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Meanings, experiences and social interactions of mothers regarding the biological neonatal screening test

Significados, experiências e interações sociais de mães acerca do exame de triagem neonatal biológica

Significados, experiencias e interacciones sociales de las madres sobre la prueba de tamizaje biológico neonatal

ABSTRACT

Objective: To understand the meanings, experiences and social interactions of mothers regarding the biological newborn screening test. **Methods:** A qualitative study with theoretical and conceptual support based on symbolic interactionism, conducted with 10 postpartum women. Data were collected through semi-structured interviews and analyzed using content analysis with a thematic approach. **Results:** The postpartum women had limited knowledge of the biological newborn screening test, revealing gaps in the health education process for this group. **Final remarks:** The meanings attributed by the postpartum women were simplistic, and their experiences highlighted flaws in the educational process during prenatal, hospital care and postpartum care. Nonetheless, most of the postpartum women sought the service within the appropriate timeframe, suggesting that, at some point, effective communication occurred, and they were made aware. However, a significant number of postpartum women still sought care later than recommended.

Descriptors: Neonatal screening; Public health; National health programs; Professional-family relationships.

RESUMO

Objetivo: Conhecer os significados, experiências e interações sociais de mães acerca do exame de triagem neonatal biológica. **Métodos:** Estudo qualitativo com suporte teórico-conceitual a partir do interacionismo simbólico conduzido com 10 puérperas. Os dados foram coletados por meio de entrevista com um roteiro semiestruturado, os quais foram analisados segundo a análise de conteúdo na modalidade análise temática. **Resultados:** As puérperas tinham conhecimentos limitados sobre o exame de triagem neonatal biológica, identificando-se falhas no processo de educação em saúde destinadas a essas puérperas. **Considerações finais:** Os significados atribuídos pelas puérperas foram elementares, as experiências revelaram que houve falhas no processo educativo durante o pré-natal, assistência hospitalar ou puerperal; mas, mesmo assim, grande parte delas procuraram o serviço no período correto, demonstrando que em algum momento uma eventual interação foi realizada e a puérpera foi sensibilizada. Contudo, um número importante de compareceu com atraso à unidade.

Descritores: Triagem neonatal; Saúde pública; Programas nacionais de saúde; Relações profissional-família.

RESUMEN

Objetivo: Comprender los significados, experiencias e interacciones sociales de las madres sobre la prueba de tamizaje biológico neonatal. **Métodos:** Estudio cualitativo con sustento teórico-conceptual basado en el interaccionismo simbólico con 10 puérperas, los datos fueron recolectados a través de entrevistas con guión semiestructurado, los cuales fueron analizados de acuerdo al análisis de contenido en la modalidad de análisis temático. **Resultados:** Las puérperas tuvieron un conocimiento limitado sobre la prueba de tamizaje biológico neonatal, identificándose fallas en el proceso de educación para la salud. **Consideraciones finales:** Los significados atribuidos por las puérperas fueron elementales, las experiencias revelaron que existieron fallas en el proceso educativo durante la atención prenatal, hospitalaria o puerperal, aun así, la mayoría de las puérperas buscaron el servicio en el período correcto, demostrando que en algún momento se realizó una eventual interacción y la puérpera se sensibilizó, sin embargo, un número importante de puérperas acudió tardíamente a la unidad.

Descriptores: Tamizaje neonatal; Salud pública; Programas nacionales de salud; Relaciones profesional-familia.

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INTRODUCTION

Currently, the Neonatal Screening Program of Minas Gerais (Portuguese Acronym: PTNMG) allows the Brazilian Unified Health System (Portuguese Acronym: SUS) to screen for six diseases through the Biological Neonatal Screening Test (Portuguese Acronym: TNB). These diseases include: sickle cell anemia and other hemoglobinopathies, biotinidase deficiency, phenylketonuria, cystic fibrosis, congenital adrenal hyperplasia, and congenital hypothyroidism(1). An amendment made in May 2021, ratified by Law No. 14.154, expanded the number of diseases and conditions to be screened through this test in the SUS to 50(2). The expansion of the test yields positive outcomes for society by increasing awareness of these diseases. However, for the test to be effective, it must maintain high coverage rates, and its implementation needs to be enhanced in regions with limited infrastructure(3,4).

The Guthrie test, commonly known as the "heel prick test", is part of the National Neonatal Screening Program (Portuguese Acronym: PNTN) and serves a preventive purpose. Its primary objective is to screen for metabolic and genetic disorders that may be asymptomatic in the early days of a newborn's life. The diseases detected by the test have effective treatments; however, if not identified and treated early, some can result in developmental delays or even death. Therefore, early diagnosis directly impacts the prognosis and improves the quality of life for affected individuals(5).

However, despite its significance for neonatal health, the lack of information among parents, family members, and healthcare professionals - stemming from insufficient understanding of the test's importance - compromises the effectiveness of neonatal screening (TNB) and the timely diagnosis of the diseases being screened. Furthermore, the unpreparedness of the healthcare team and the insufficient dissemination of information about the test through widely accessible media by the relevant authorities undermine the program's success(6). It is also important to note that the timing of when this information is provided can influence how the family understands the issue(5), with greater effectiveness when offered throughout pregnancy to promote maternal health literacy.

In this context, maternal health literacy can be defined as the acquisition of cognitive and social skills that empower pregnant women to access, understand, analyze, and apply the information necessary to maintain and improve their health. The World Health Organization (WHO) emphasizes that health literacy and the empowerment of pregnant women are two essential components of programs designed to improve maternal health. Therefore, offering pregnant women education and training in various contexts is a crucial factor for their empowerment, success, and overall well-being(7).

Further studies on the subject are needed to improve care, expand healthcare measures, and enhance the scope of public policies(8). Given the above, the objective of this article is to explore the meanings, experiences, and social interactions of mothers concerning the neonatal screening test (TNB).

METHODS

A qualitative study was carried out based on the theoretical-methodological framework of Symbolic Interactionism (SI). SI is grounded in three fundamental premises: human actions stem from the meanings that things hold for the individual; these meanings, in turn, arise from social interactions with others; and such meanings can be transformed through the interpretive process the individual undergoes as they encounter various experiences along their journey. Thus, SI is manifested in three theoretical aspects: meanings, acquired experiences, and social interactions(9). The study adhered to the recommended steps outlined by the Consolidated Criteria for Reporting Qualitative Research (COREQ).

The research was conducted at a Basic Health Unit (Portuguese Acronym: UBS) in a municipality in the northern region of the state of Minas Gerais, Brazil. The UBS selection was made through simple random sampling, with the sole criterion being that the UBS had a basic family health team, consisting of at least one doctor, one nurse, one nursing assistant or technician, and community health agents, as stipulated by the National Primary Care Policy(10).

The study population consisted of mothers of newborns in the early neonatal period, defined as the stage of life from birth to six days, 23 hours, and 59 minutes(11). For sampling, all women who gave birth within the service area of the UBS during the second half of 2018 (July to December), which was the data collection period, were considered. Therefore, the sampling was based on convenience, and the final sample consisted of 10 postpartum women. The exclusion criteria included mothers with communication barriers, low cognitive abilities (such as difficulties with concentration, attention, comprehension, or understanding, assessed through simple observation by the researchers), and caregivers who brought the newborn for the neonatal screening test but had not attended prenatal, postpartum, or childbirth consultations with the mother.

For data collection, two instruments were used: a questionnaire containing sociodemographic variables and a semi-structured interview guide developed by the researchers, which included the following guiding questions: “In your opinion, what is the heel prick test?” and “how did the healthcare professionals provide guidance regarding the test?”. A pre-test of the instruments was conducted with postpartum women in the coverage area of a UBS (Basic Health Unit) other than the one selected for the study. As a result, the UBS used for the pre-test was excluded from the simple random sampling process. In the UBS, there was a room where nursing procedures were conducted, including blood collection for the neonatal screening test (TNB), which was usually carried out by the nursing technician, or, in their absence, by the nurse. It is important to note that the mothers stayed with their newborns during the blood collection procedure. After the blood collection procedure, the mothers were approached, and the interview was conducted in the presence of the researcher only. The nursing technician was responsible for filling out the necessary records in a separate office adjacent to the procedure room. The researchers did not interfere with any instructions regarding the test.

The audio recordings of the interviews were made with the participants' consent and later transcribed individually by the researchers, ensuring the preservation of the literal content of the responses. Each interview was coded with the letter "M" (for mother), followed by a sequential Arabic numeral. Afterward, the collected material was cross-checked by pairs of researchers to minimize interpretative bias. The content was then organized based on Bardin's Thematic Content Analysis(12), which includes the stages of pre-analysis, material exploration, result processing, and interpretation. After an exhaustive reading of the content, responses related to each thematic axis were identified, thus forming the analytical categories. These data were then interpreted through the lens of Symbolic Interactionism (SI).

National and international standards for research involving human beings were followed, in accordance with Resolution No. 466/2012 of the National Health Council. In this regard, confidentiality was ensured, and the Free and Informed Consent Form (Portuguese Acronym: TCLE) was provided in two copies, along with explanations about the study and the right to withdraw at any stage of the research. The study was approved by the Research Ethics Committee, under the Certificate of Presentation of Ethical Appreciation (Portuguese Acronym: CAAE) No. 93401518.7.0000.5141.

RESULTS

Ten postpartum women participated in the study. Regarding age, most participants were between 20 and 30 years old (60%); in terms of family income, 20% earned a minimum wage; in relation to race, the majority identified as black (70%); 60% were married, and 70% had completed high school. All postpartum women reported attending prenatal care, with 80% having had six or more appointments. Nine women (90%) reported not participating in any educational or similar groups during prenatal care or the postpartum period, and nine women (90%) had attended postpartum consultations. Thirty percent of the women attended the neonatal screening test (TNB) collection more than five days after the newborn's birth, indicating a delay in the collection of the sample.

While analyzing the responses, it became clear that the postpartum women had only basic knowledge and a limited understanding of the neonatal screening test (TNB), with significant gaps in their interactions with healthcare professionals. These gaps ultimately undermined the effectiveness of the health education provided. Therefore, gaps were identified in their social interactions with healthcare professionals, which negatively affected the health education process for these women. As a result, the experience of undergoing the test itself did not lead to a clear or satisfactory understanding of it. Thus, the following thematic categories were established: meanings attributed to the TNB test, and experiences and social interactions related to their knowledge of the TNB test, as shown in Chart 1.

Chart 1 – Categories based on symbolic interactionism and the mothers' responses

Meanings attributed to the Biological Neonatal Screening Test
"I don't know much about the heel prick test; only that it's used to detect several diseases early in a child's life" (M1).
"I know what the heel prick test is; first, they prick the baby's foot, collect the blood, and send the sample to the lab for some tests, but I don't know what these tests are for" (M2).
"I know what the heel prick test is; they make a small hole in the baby's foot but I'm not sure if they place the drops of blood on five spots to check if they have some autoimmune disease" (M3).
"The heel prick test is made for early detection of any congenital diseases, and I know how it's done" (M4).
"I'm not exactly sure what the heel prick test is, all I only know is that they take a small sample of blood from the baby's foot, that's all I know" (M5).
"[...] I know what the heel prick test is, it was done, but I wasn't given any information about it" (M6).
"The heel prick test, which shows if there is any serious disease, has already been done on the baby; they collect a drop of blood" (M7).
"It seems that the heel prick test is used to screen for five diseases. I was somewhat informed about how it's done, and I know they take blood from the baby's foot to test for these diseases" (M8).
"I know what the heel prick test is, I know they pricked the baby's foot, then put it on a piece of paper" (M9).
"I know what the heel prick test is, they prick the baby's foot to detect some disease" (M10).
Experiences and social interactions related to the knowledge of the Neonatal Biological Screening Test
"I didn't receive any information during prenatal care or postpartum care" (M1).
"During prenatal care and postpartum care, I didn't receive any information about the tests" (M2).
"During prenatal care, I was not informed about the tests" (M3).
"During prenatal care, I didn't receive any guidance. I know the test should be done, and I was only instructed to do it when I was at the hospital" (M4).
"During prenatal care, I didn't receive any guidance" (M5).
"I didn't receive any guidance during prenatal care, as far as I remember" (M6).
"I don't know what it's for and I wasn't given any guidance about these tests" (M7).
"I did not receive any clear guidance about these tests" (M8).
"During prenatal care, I received guidance about the tests" (M9).
"I did not receive any information during prenatal care" (M10).

Source: Prepared by the authors.

DISCUSSION

The responses revealed that the postpartum women attributed superficial meanings to the Neonatal Biological Screening Test (TNB); however, they acknowledged its importance, as most attended the hospital between the third and fifth day of the newborn's life, as recommended by the Ministry of Health, for the baby's blood collection and the test to be performed. This suggests that at some point, they were made aware that the test should be carried out, with the timing determined based on the birth date recorded in the child's health booklet. A study conducted in a northeastern state of Brazil with parents and caregivers of newborns also found that they had basic knowledge of the test(13). Another study involving mothers of newborns who underwent the test showed that while they understood the importance of the test, they reported not being adequately informed about its purpose(6). Therefore, the superficial knowledge about the TNB may be linked to the information received, which often focuses solely on the necessity of performing the test without elaborating on the steps involved, the benefits, and the potential outcomes of not performing it(5).

In the present study, 30% of the postpartum women attended the UBS later than recommended for the neonatal screening test (TNB) blood collection. This outcome is significant as it highlights gaps in the maternity care network, whether during prenatal or obstetric care, which could undermine the potential for early diagnosis and timely treatment if a newborn presents with any health condition.

The data collected revealed a range of conceptions attributed by the postpartum women to the neonatal screening test (TNB), with notable mentions including: early detection of diseases, heel prick, blood drop, sample sent to the lab, autoimmune disease, congenital disorders, and serious illness. The responses revealed that while some mothers recognized certain important aspects of the test, they were not familiar with the specific diseases screened for, the associated signs and symptoms, or the necessary care. This highlights there is lack of knowledge or even conflicting information, indicating weaknesses in the educational process during prenatal care, hospital assistance, and postpartum care. Regarding the experience itself, it is important to note that even during or after the test, the women were not adequately informed, which could, in turn, limit the continuity of care for the newborn. Therefore, it is believed that the information provided to the mothers at the time of the test is often insufficient, or sometimes even absent, as the postpartum women did not fully grasp the essence of the neonatal screening test (TNB)(6).

The diseases detected by the test, being relatively rare, may not be widely known; therefore, it is crucial to offer guidance on their signs, symptoms, and potential lethality to the population(6,13). Therefore, during prenatal care, it is crucial to provide clear guidance to pregnant women and their family members on how and where to perform the test, based on the available collection network in their state of residence, while emphasizing the importance of having the sample collected by the 5th day of the newborn's life(1).

Considering the experience of undergoing the test and the social interactions resulting from it, parents often encounter professionals who are overwhelmed by the routine of delivering services and following technical procedures, which can lead to a lack of humanization and the educational dimension of care. Thus, an important reflection concerns the compassionate approach that can enrich these caregiving relationships. This principle fosters an expansion of dialogue in caregiving relationships and educational actions by incorporating emotional exchanges and sensitivity, thus enabling a deeper connection beyond a discourse based solely on knowledge and systematically organized arguments(12). Additionally, it is important to employ gentle care technologies that rely on intersubjective processes such as therapeutic listening and therapeutic communication, which enable the focus of care to be on the person, rather than the illness(6).

In this context, key sources of information for pregnant women and postpartum mothers regarding the neonatal screening test (TNB) include the community and the media, in alignment with the principles of primary health care, especially community-oriented guidance. A significant strategy is to promote health education in community spaces within the UBS's service area to disseminate information about the test, ensuring that the community has access to accurate and relevant knowledge. When pregnant and postpartum women are not properly informed, the opinions of non-professionals can make them vulnerable and influence their decision-making process(14). Therefore, creating educational materials about the TNB can help raise awareness and provide essential education for pregnant women, postpartum mothers, and healthcare professionals.

The learning process shared with others who have the same clinical condition facilitates the exchange of experiences and knowledge, nurtures feelings of altruism, and fosters the development of bonds and unity among individuals, outcomes achieved through operative groups(15). Studies conducted in Iran(16) and Turkey(7) highlighted positive health outcomes for pregnant women who participated in structured educational programs and demonstrated satisfactory levels of health literacy.

Groups of pregnant women provide opportunities for action and reflection, focused on identifying care needs, which in turn facilitate the planning and delivery of care. These groups also strengthen relationships with healthcare professionals and encourage the use of effective learning strategies(17). From this perspective, the quality of educational practices provided during comprehensive and continuous prenatal care serves as a preventive strategy to mitigate negative outcomes. It promotes reflection and understanding of the determinants of the health-disease process, enabling problem-solving and ultimately improving quality of life(18).

In this context, health education programs aim to demystify and guide both healthcare professionals and the individuals they serve, as the educational process fosters mutual growth and improvement. It is crucial to emphasize that evaluating the methodologies used in health education for pregnant women is key for professionals to identify and implement the most effective strategies, successfully empowering both the individual and their family. This is achieved by providing clear information on positive health habits and practices(19) that contribute to building health literacy.

Thus, educational practices focus on health education activities and the development of both individual and collective capacities, with the goal of improving quality of life and health. Health education is not merely an intervention focused on disease, but a process through which individuals and communities learn strategies to preserve or restore health, encompassing physical, psychological, socioeconomic, and spiritual dimensions(18).

This study found that, regarding social interactions, pregnant women attended prenatal care visits, although there was no consensus on the ideal number of consultations. Most attended postpartum consultations, and none participated in health education meetings or groups, which limited their access to information about the TNB. It is crucial to highlight that a greater number of prenatal care visits is associated with positive obstetric and neonatal outcomes, also serving as a protective factor against various complications, including prematurity, maternal, fetal, and neonatal mortality, low birth weight, postpartum depression, and closely spaced pregnancies(20).

A study conducted in the central-southern region of the country found that, in some healthcare institutions, mothers are only informed about the need to refer the newborn for the TNB test at the time of hospital discharge, when the blood collection is scheduled(21). In contrast, guidance on screening should be provided early during prenatal care, as this is the stage when women are often better able to absorb the information. This is, therefore, the optimal moment, as the care provided aims to ensure the healthy development of pregnancy, and it is also the time to offer guidance on self-care and autonomy. Thus, information about the TNB test should be provided throughout the entire pregnancy and postpartum period, with particular emphasis during the blood collection process(22).

Healthcare professionals should implement measures to strengthen educational actions throughout prenatal care, guiding, informing, and raising awareness among pregnant women about the importance of having the test performed within the recommended timeframe after birth. The goal is to detect genetic and metabolic conditions early, thereby preventing complications that could result in intellectual disabilities and death(23). It is also important to highlight that postpartum consultation is a crucial moment of care, as it is when actions related to newborn care and self-care are promoted, information on breastfeeding, sexual and reproductive health is provided, and physical, social, and emotional well-being are assessed, while family bonding is strengthened.

Consequently, the lack of knowledge among pregnant and postpartum women regarding the test can directly affect the execution of the TNB, compromising diagnosis, the initiation of treatment, and the ongoing health monitoring of the child. Therefore, the TNB can be considered a crucial healthcare tool for children's well-being. In this way, it is essential for healthcare professionals to provide relevant information to pregnant and postpartum women during every interaction. Additionally, it is crucial for professionals to routinely check with pregnant women during their daily practice to ensure the test is performed on time. In cases of non-compliance, educational measures should be implemented, along with active follow-up.

The findings of this study reaffirm

that mothers' understanding of the TNB plays a key role in the program's effectiveness; however, this knowledge remains limited. Implementing strategies to raise awareness about the topic through the media, health education actions during prenatal consultations and obstetric care, health education groups, and postpartum care can greatly enhance the success and coverage of the program(24).

In this regard, all professionals working in healthcare units and testing centers must offer quality support to postpartum women regarding the appropriate timing for the TNB test, regardless of the care setting. This should involve reinforcing other key guidelines to ensure the newborn's access to the service, ultimately contributing to the successful attainment of the program's goals(25).

FINAL CONSIDERATIONS

The meanings attributed by postpartum women were simplistic, as the experiences revealed gaps in the educational process during prenatal care, hospital assistance, or postpartum care. Nevertheless, a significant number of postpartum women sought the service at the appropriate time for the blood collection, suggesting that, at some point, there was an interaction and awareness regarding the test. However, a substantial number of postpartum women delayed their visit to the primary healthcare unit for the test. It was found that even after the test was performed, the family members did not adequately understand the TNB test, which could jeopardize the continuity of the child's healthcare. This study highlights the crucial role of professionals in incorporating the educational aspect of care across all settings and interactions with users. It emphasizes the need to foster compassionate relationships between the user and the professional while utilizing gentle care techniques such as therapeutic listening and therapeutic communication.

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