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NEONATAL SCREENING: (RE)THINKING NURSING PRACTICE

TRIAGEM NEONATAL: (RE)PENSANDO A PRÁTICA DE ENFERMAGEM

TAMIZAJE NEONATAL: (RE)PENSANDO LA PRÁCTICA DE ENFERMERÍA

Daniele Ferreira Acosta¹, Ivanete da Silva Santiago Strefling², Vera Lucia de Oliveira Gomes³

ABSTRACT

Objective: to know the guidelines on neonatal screening, shared by nurses with fathers/mothers. **Method:** this is an exploratory and descriptive study with a qualitative approach, with 13 nurses working at the units of the Family Health Strategy in a town in the extreme south of Brazil. Data were collected through semi-structured interviews and analyzed according to Bardin. The study was approved by the Research Ethics Committee of the School of Nursing of Universidade Federal de Pelotas (UFPel), under the Opinion 53/2009. **Results:** one showed that nurses are concerned with advising caregivers about all stages of neonatal screening, but few demonstrate to use strategies to promote fathers/mothers' awareness on the importance of the Guthrie Test, and few focus on it during prenatal care. **Conclusion:** there's a need to rethink nursing practice, something which includes the empowerment of individuals through health education and the sharing of knowledge. **Descriptors:** Health Education; Nursing; Neonatal Screening.

RESUMO

Objetivo: conhecer as orientações acerca da triagem neonatal, compartilhadas pelos enfermeiros com pais/mães. **Método:** trata-se de estudo exploratório e descritivo com abordagem qualitativa, com 13 enfermeiras atuantes nas unidades da Estratégia Saúde da Família de um município do extremo sul do Brasil. Os dados foram coletados por meio de entrevistas semiestruturadas e analisados de acordo com Bardin. O estudo foi aprovado pelo Comitê de Ética em Pesquisa da Faculdade de Enfermagem da Universidade Federal de Pelotas (UFPel), sob o Parecer n. 53/2009. **Resultados:** evidenciou-se que os enfermeiros preocupam-se em orientar os cuidadores acerca de todas as etapas da triagem neonatal, mas poucos demonstram utilizar estratégias para favorecer o conhecimento dos pais/mães sobre a importância do Teste do Pezinho, e poucos o enfocam durante o pré-natal. **Conclusão:** é preciso repensar a prática de enfermagem, o que inclui o empoderamento dos indivíduos através da educação em saúde e do compartilhamento de saberes. **Descritores:** Educação Em Saúde; Enfermagem; Triagem Neonatal.

RESUMEN

Objetivo: conocer las orientaciones acerca del tamizaje neonatal, compartidas por los enfermeros con padres/madres. **Método:** esto es un estudio exploratorio y descriptivo con abordaje cualitativo, con 13 enfermeras que actúan en las unidades de la Estrategia Salud de la Familia en un municipio del extremo sur de Brasil. Los datos fueron recogidos por medio de entrevistas semi-estructuradas y analizados según Bardin. El estudio fue aprobado por el Comité de Ética en Investigación de la Facultad de Enfermería de la Universidade Federal de Pelotas (UFPel), bajo la Opinión 53/2009. **Resultados:** se evidenció que los enfermeros se preocupan de orientar a los cuidadores acerca de todas las etapas del tamizaje neonatal, pero pocos demuestran utilizar estrategias para promover el conocimiento de los padres/las madres acerca de la importancia de la Prueba de Guthrie, y pocos se centran en él durante la atención prenatal. **Conclusión:** hay que se repensar la práctica de enfermería, lo que incluye el empoderamiento de los individuos a través de la educación en salud y del intercambio de conocimientos. **Descriptores:** Educación En Salud; Enfermería; Tamizaje Neonatal.

¹Nurse. MS student at the Graduate Program of the School of Nursing of Universidade Federal do Rio Grande (FURG). Member of the Group for Study and Research on Nursing, Gender, and Society (GEPEGS). Rio Grande (RS), Brazil. Email: daniele_acosta@hotmail.com; ²Nurse. MS student at the Graduate Program of the School of Nursing of FURG. Rio Grande (RS), Brazil. Email: ivanete25@hotmail.com; ³Nurse. PhD degree in Nursing obtained from Universidade Federal de Santa Catarina (UFSC). Full Professor at the School of Nursing of FURG. Leader of GEPEGS. Rio Grande (RS), Brazil. Email: vlogomes@terra.com.br

INTRODUCTION

Life expectancy, over the last centuries, has significantly increased in most of the world. Technological development is one of the phenomena directly related to these settings. The creation of new phenomena directly related to this setting. The creation of new vaccines and medicines, besides new prevention and early detection services, has allowed an intervention in the health-illness process covering most predisposing factors.¹

Although still persists a focus on curative disease control, the prevention field has shown to be invaluable from the perspective of promoting quality of life. In this sense, neonatal screening (NS) stood out, this is known by the name of "Guthrie Test" (GT). This test constitutes an important strategy for screening metabolic, genetic, and infectious diseases², and it's conducted by means of a laboratory examination which analyzes drops of blood taken from the heel of children within the neonatal period. However, it would be ideal that the examination was conducted between the 3rd and 7th days of life, since early diagnosis interferes with the course of disease, thus allowing the implementation of specific treatment and the prevention of sequelae.²

In Brazil, NS became mandatory from 1992. In 2001, the Ministry of Health created the National Program of Neonatal Screening (PNTN), aiming to increase the number of diagnosed diseases which, until then, were limited to congenital hypothyroidism and phenylketonuria. Through PNTN, one included pathologies such as sickle cell anemia and cystic fibrosis, and the examination was included in the neonatal care protocol in all Brazilian states, providing the population of newborn infants (NBIs) with 100% coverage. Besides the diagnosis, the program started providing treatment and monitoring of children, showing positive results.^{2,3}

To ensure such coverage, there's a need for involving fathers/mothers through educational activities which constitute themselves as one of the best strategies, in order to ensure adherence to the program and, as a result, decrease children's morbidity and mortality.⁴ In this groundwork, strengthening the purpose and importance of carrying out NS is unique, since, for providing prevention, it's a must that people know what and why they are preventing. When the client understands the meaning and importance of advice received, there's a tendency to effectively and efficiently adhere to them.⁵

It's usual that mothers feel anxious about

the care procedures with NBIs, which is intensified insofar as the knowledge and skills needed increase, especially when they're primiparous.⁶ Thus, the nurse, responsible for promoting health, as well as for all screening stages, needs, from prenatal care, discuss with pregnant women the purpose, collect way, and benefits of this examination. To achieve the goals of PNTN, the educative role must not start only after birth^{1,7,8}, since fathers/mothers need time to process the information received, question them, and, thus, put them into practice.

Whereas the nurse has, among her/his duties, health promotion and disease prevention through health education; whereas such actions need to be performed so that father/mothers, indispensable agents needed for the harmonious growth and development of their children, are able to act as subjects in the care process; whereas, also, the lack of researches focusing on nurses' knowledge about neonatal screening and how she/he advises the caregivers, this study aimed to investigate the following question: "What guidelines, about neonatal screening, are shared by nurses with fathers/mothers?"

METHOD

This is an exploratory and descriptive study with a qualitative approach carried out with nurses who work at Family Health Basic Units (UBSFs) in a town in the extreme south of Brazil.

One included as informants nurses who performed this procedure in a UBSF; who have availability and interest in participating in the study; and who authorized the recording of interview. Data collection was conducted within the period from March to October 2010, through individual semi-structured interviews. The interviews were recorded after approval and signing of the free and informed consent term.

After conducting the interviews, one adopted the content analysis technique for processing data.⁹ For this, first, one got a fluctuating reading and prepared the material, then, there was encoding and investigation, moment at which the context units were delimited. The study subjects were identified through the letter I followed by ordinal numbers, in order to ensure their anonymity.

The study was authorized by the Municipal Health Secretariat of Pelotas and approved by the Research Ethics Committee of the School of Nursing of Universidade Federal de Pelotas (UFPEl), under the Opinion 53/2009.

RESULTS

One interviewed 13 female nurses working at 7 UBSFs in a town in the extreme south of Brazil. All of them mentioned to have attended a postgraduate course in any health area, not necessarily in public health or family health. The age of respondents ranged from 42 to 47 years, everyone worked as a nurse for about 10 years, however, when asked about the area they were practicing in, some referred to have worked, previously, in a hospital environment.

Regarding the guidelines shared by the female nurses with fathers/mothers on neonatal screening, one realized that, although the advantages are apparent by conducting it from prenatal period, only one nurse stressed the importance of this practice.

[...] During prenatal care itself we talk about everything that will happen, [...] we ask them to bring the newborn infant for the Guthrie Test after the third day of life. (I1)

Eight interviewed nurses indicated that they advise fathers/mothers on the purpose of neonatal screening.

[...] I emphasize the importance of examination for early detection of diseases which can cause mental retardation. (I3)

[...] We advise about the importance of performing the examination because these diseases have no cure, but there's a treatment for them. (I10)

One observed in the testimonies that three nurses showed to worry about using teaching and learning strategies in an individualized way, taking into account the previous knowledge of fathers/mothers.

Before performing GT, we ask the father and mother: do you know what is Guthrie Test? (I1)

[...] We always extend it, according to the mother's understanding capacity [...]. (I3)

[...] We explain: Ah! Have you ever read in the Coca-Cola bottle that it contains phenylalanine? You know, the person with phenylketonuria can't drink it [...] so, we explain it. (I6)

Rather than advising on the technique recommended, one noticed that there's a commitment to provide a good embracement, aiming at the calmness not only of the baby, but also of the mother, during the collection needed for examination:

[...] I ask them to stay chest to chest and belly to belly [mother and NBI] because, this way, the baby gets close to the breast and notices that the child calms down, because he is smelling the mother and the milk. (I2)

Guidance on the care for the NBI after blood collection also showed to be relevant.

Regarding the child's foot, I advise that there're no risks, that usually blood stops fast, and that one has to maintain hygiene as usual. (I8)

[...] That one can leave the wound dressing there for thirty minutes and, then, it may be removed without any bleeding. (I4)

Many reports stress that, besides advising on the importance of taking the children to perform the examination, it's essential to encourage caregivers to go get the result.

[...] After collection, we advise to come get the result soon. (I7)

I advise them [fathers and mothers] to come back to get the result. I think it's very important and, if there's some abnormality, they'll be informed. (I12)

Finally, in the face of the reports, one realized that there's a certain lack of theoretical grounding and knowledge updating, as some behaviors don't match or go against what is recommended by the *Manual de normas técnicas e rotinas do Programa de Triagem Neonatal*.

Nowadays, there isn't that urgency for collecting the exam within the first 7 days of life, since there're already studies stating the test collected within the first 30 days of life won't cause any harm to the child. (I6)

[...] Phenylketonuria is a disease related to the central nervous system [...] detecting mental retardation, you know, and congenital hypothyroidism is related to the height and weight of this child, whether she won't have a normal growth. (I13)

In this sense, one highlights the importance of continued education, to ensure the effectiveness of the assistance provided by nurses and, thus, the quality of life of NBIs, through the care offered by the fathers and mothers.

DISCUSSION

In order to prevent the diseases detected through neonatal screening from causing sequelae in the babies, there's a need for diagnosing and treating them early, and the nurse is one of the persons responsible for this preventive measure.

Although PNTN has been implemented in Brazil for more than a decade, there're studies showing the lack of knowledge of mothers and their relatives on GT.^{1,7,8,10,11} One example of this situation may be observed in a research in Cárceres, Mato Grosso, Brazil, which aimed to analyze the knowledge of the puerperal women on the importance of neonatal screening. In that study, one observed that most mothers reported having heard about the exam, but they mistook it for the NBIs footprint record¹⁰, collected at birth. They also thought GT was able to cure the pathologies, without mentioning the

“importance of early detection and prevention of sequelae, neither the improved quality of life”.^{10:285}

It's worth highlighting that, to ensure fathers/mothers' understanding on the examination and, therefore, the children's quality of life, this information should be part of the gravidic-puerperal cycle, instead of being restricted to the postpartum period and the time of neonatal screening collection. Researches demonstrate the ineffectiveness of these nursing guidelines, by presenting reports of caregivers who state to have acquired this knowledge in the maternity hospital or in previous pregnancies, but it's known that it must occur during prenatal care.⁸ In this study, only one nurse reported the importance of this approach, even before the baby's birth.

One recommends that all stages of neonatal screening are explained to fathers/mothers, since the lack of information may hinder understanding, leading them to regard the examination only as mandatory, instead of something indispensable for the harmonious growth and development of the child. The guidelines, through health education, are essential, regardless of the nurses' workplace¹⁰, because it's an invaluable and essential tool for providing an effective care.

However, more than guiding, one should ensure that information is understood, something which may be facilitated by repetition at different moments during the contact with fathers/mothers. In order to have a complete adherence to the program, it's essential that caregivers know the purpose of examination and understand its sequelae prevention nature, in case of positive diagnosis, and, thus, demystify the perception that it's “just a test sticking the foot”.^{1,8,10}

In this research, one realized that there're few female nurses who show to be concerned with using teaching-learning strategies to allow the understanding of mothers/relatives on GT. Such measures refer to individualized guidance, based on the prior knowledge and each caregiver's capacity for understanding. One also highlights the report of one respondent who uses daily life examples, such as the soda bottle, to address phenylketonuria with caregivers, in order to facilitate understanding. This disease refers to deficiency or absence of the phenylalanine hydroxylase enzyme in the body, something which requires a phenylalanine-free diet from the child.² These actions corroborate nurses' educating-caring practices, aimed at the particularities of each human being, according

to her/his social context, addressing her/him only as a unique and singular subject.¹² Similarly, it's directed towards problem-solving education, having the subject as the builder of her/his own knowledge.¹³

It's usual for mothers to feel anxious towards the test, because sticking the baby's heel generates discomfort. A study revealed the astonished reaction of a mother by witnessing her child undergoing the examination.¹⁴ Otherwise, one respondent reported that she ensures the calmness of mothers. For this, instead of just requesting the correct positioning of the baby to facilitate the collection, she also seeks to make the genitor feel to be protecting her son, a fact which eases her stress, as well as the baby's stress. This finding contributes to potentiate the bond between mother and child, as well as the establishment of a co-accountability between health professionals and the community.

Regard the guidelines concerning the procedure, one found out that ten female nurses focus on the care around the baby's heel injury. This conduct is needed and reassuring, as it clarifies the mother with regard to the post-collection care, however, it isn't enough. It should be just the complement of a set of aspects which starts with prenatal care and ends with the result delivery.

This way, most female respondents highlighted the importance of searching for the results, regarding it as a must, taking into account that GT enables the prevention of sequelae due to disease when promptly diagnosed. One observed that most female nurses provide guidance on this need, exemplifying that the presence of a disease without immediate treatment may cause serious damage to the child, as detected through an analysis of medical records of patients diagnosed with sickle cell anemia.¹⁵

In that study, delayed treatment was due to the fact that the health unit hadn't, apparently, received the result of GT and the family was unaware of the diagnosis.¹⁵ Therefore, health education constitutes itself as a tool able to provide the relatives with autonomy, through a critic-reflective practice, with transformation-action and dialogic education.¹²

Finally, in order to carry out all these steps successfully, nurses' knowledge on NS is a must. One noticed that most of them rely on standardized guidelines in accordance with the *Manual de normas técnicas e rotinas do Programa de Triagem Neonatal*. However, it was possible to detect some mistakes, such

as, for instance, with regard to the period indicated to perform the screening. For early identifying and treating the diseases screened, the examination should be carried out between the 3rd and 7th day of baby's life.² Moreover, phenylketonuria doesn't detect mental retardation, as told by a nurse, but prevents this problem if the examination is performed in a timely manner.

The nursing team's lack of knowledge is addressed in other studies^{7,16}, showing that none of the 21 respondents mentioned the actual importance of NS.¹⁶ Thus, it's a must to the implementation of continued health education in institutions with the participation of managers, health professionals, and users, so that the professional qualification is effective. The nurse qualified for professional practice performs her/his tasks efficiently and effectively, ensuring a global and humanized service.¹⁷ Distance education also emerges as an alternative able to enable the nurse to perform NS, through updated information, sensitization, awareness, education, and training with regard to the collection technique.¹⁸

This study urges one to rethink on how "our" actions have been developed along with clients. Teaching isn't transferring knowledge, but rather creating opportunities for its production or its construction¹², regardless of location, class, race, age, or gender. Health education, performed in an effective way, tends to empower individuals for reflecting and adopting healthier habits and lifestyles through, of course, the support and encouragement of health professionals.

CONCLUSION

The results obtained by this research reached the initial goal, since, by analyzing the guidelines provided by the female nurses on NS, one noticed that most of them is concerned with sharing guidance on all stages for performing GT.

Some strategies were mentioned as being part of the teaching-learning process, in order to facilitate the caregivers' understanding, but this data proved to be inadequate, taking into account that health education is one of the main duties of nurses. Moreover, there was shortage in the reports concerning the purpose of the examination and its approach during the gravidic-puerperal cycle. The one who acts in a horizontal way, through a dialogic and reciprocal relationship with fathers and mothers, will certainly contribute to the babies' healthy growth and development.

There were also some mistakes during the

interviews with regard to the time appointed for the examination collection and its purpose with regard to phenylketonuria. With this, it's understood that there's a nursing need to constantly seek to update knowledge. Continued education arises as needed to maintain the quality of nursing care.

Therefore, there's a need for seeing NBI and their relatives beyond the physical and biological needs. This sensitivity is developed through listening, embracing, humanized relationship, and encouragement to the subject's autonomy, which should be valued by those who act as co-participants in care.

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Corresponding Address

Daniele Ferreira Acosta
Avenida Presidente Vargas, 881, casa 3 –
Parque
CEP: 96202-100 – Rio Grande (RS), Brasil