

Guthrie test: pregnant women's perception during prenatal care

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Abstract

Objectives: to investigate pregnant women's perception on Guthrie test and verify how this matter is approached during prenatal care.

Methods: this study is an exploratory - descriptive, cross-sectional and quantitative approach design, carried out with 160 pregnant women who attended the Prenatal Care service at the Primary HealthCare in the city of Uberaba-MG. Data collection was performed between December 2014 and February 2015, using a semi-structured questionnaire. A bivariate descriptive statistics was applied by using the Pearson's Chi-square test.

Results: 75% of the pregnant women could not report which pathologies were to be screened, 16.3% reported that the diseases detected by Guthrie test had etiology genetic, 82% mentioned it was necessary to have more information on Guthrie test, 60% referred the necessity on focusing which diseases to be diagnosed. Only 36% of the pregnant women indicated the correct period (3rd to 7th day of the newborn life) for exam collecting. An average of 50% of the participants did not know about this prenatal test.

Conclusions: pregnant women showed a low understanding regarding the test; there was a lack of understanding about prenatal matters. The nursing personnel play an important role in this stage to demonstrate their abilities in health education.

Key words Neonatal screening, Prenatal care, Neonatal nursing

Introduction

Newborn Screening (NS) includes hearing test, ocular exam, heart test and Guthrie test).¹⁻⁴ The latter one allows early screening, diagnosing, treating and following individuals with metabolic disorders. Early diagnosis and treatment avoids irreversible sequels such as neurological delay, guaranteeing a future with a better quality of life for the affected child and a substantial economy for the Health System.⁵

In Brazil, NS was initiated in 1976 and has the Parents and Friends of Exceptional Children Association (APAE-SP) in São Paulo city as a precursor for phenylketonuria (PKU) screening, extending for Congenital Hypothyroidism (HC) in the 1980s. A Brazilian Federal Law number 8069 in 1990, reference to the Child and Adolescent Statute (Estatuto da Criança e do Adolescente) that also predicts the diagnosis and therapeutics of metabolic abnormalities in its article 10, item III. In 2001, the Ministry of Health (MS) created the National Neonatal Screening Program (PNTN) by the decree number GM/MS 822 in June 06, which the Brazilian states were classified in three implementation phases, according to the tracked diseases (Phase I= PKU and HC phase II= PKU, CH and Hemoglobinopathies/Hb and Phase III= PKU, HC, Hb and Cystic Fibrosis/CF).¹ In 2012, there was an expansion for phase IV which included tracking of Congenital Adrenal Hyperplasia and Biotinidase Deficiency.⁶ Minas Gerais (MG) state is in phase IV of the PNTN.

This is a compulsory exam and it is financed by the Public Health System (SUS). The ideal period to perform this exam is on the 3rd to the 7th day of the newborn's (NB) life, and not inferior to 48 hours or over 30 days. During the exam, blood drops are collected from the newborn's heel and applied on the heel prick card.¹ This procedure is performed by the nurse, as well as to orient the parents.⁷

Since mothers are the ones in charge for the newborn's care, this current study justifies the importance in obtaining the mothers' knowledge about Guthrie Test, because only a correct understanding and a good timing will make them take their children for the test collecting at appropriate time, avoiding future sequels. A few studies in the medical literature address to orient about NS during the pregnancy, which is the ideal period for this. Previous orientation is an important element to prevent severe consequences caused by detecting and late treatment, as for many mothers do not take their children to perform the test due to the lack of appropriate

information. Therefore, the objective of this study was to describe the pregnant women's perception about NS and verify how this matter is being approached during prenatal care.

Methods

This study is an exploratory-descriptive, cross-sectional and quantitative approach design, whereas the sceneries were at the Basic Health Units (UBSs) in the city of Uberaba-MG. The data collection was carried out between December 2014 and February 2015.

Case by case was composed of 160 pregnant women, who attended the Prenatal Service in the period of the data collection. To select the subject for this study the following inclusion criteria were used: (1) pregnant women who were in third trimester (7th to 9th months of gestation), (2) those women who had prenatal care at the UBS, (3) ages equal or over 18 years and (4) who were interested and available to participate in the research. Women who did not fulfill the criteria previously mentioned were excluded.

While the pregnant women were in the waiting room at the UBS reception, they received detailed explanation of the goals, the research procedures and afterwards were invited to participate in the research. After agreeing, an Informed Consent Form was obtained and a questionnaire was applied by one of the authors. This instrument was elaborated by the researchers containing closed questions with the option of dichotomous and multiple choice answers and was composed in two parts: I – sociodemographic characterization and II-knowledge about NS. The data were stored in an Excel format database, afterwards imported to the statistical program, Statistical Package for Social Sciences (SPSS) version 21.0 for processing and analysis. The descriptive statistics was used for data analysis, with proportions of categorical variables distribution. Pearson's Chi-square test was used, considering a significance level of 5% ($p \leq 0.05$), to estimate the association of the dependent variables, the purpose and test importance, orientation about the examination during prenatal care, if they have heard about NS or Guthrie Test and if they wanted to know more details about the information and about the other independent variables, such as income, schooling, marital status, number of children, gestational month and the number of prenatal consultation.

This study was approved by the Ethics and Research Committee on Human Beings from the Federal University of Triângulo Mineiro/UFTM

(Universidade Federal do Triângulo Mineiro/UFTM) (Protocol number 853.544). According to the Resolution number 466/2012, all ethical principals were observed.

Results

The 160 pregnant women's age group ranged from 18 to 40 years old (average \pm standard deviation: 24 ± 6), predominating those aged 18 to 24 years old (57.3%). Regarding to marital status, 63.1% were married or presented a stable union and 36.9% were single. About 85% of the pregnant women had only elementary schooling (47.5%) or high school (36.9%). As for gestational age, 42.5% were in their 7th month, 38.1% in the 8th and 19.4% in the 9th month of pregnancy. From the total of pregnant women, 42.5% were pregnant for the first time. Referring to prenatal care, half of them had six or more consultations, as recommended by the MS. Most of them had a monthly family income up to

R\$1,000.00 (64.4%), followed by an income between R\$1,000.00 and R\$2,000.00 (25%) and more than R\$2,000.00 (10.6%). From the participants, 55% did not contribute with the family income.

General and specific data about Guthrie Test are in Tables 1 and 2. From those who have heard about Guthrie Test, 70% reported being done at the UBSs. From the total, 75 pregnant women referred to have the knowledge during prenatal care, although 24.4% were informed by the nursing team and 23.8% by the physician. When evaluating the quality of information they received, 28.1% considered as good, 15.6% excellent and 3.1% regular. Eighty three pregnant women referred that the test is carried out at UBS (44.4%), followed by hospital (6.3%) and laboratory (1.3%). A minority (6.3%) believe that the exam can bring some risks for the baby. The multiparous women, only 2.5% had not performed the test with their other children due to the following reasons: they did not think it was not important, it

Table 1

General data about Guthrie test informed by 160 pregnant women investigated.

Variables	N	%
Have you heard about newborn screening		
Yes	79	49.4
No	81	50.6
Have you heard about Guthrie test		
Yes	152	95.0
No	8	5.0
Obligation		
Mandatory	114	71.3
Optional	2	1.3
Do not know	44	27.5
Guthrie test during prenatal care		
Yes	75	46.0
No	85	53.1
Gestational age at orientation		
First trimester (1 st to 3 rd month)	43	26.9
Second trimester (4 th to 6 th month)	27	16.9
Third semester (7 th to 9 th month)	16	10.0
Was not oriented	74	46.3
Need additional clarification on Guthrie test		
Yes	131	81.9
No	29	18.1
Issues to be approached in details*		
Which diseases can be detected	94	58.8
What is the test for	54	33.8
Information on how to proceed if the result is positive	54	33.8
Appropriate period for collecting	34	21.3
A place where Guthrie test is performed		
Yes	83	51.9
No	77	48.1

Source: Research data, 2015. *In this question the pregnant woman may answer more than one answer.

could be painful for the baby and because they did not have time. From those who performed the test in previous pregnancies, 47.5% came to get the results of the exams.

Of the diseases detected by the test, a significant number of pregnant women (75%) could not report which disease was. Among the disorders screened by Guthrie Test in MG, the most mentioned by pregnant women were: sickle cell disease (10.6%), biotinidase deficiency (5.6%), cystic fibrosis (5%), HC (3.1%)

and PKU (1.9%). Although they were diagnosed by Guthrie Test, congenital adrenal hyperplasia was not mentioned by the participants.

Down syndrome, a chromosomal disturbance, was the second disease most mentioned (7.5%), however, it is not diagnosed by this exam.

Regarding to the bivariate analysis, the dependent variables were, orientation about the exam during prenatal care and if the pregnant women would like to know more details about the

Table 2

Specific data about Guthrie test related to the purpose, importance, accomplishment and period for this exam collecting.

Variables	N	%
Purpose		
To know if the child has any disease	79	49.4
To know if the child will have any genetic disease	26	16.3
To know the child's blood type	5	3.1
To know if the child has any foot problem	5	3.1
Do not know	45	28.1
Importance		
Early detection of some incurable diseases	25	15.6
Early detection of some treatable diseases	64	40.0
Routine test only	5	3.1
Do not know	66	41.3
Accomplishment*		
Blood collection from the newborn's foot	136	85.0
Plantar impression of the child's foot	11	6.9
Blood collecting from the arm by venous puncture.	2	1.3
Do not know	14	8.8
Period for blood collection		
Within the first 48 hours of life	36	22.5
From the 3 rd to the 7 th day of life	58	36.3
From the 8 th to the 9 th day of life	3	1.9
From the 11 th to the 30 th day of life	12	7.5
30 days after birth	7	4.4
Do not know	44	27.5

Source: Research data, 2015. * In this question, the pregnant woman may answer more than one answer.

Table 3

Result of the bivariate analysis of the variables showing significant association

Variables	Number of children				Total	p*
	No children		Children			
	n	%	n	%		
Orientation about TP during prenatal care						
Yes	24	35.3	51	55.4	75	46.9
No	44	67.7	41	44.6	85	53.1
More detail about Guthrie test						
Yes	62	91.2	69	75.0	13	81.9
No	6	8.8	23	25.0	29	18.1

TP: Guthrie test, * Pearson's Chi-square test, $p \leq 0.05$, Source: Research data, 2015.

exam associated significantly to the number of children ($p \leq 0.05$) (Table 3). The other variables did not show any statistically significance ($p \geq 0.05$).

Discussion

About 40% of the women are not mothers, what makes them inexperienced concerning care and appropriate health procedures and well-being of the child. This finding was necessary to give the population orientation about Guthrie test.

Although, pregnant women have already heard about Guthrie test, but many do not know anything about NS. A study with 55 puerperal multiparous women showed that 89.9% had already heard about Guthrie test and 10.9% answered they were not aware about this test.⁸ Another study showed that 97% of the mothers had already heard about Guthrie test and 99% think it is important, but mothers do not know the purpose and the importance of this test.⁹

Many pregnant women reported the need for more information about Guthrie test (82%), focusing on which diseases to be diagnosed (60%). Observe that a significant number of these pregnant women mistakenly answered in relation to the diseases, showing no knowledge about them. Among the pathologies screened by Guthrie test, Down syndrome was mentioned. This finding justifies that it is widely recognized and has a high incidence. Another disease mentioned was the Sickle Cell Disease, which is also frequent in the population. A study was carried out with 119 mothers, whose children presented altered neonatal screening test for hemoglobinopathies revealing that 58% of them had children with sickle cell trait. Another interesting finding in this research was that only 17 (14.3%) of them recognized the difference between trait and disease and 42 (35.3%) considered that a altered screening test could have implications for future pregnancies. This finding reveals the importance of clarifying about the genetic pattern of the disease and the differences between disease and trait.¹⁰ A research with 171 professionals of the nursing team, who worked at a Maternal-Child Units showed that 99% and 96% of them mentioned about Down syndrome and Sickle Cell Disease, respectively, as a genetic abnormalities mostly known to them,¹¹ corroborating the data of our research. The authors also showed lack of preparation of the team, especially about the family approach of children with genetic disorders.¹⁰ It was evident in this study that a higher demand was necessary for more information about Guthrie test. A previous study

carried out in Belém city, with 200 newborn parents or caregivers showed that, although most of them did not have good understanding about Guthrie test, 56% of the participants said they did not need any further clarification.¹²

Another very concerning finding is that approximately 50% of the pregnant women were not oriented about the prenatal exam. A research was carried out with pregnant women in the countryside of São Paulo state showed that a significant number (93%) did not receive any orientation about Guthrie test during this period.¹³ Only three (7%) received orientation by the physician during prenatal care ($n=2$) and one in a course for pregnant women. Another study showed that only one of the 13 nurses working at the Family Health Strategy Units in Rio Grande do Sul State addressed the matter on NS during prenatal care, highlighting that a few professionals had used these strategies in order to favor the understanding of the parents on the issue.⁷ In another research, only five (10%) referred in receiving orientation during prenatal care and 35 (70%) had information about the test when they were discharged from the maternity hospital.¹⁴ These findings highlight failures in the prenatal care service which every pregnant woman should receive a complete information about Guthrie test since the first consultation with a reinforcement during the subsequent consultations.^{7,9,13,14} Prenatal care is the most adequate moment to orient parents about Guthrie test, so that they have enough time to assimilate the new knowledge and clarify their doubts. Orientation at hospital discharge can have its effectiveness compromising many factors that may influence the mother not to pay attention, among those are: little time, baby's crying, worries, fear and anxiety with the new member of the family.⁷

A study with 16 mothers showed that 13 of them had information about NS when they were discharged from the hospital where the baby was born. Although, 15 of them had prenatal care, but only one was oriented about the referred test during this period.⁵ At the UBSs, during the prenatal care for pregnant women, the nurse should promote actions on Health Education on Guthrie test, focusing in: which diseases can be detected, its severity, if these diseases are not early treated they can result in irreversible sequelae, which is the location for collecting, how is the test carried out and to inform about public politics which grounds its requirement. It is also convenient that a simple language should be spoken in order to make it easier for the mothers' to understand.^{15,16} Nowadays, the

focus on newborn care, especially in courses for pregnant women, they are limited exclusively for breastfeeding and vaccination, leaving the orientation about Guthrie test in a second plan. It is also important to point out that, in our study, around 40% of the participants are in their first pregnancy and they do not have any knowledge on previous pregnancies.

As for the purpose of the test, only a minority (16.3%) mentioned that the Guthrie test allows to have the diagnosis of the diseases which mostly only exhibit genetic etiology. However, its importance in detecting treatable diseases was reported by 40%. The first result deserves attention because the genetic diseases present risk of recurrence in families and this information is important for the genetic counseling and family planning. Regarding to the treatment, such pathologies are chronic; however, with a good prognosis in case they are detected and treated early. However, it is extremely important an adequate period for the exam collection, if screening is positive, then it is necessary the mediate confirmation using a diagnostic test. Delays in these phases might have direct impact in the treatment of the affected patients.

As regarding to the collection form, 85% of the participants believed it was only a blood collection from the newborn's heel, however, 6.9% related to Guthrie test with the plantar impression carried out at birth. Many parents are not aware about the possibility of a venous puncture when collecting blood from the heel is not possible. A study about this matter showed that mothers were confused about the plantar impression and with Guthrie test by associating it to the name of the exam.⁸

According to the MS, the appropriate period for Guthrie test collection is from the 3rd to the 7th day of the newborn's life. In this study, only 36% of the pregnant women indicated the correct period. About 25% of them did not know or reported that the exam can be performed within the first 48 hours of life. For PKU screening, the child's age at the moment of collecting is a constraining factor, because children with less than 48 hours of life did not take enough protein in order to be safely detected by the exam. A study with 42 pregnant women showed that 95% did not know the ideal period for the test and 52% referred not having any knowledge about Guthrie test.¹³

In this study, half of the puerperal women had the minimum of six prenatal consultations, recommended by the MS. It is necessary to review how actions on health education are being carried out, because, during prenatal care at UBSs, the

nursing team is the one in charge for informing and orientating pregnant women about the Guthrie test. Orientations, by health education, are part of the nurse's attributions and constitute an important and necessary instrument for care.⁸ And, also to highlight on the knowledge of the pregnant women relating to the requirement of this exam, as well as UBSs as a reference of its performance.

The pregnant women that were oriented about Guthrie test received this information from the physician or the nursing team equally (about 25%). Findings from this study contradict those found in the medical literature, since orientation about Guthrie test is an attribution from Nursing. These findings are evident in two studies, one showing 51% of the puerperal women receiving orientation from the nurse and 22.4% from the physician.⁸ Another research revealed that 93.3% (n=111) of the mothers referred in receiving information from the nurse and only 5.9% (n=7) from the physician.¹⁰ Although the pregnant women have considered the quality of the information as good, they presented misunderstanding about specific items of the exam. The lack of bond between the professional nurse and the pregnant woman, as well as the absence of an adequate location for an active communication brings limitations to the development of the prenatal care, making woman into a passive human being and not a protagonist of the process of being a mother. The biomedical model of health and overloaded work cause many challenges for the Nursing team, jeopardizing performances in private actions with the nursing consultation, which ends up having a complementary aspect of the medical consultation. Nursing consultation is an important instrument in health education, since it facilitates the development of the bond, empowering women who have the knowledge in Family Health Strategy.¹⁷

In a overall, the knowledge for pregnant women about Guthrie test was substantially superficial, due to failure in prenatal orientation, mentioned as being performed at around 50% of the pregnant women investigated, or because of the nursing team action, which according to medical literature, weakness has revealed in the NS area.^{7,18-20} The nurse has an important participation in PNTN because he/she is the professional who has direct contact with the target clientele, the mother and the newborn, since the prenatal care at UBSs. Therefore, his/her actions cover: to inform, clarify and orientate pregnant women about the exam, method and period of collecting, its importance, purpose and pathologies screened.

A possible limitation of this study is associated to the memory bias, as many aspects investigated

referred to past events and there is a possibility of having memory failure by the pregnant women that were interviewed. A strong point was the approach of the matter during prenatal care, a fact that needs more investigation in scientific literature.

The interviewed pregnant women in this study reported that Guthrie test is important for the baby and they know about their obligation. However, they have showed low understanding about this exam. This finding is a very concern issue, as these mothers are essential for their newborn care.

Also, there was lack of orientation on the matter during prenatal care. It is the most appropriate moment to give orientation to pregnant women, because it favors learning, as there is a longer time to clarify their doubts. At hospital discharge, puerperal women are living new emotions with their newborns and end up not paying enough attention to the information received. The nursing professionals

have an essential role in this phase with a view to their ability in health education. This professional should guarantee this population adequate information in order to have the exam performed in a timely manner with the purpose of preventing neurological delay.

It is worth to point out that the diseases detected through Guthrie test are chronicle, but with a good prognosis if diagnosed and treated early. Therefore, the empowerment of knowledge of these pregnant women guarantees a better quality of life for their children.

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