock on and explain to the mother not to rub it. After the samples have been taken, they are sent off,

via the Health Department, to the state laboratory and thirty days later, the result comes through to know if the child needs to re-do the collection or whether the result is normal. (N4, N8, N9, N11, N12, N13)

When questioned about the diseases covered by the PNTN, the majority of the interviewees indicated three of the pathologies tracked and covered under phase II, which the State of Rio Grande do Sul is accredited to diagnose and treat. This was evidenced in CI: Identification of the diseases tracked by the Neonatal Screening test:

In the network we detect three, but the neonatal screening encompasses various tests, depending on the laboratory. Ours is the basic one, so it just covers these three diseases: Phenylketonuria, congenital hypothyroidism and sickle cell anemia. (N5, N11, N12)

In each discourse, the interviewees also expressed their understanding in relation to each one of the diseases screened. Hence CI: The focus of each disease tracked by the NS:

As far as I remember, the phenylketonuria test will track if the child has the possibility of being intolerant to some type of protein, it is a disease related to the central nervous system, it detects mental retardation; congenital hypothyroidism, on the other hand, refers to the child's height and weight, she will not have normal growth. In this case, the test will track whether the levels of the child's hormones, produced by the thyroid gland, are appropriate for the child's normal growth and development. There is also sickle cell anemia, a disease which primarily affects people of African descent, who have a higher incidence of this type of anemia. The person gets pains in their joints because the red blood cells, in the case of sickle cell anaemia, are sickle-shaped, so the organism identifies them as abnormal, destroys the red blood cells and thus causes sickle cell anemia. As we know, it's a type of anemia in which there is no drop in red blood cell numbers, but the red blood cell has a defect and the blood, in passing through the joints, ends up meeting a little more resistance – so the people generally get a lot of joint pain. In the tracking under the basic Neonatal Screening, if changes are found, another complete test is carried out for the other diseases. (N2, N3, N6, N7, N8, N9, N11).

DISCUSSION

The nurse has an important role in the implementation of the PNTN, above all in the ESF teams, as she has greater closeness to the mothers, monitoring the pregnant women from the prenatal check-ups through to the end of the puerperal period^(4,9). In addition to this, the nurse has actions for the promotion and maintenance of health and prevention of ill health as essential duties.

In her educational-assistential practice regarding the NS test, the nurse needs to make correct and complete information available, because if the parents and/or family members understand the importance of the test and the consequences of failing to diagnose the diseases screened for at an early stage, they are also more likely to act as promoters of the healthy growth and development of their children⁽⁵⁾.

In the present study, in discoursing on what they consider the Neonatal Screening test to be, the nurses indicated important points which are part of the test, such as the tracking, diagnosis and/or discovery of the health problems which can affect the newborns' development. However, they did not mention the next stages which follow the collection in the PNTN, such as, for example, the importance of sending the sample to the state SRTN, of passing the results on to the child's parents or family members, and of the active search for suspected cases⁽³⁾.

Although more than a decade has passed since the implantation of the PNTN in Brazil, there are studies which corroborate the existence of some weak points in relation to the nursing team's knowledge regarding the heel-prick test^(9,11-12). One example of this is a study undertaken in a Neonatal Intensive Care Unit in a city in the state of São Paulo, which aimed to identify the nursing team's perception of NS. The study's authors noted that although the interviewees thoroughly understood terms such as identifying, detecting, seeing and diagnosing, they had difficulty in stating the real importance of the NS⁽¹¹⁾. According to the conclusions of another study⁽¹²⁾, this difficulty is due to the fact that a large part of the advice on the heel-prick test is given only by the doctors, and during inpatient treatment in hospital.

Therefore, the success of the PNTN depends on multiprofessional and cross-sectional work by all the health professionals, principally in the prenatal period, during which the future mothers, and family members, are more disposed to interact and exchange information relevant to preventive measures and quality of life⁽¹³⁾.

Furthermore, to obtain the desired results, the system for collecting the samples requires special care; all the activities carried out are directly or indirectly important, from the choice and training of the professional who shall take the sample, through to the organization of the system for transporting the samples to the laboratory which shall undertake the analysis⁽¹⁻³⁾.

The collection of blood samples is the first in a series of stages which make up the preventive process⁽³⁾, it being recommended that these should be taken 48 hours after the newborn's ingestion of protein, either through breastfeeding or through parenteral nutrition⁽²⁻⁴⁾. Moreover, the PNTN recommends that the collection should ideally occur in the baby's first week of life⁽¹⁾. In the present study, however, it may be observed that the nurses interviewed stated that they knew the favorable period for taking the samples, but that they did not demonstrate confidence regarding the relevancy of the collection happening in this window. It is important to respect the neonatal period for undertaking the collection for the NS, as the child may be born with one of the pathologies screened for, such as congenital hypothyroidism, which can be manifested from the fourth week of the baby's life if the treatment is not initiated early⁽³⁾. This being the case, the importance of the nursing team including in the guidance given to parents information regarding the appropriate period for undertaking the test, rather than only information regarding its undertaking, becomes evident⁽¹⁻⁴⁾.

As mentioned by the interviewees in the present study, when the child remains hospitalized for some time after the birth, the collection may be delayed until the child is in a better condition for the same to occur. However, this period must not pass the child's first 30 days of life⁽³⁾. In cases of prematurity, the sample must be taken in the usual way in the first days of life, with another collection being taken after 90 days, for confirmation of the result⁽³⁻⁴⁾.

Although the literature stipulates a period of 30 days after the birth for undertaking the test, contradicting what was stated by the interviewees, there are restrictions regarding taking the sample after this period, as, if it happens that some disease tracked by the test should be diagnosed, the child could be harmed, due to the delay in confirming the diagnosis and initiating the treatment^(3,12).

In addition to the ideal period, another issue emphasized by the nurses interviewed is the collection technique. According to the Ministry of Health⁽¹⁾, the correct technique for collecting blood samples for the

NS test is a nursing procedure, and in any place where the heel-prick test is undertaken there needs to be, at the least, one nursing technician and the nurse, appropriately trained. In addition to this, the nurse needs to know how to guide and undertake the collection, as it is essential to follow the appropriate technique carefully⁽¹¹⁻¹³⁾.

According to the PNTN Manual of Technical Regulations and Operational Routines⁽¹⁾, in order to obtain a good result in the collection of the sample, the professional who shall undertake it shall: if necessary warm the baby's foot with a luke-warm hot-water bottle or a warm compress, so as to obtain the sample better; clean the correct place on the left foot with cotton lightly moistened in alcohol 70%; puncture the skin with a sterile disposable lancet with a single firm movement; always reject the first drop of blood; do not squeeze excessively the place of collection, avoiding hemolysis; start the collection while always letting the blood drip onto the filter paper, observing the circles and the complete filling out of the two sides of the paper.

However, it was observed in the statements that although the nurses mentioned receiving training and having access to the protocols which provide guidance as to the correct way of undertaking the heel-prick test, some dubious procedures were described which could invalidate the samples, making it necessary to recall the child for a further collection, causing delay in the initiation of the treatment and harming the same.

In the light of these statements, the need was ascertained for health service managers to encourage the nurses involved in taking samples for the NS test to undertake training through continuous education in health and to be dedicated to maintaining the quality of the nursing actions. It must be borne in mind that working for a long time in the same role, or since doing the training, can lead to the carrying out of procedures in a routinized way⁽²⁾ and that this can be harmful should there be no investment in continuous training.

In the same way, in places with higher turnover of nurses, the process of taking samples needs to be constantly studied for the exam's effectiveness not to be compromised. The encouragement for seeking updating and professional training can be reflected in the nurses' practice, as a professional aware of both the importance and the aim of the actions tends to value each act during the provision of the care⁽⁴⁾.

Regarding the pathologies diagnosed, based on the blood sample collected by the nursing staff, all of the interviewees were able to cite at least the three

diseases covered by the PNTN in SRTN of the State of Rio Grande do Sul. In the same way, the interviewees discussed each of the three pathologies, indicating some aspects on their worsening, should they not be diagnosed and treated early.

A full awareness of the test's aim is fundamental for the program's success, as it brings more efficiency to the process, reaching all of the newborns with quality⁽¹²⁾. Theoretical knowledge about the procedures and the pathologies involved, however, is not enough if this knowledge is not shared with patients and family members. Indeed, one study undertaken with puerperas⁽⁹⁾ observed that 89% of them demonstrated that they knew about the heel-prick test but that they could not state which diseases the test identifies and the possible harm to the newborn, should the test not be undertaken and the conditions detected early.

Thus, based on the interviewees' accounts and on studies which emphasize the poor quality of the information and of the professional commitment of the professionals who interact with the target population of the PNTN^(5-6,9), it is possible to assert that the extent of knowledge about the test's aim, on the part of the mothers and family members, results from how the guidance is passed on by the health professionals, in this case, by the nurse, as, in order for prevention to exist, it is essential for people to have appropriate information.

CONCLUSION

The discourses obtained evidenced what the interviewed nurses knew about NS, as well as its purpose, the ideal period for collecting the blood, and the collection technique, as well as regarding the diseases which are tracked and which of these the State of RS is accredited to diagnose. However, this knowledge was shown to be weak, as it was covered by the interviewees very briefly and with little theoretical underpinning when they responded to questions.

Thus, it is believed that nurses, the leaders of the teams, need to reflect on their social role and continuously seek training. In their turn, the public managers need to show that they are interested in providing greater opportunities for training through continuous education for the health professionals in the different spheres of health care in Brazil, so as to strengthen the population's access to NS, as called for by the PNTN.

It should be noted that, due to the constant appearance of technological innovations in the area of diagnosis of congenital diseases, health professionals must

be appropriately trained and updated, so as to provide appropriate guidance to parents and family members regarding NS and the related pathologies, and how they can progress and be treated.

Thus, the present study contributes to the science of nursing, as it addresses important aspects for improving the nurse's assistential, educational and managerial practice. This knowledge can positively influence the implementation of NS programs.

Nevertheless, the present study has limitations, as it was undertaken only with primary care nurses. For a greater understanding of the problem proposed, the undertaking of further studies is suggested, addressing different scenarios and including the other health professionals who also participate in the undertaking of NS.

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