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The speech of mothers of babies in newborn jaundice treatment

O discurso das mães de bebês em tratamento para icterícia neonatal

El discurso de madres de bebés en tratamiento de ictericia neonatal

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Priscilla Zaleski[1]
Cledir Miguel Raissa[2]
Adriana Moro[3]
Idonézia Collodel Benetti[4]
Luciana Maria Mazon[5]

This investigation aims to check the popular knowledge and scientific knowledge of mothers of babies with jaundice treated with phototherapy. This was a field research, with direct observation and qualitative approach, based on the Discourse of the Collective Subject (DCS), held in mid-2011. The survey was conducted in a state maternity ward in Mafra, Santa Catarina, Brazil, with mothers of babies in phototherapy treatment of jaundice. 7 central ideas and 11 CSD were shown. Results revealed that mothers interviewed did not recognize neonatal jaundice as an illness or phototherapy as a treatment. It was evident that the mothers bring with themselves popular beliefs and knowledge about jaundice, which need to be respected and valued to strengthen bond and care.
Descriptors: Jaundice; Mother-child relations; Culture.

Esta investigação tem como objetivo verificar o conhecimento popular e o conhecimento científico das mães de bebês com icterícia em tratamento com fototerapia. Tratou-se de uma pesquisa de campo, com observação direta e abordagem qualitativa, baseada no Discurso do Sujeito Coletivo (DSC), realizada em meados de 2011. A pesquisa foi realizada em uma maternidade estadual na cidade de Mafra em Santa Catarina, com mães de bebês em fototerapia para o tratamento da icterícia. Evidenciaram-se 7 ideias centrais e 11 DSCs. Os resultados revelaram que as mães entrevistadas não reconheceram a icterícia neonatal como um agravo, assim como a fototerapia como medida de tratamento. Evidenciou-se que as mães trazem consigo crenças e conhecimentos populares sobre a icterícia, os quais precisam ser respeitados e valorizados para o fortalecimento do vínculo e do cuidado.
Descritores: Icterícia; Relações mãe-filho; Cultura.

Esta investigación tiene como objetivo verificar el conocimiento popular y el conocimiento científico de las madres de bebés con ictericia en tratamiento con fototerapia. Se trató de una investigación de campo, con observación directa y abordaje cualitativo, basada en el Discurso del Sujeto Colectivo (DSC), realizada a mediados del 2011. La investigación fue realizada en una maternidad estatal en la ciudad de Mafra en Santa Catarina, Brasil, con madres de bebés en fototerapia para el tratamiento de la ictericia. Se evidenciaron 7 ideas centrales y 11 DSCs. Los resultados revelaron que las madres entrevistadas no reconocieron la ictericia neonatal como algo grave, así como la fototerapia como medida de tratamiento. Se evidenció que las madres traen consigo creencias y conocimientos populares sobre la ictericia, los cuales precisan ser respetados y valorizados para el fortalecimiento del vínculo y del cuidado.
Descriptores: Ictericia; Relaciones madre-hijo; Cultura.

1. Nurse. ORCID: 0000-0002-0820-381X E-mail: zaleskipriscilla@hotmail.com
2. Nurse. Specialization student in Nursing Medical Residency at Hospital Pequeno Príncipe, Curitiba, PR, Brazil. ORCID: 0000-0003-1772-8826 E-mail: cledirmraissacmr@hotmail.com
3. Nurse. Specialist in Neonatal Intensive Care Nursing. Specialist in Acupuncture. Master's in Regional Development and Public Policies. PhD in Public Policies. Professor at Nursing Department, Universidade de Contestado, Campus Mafra, SC, Brazil. ORCID: 0000-0002-5807-725X E-mail: adri.moro@gmail.com
4. Psychologist. Bachelor of Arts degree. Specialist in Psycho-pedagogy. Master's in Psychology. Master's in English Language and Literature. PhD student in Collective Health at Universidade Federal de Santa Catarina (UFSC), Florianópolis, SC, Brazil. ORCID: 0000-0002-8413-0632 E-mail: idonezia@hotmail.com
5. Nurse. Specialist in Neuroscience. Specialist in Public Health Management. Master's in Regional Development. PhD student in Collective Health at UFSC. Professor at Instituto Federal de Santa Catarina. ORCID: 0000-0002-6380-2233 E-mail: lucimazon@hotmail.com

INTRODUCTION

Hyperbilirubinemia, jaundice or "amarelão" as is popularly known in Brazil, is common in most premature and full-term newborns (NB), usually associated with low birth weight, inefficient or late breastfeeding, among other probable causes. It is characterized by high concentration of bilirubin (up to 2 mg/dl) in the plasma that results in a yellowish color of the skin, mucous membranes, and sclerotic because of the substance in these places[1-2]. The accumulation of bilirubin in the brain leads to the appearance of irreversible brain damage, the kernicterus. Breastfeeding is one of the most significant factors involved in infant kernicterus[1].

Phototherapy is the most widely used form of treatment to reduce bilirubin levels, because of its non-invasive nature, high availability, low cost and low occurrence of side effects. Light promotes the excretion of bilirubin through the photo isomerization, which changes the structure of bilirubin to a soluble form of easier excretion[3].

Jaundice, in most cases, is characterized as physiological, starting after the first 24 hours of life of the NB and lasting, on average, one week. But it can also relate to a syndrome or disease, appearing before the first 24 hours of life. In view of this, it is important to carry out the treatment immediately after discovered[1], because if not treated, can cause severe injury, primarily affecting the nervous system[1].

Complications include bilirubin or Kernicterus encephalopathy, in which bilirubin crosses the immature blood brain barrier, going into the cores of the base and other brain areas[4]. While bilirubin is neuro-cytotoxic, it is also a potent antioxidant, contributing to the improvement of some conditions.

It is verified, in practice, that the knowledge of mothers with babies that present jaundice, particularly in relation to the treatment generates nervousness in the mother and/or family, to see their baby exposed to a treatment that is unknown to them. The mother may be taken for a range of feelings when they see their baby in front of the targeted treatment to reduce jaundice[5].

For health professionals, starting phototherapy in a neonate is a quite common therapeutic procedure, because it is part of the familiar routines for them[6], making it appear simple and incipient. For the mother, however, who does not know the treatment, or doesn't even know why it is being used, this procedure may seem scary or, at least, strange, according to their perception in relation to the treatment, its risks and benefits.

On this information, it becomes relevant for Nursing to identify mothers' myths in relation to neonatal jaundice, for a humanized care, transmitting information securely. Therefore, it is essential to establish proper communication between the health team and the mother[7,8].

This investigation aims to check the popular and scientific knowledge of mothers of babies with jaundice treated with phototherapy.

METHOD

Anchored in the exploratory-descriptive method, this is a field survey, with direct observation and qualitative approach, based on the discourse of the collective subject (DCS)[9]. The research was carried out in a maternity ward of Mafra, Santa Catarina State, Brazil, a public institution administered by the State Government, through the State Secretariat of Health, focused on birth and neonatal attendance.

Over the years, since its inauguration on March 15, 1972, this institution has become a reference for the North Plateau region of Santa Catarina in assisting high risk pregnant and newborns. This institution was the first in southern Brazil

to win the title of "Child Friendly Hospital", keeping it until today due to the work commitment in its milk bank, encouraging, supporting and promoting the breastfeeding[10].

Data collection was carried out in the rooming-in unit. The research universe were mothers with newborns in the rooming-in unit in the maternity ward in study. The subjects of the research were chosen according to the occurrence of the cases of jaundice in the collection period, which began on July 5, 2011 and ended on August 17, 2011.

According to information collected in the institution's Daily Registration book from June to December 2010, 34 infants were registered in the rooming-in unit receiving phototherapy treatment. Based on this data, the survey sample was composed of seven participants (20% of the average of the previous semester).

The research inclusion criteria were: mothers of children who were in jaundice treatment, using phototherapy in the rooming-in unit; who were 18 years old in the period established for the collection and who agreed freely and spontaneously to participate in this survey by signing an informed consent. This research was approved by the Research Ethics Committee, embodied Opinion number 221/2011.

Data collection was carried out from a sub structured interview script. The interviews were recorded and fully transcribed in the field journal. The data were analyzed by means of the DCS, which consisted in analyzing statements from an open question, grouping the strata of the statements of similar meaning in speeches – summaries written in the first person singular, as if a collectivity was speaking[11].

The steps followed in the production of the DCS are called operators, and they are: key expressions; central ideas; anchors; and the speech of the collective subject itself[12]. All the mothers received information about the research, anonymity assured, using, for this, identification with the letter M followed by the numbers 1 to 7, representing the seven mothers investigated.

RESULTS

Analysis of the participants' profile

The mothers were between 18 and 38 years old, most of them older than 25 years old. Their newborns were between four and thirteen days of life and remained at most two days in phototherapy. All the participants interviewed had companions and, at the very least, complete elementary school, two of whom had complete higher education, three of them, full middle school and two mothers, incomplete high school.

Only three of them had employment relationship and the others referred to themselves as housewives. Five women reported that their family income was above two minimum wages and two reported income between one to two minimum wages. In relation to the number of children, three of them said it was the first child and four of them had two to three children. This data is in Table 1.

Table 1. Profile of mothers of NB with jaundice, Matermity Ward, Mafra/SC, 2011.

Identification	Age	NB days of life	Treatment in days	Marital status	Schooling	Profession	Family income in wages	NB kids
M1	29	13	1	Married	Higher education	Administrative Assistant	> 2	1
M2	26	10	2	Married	Secondary education	Farmer	More than two	2
M3	19	4	1	Stable union	Incomplete Secondary	Housewife	More than two	1
M4	38	6	1	Married	Higher education	Teacher	More than two	3
M5	29	7	1	Married	Secondary education	Housewife	More than two	2
M6	32	7	1	Married	Secondary education	Housewife	From one to two	2
M7	18	4	2	Stable union	Incomplete Secondary	Housewife	From one to two	1

All the mothers interviewed RB were more than 48 hours old. To meet the specific objectives of this research, data were also collected regarding the participants' previous knowledge of jaundice; whether they already had some knowledge or experience about this condition. This information is shown in Table 2.

Table 2. Previous knowledge and experience in relation to jaundice and health care professional who reported the diagnosis, Maternity Ward, Mafra/SC, 2011.

Identification	Previous knowledge about jaundice		Other experience about jaundice		Professional who reported the diagnosis	
	Yes	No	Yes	No	Nurse	Doctor
M1	X			X		X
M2	X			X		X
M3		X		X	X	
M4	X			X		X
M5	X			X	X	
M6		X		X		X
M7	X			X		X
Total	5	2	0	7	2	5

It was observed that five of the mothers had heard about jaundice or "yellowing" and two had never heard of.

They all report they had never had any previous experience with "yellowing", even those who had already heard about it. Five of them reported the pediatrician gave them the diagnosis of jaundice in two cases, the nurse of the unit.

Speeches of the Collective Subject

Data collected were analyzed under the aegis of the DCS approach and presented central ideas emerging from the participants' speeches. Sometimes speeches were stressed for better understanding.

Table 3 provides central ideas and discourses on knowledge and ignorance of neonatal jaundice. When topic 1, (Un) knowledge about neonatal jaundice, is

emerging, we observe that popular understanding is that all babies will have "yellowing". We noticed in the speeches that mothers are unaware of the phototherapy treatment.

Table 3. (Un) Knowledge of neonatal jaundice. Mothers of NB with jaundice, Maternity Ward, Mafra/SC, 2011.

CENTRAL IDEA 1	DISCOURSE OF COLLECTIVE SUBJECT 1
Popular knowledge about "yellowing"	*"In the beginning we get kind of scared, knowing that our baby has the "yellowing" but they say* ***almost all the babies got****, then we soon calm down"* *"Oh what we know is that almost all babies have, and we never think that our baby will go through it, but they say* **in a week they are good***"*
CENTRAL IDEA 2	**DISCOURSE OF COLLECTIVE SUBJECT 2**
Ignorance	*"I* ***didn't know anything****, it is a thing of mother, grandmother and mother-in-law, they talked about the disease,* ***I don't know if I can call this disease****, I didn't know how it appears, or how it would heal and what would happen if it was not cured"* *"In fact* ***I didn't know*** *a lot, I knew "yellowing" existed but I just didn't know what it really was "* *"I knew the child was more yellow, but* ***I didn't know they would need treatment****"*

Figure 4 brings the theme about believing or not in popular treatments for jaundice and records the emergence of three central ideas. The first, evidenced by DCS 1, refers to the knowledge of home treatments, but the mother, even under family pressure, opted not to perform alternative treatment; she reports that this would not be effective.

In the DSC 2 of central idea 2, the mother says that she used the treatment, in the case of tea it worked, a fact that tends to affirm the cultural issues of this family. In the DSC of central idea 3, the mother says that she believes in homemade treatments she received passed, she used them, but they were not effective.

Table 4. Belief in popular treatment for neonatal jaundice. Mothers of NB with jaundice, Maternity Ward, Mafra/SC, 2011.

CENTRAL IDEA 1	DISCOURSE OF COLLECTIVE SUBJECT 1
Not believing in popular treatments	*"What we most hear at home is "yellowing" treatment,* ***bathing with I don't know how many yellow flowers, bathing with tile****, my God in heaven, but* ***I didn't do*** *them because* ***I don't believe*** *in these things. Everyone says that did something homemade, but I don't know"*
CENTRAL IDEA 2	**DISCOURSE OF COLLECTIVE SUBJECT 2**
Buying and using popular treatments for jaundice	*"Marcela Tea, my mother* ***used and it worked****"*
CENTRAL IDEA 3	**DISCOURSE OF COLLECTIVE SUBJECT 3**
Using, but no effectiveness	*"Wearing yellow clothes, yes, yellow vest, but it didn't work"*

It can observe in the central idea 1 of Table 5, in DCS 1, that the mother, even though the treatment would be simple, did not have the knowledge that the longer it took to go to the maternity, more serious the state of health of her NB would be. Also, she did not know the importance the phototherapy would have for this child.

In central idea 2, in DCS 1 and 2, mothers say they were very worried, nervous and shaken, not only because their babies were being exposed to a treatment new for them, but also because they had never seen or heard of this method or what "yellowing" was.

Table 5: fears and insecurities about diagnosis and treatment of neonatal jaundice. Mothers of NB with jaundice, Maternity Ward, Mafra/SC, 2011.

CENTRAL IDEA 1	DISCOURSE OF COLLECTIVE SUBJECT 1
Knowing diagnosis and medical treatment for jaundice but even feeling insecurity and fear	*"I was nervous right? Like any mother would be, and worried, even though the treatment would be simple, but the fact that if we didn't know in time and treat **would be severe**... We did the first review that resulted in 13 something and at home people went visiting him and began to say that he was yellow and so I went to the maternity and the pediatrician did an exam again and was 17 and then I was admitted, so now the last was 10 and I am being discharged"*
CENTRAL IDEA 2	**DISCOURSE OF COLLECTIVE SUBJECT 2**
Fear for lack of information	*"**I was worried** because I didn't have a lot of information and I didn't know why it happened to him, test there said he was dark yellow, there I took him to the pediatrician to do the exam and I had the result"* *"I was pretty upset because I didn't know what was the "yellowing" was, I was pretty nervous and I'm still (laughs)"*

DISCUSSION

Jaundice within 48 to 72 hours after birth is considered physiological, when serum bilirubin level is 4 to 12 mg/dl around the 3rd to 5th days after birth. Commonly, this phenomenon disappears around the end of day 7, but it is worrying at high levels[13].

Health professionals assume a key role to assist families, identifying specific support interventions that may be directed to reduce parental stress, making their adaptation easier and improving their relationship with the baby[14]. The experience of having a newborn hospitalized with jaundice, raises concern and stress to parents/family, which makes necessary a holistic look and humanized care from all the health team.

The analysis on the (Un) knowledge of neonatal jaundice identified mothers' ignorance about the situations that can lead to its ocurrence. Jaundice occurs in some physiological situations, starting after the first 24 hours of the NB life and lasting on average a week. But, it can relate to a syndrome or disease, when appearing before the first 24 hours of life[15].

However, when the NB remains in the hospital for a short time, the observation of physiological jaundice is hindered, since it appears after the first 24 hours of life, not allowing interventions and often requiring readmission of the NB to the phototherapy treatment, which can generate more expenses and, in addition, harm breastfeeding.

Due to this and other associated factors, the Department of Neonatology of the Brazilian Society of Pediatrics recommends discharging term, healthy and uneventful NB, only after 48 hours of life and ask them to return 48 to 72 hours after discharge, for an outpatient consultation[16].

In this context, the mother plays the role of the main character of baby's care. She is the one who perceives and seeks care for health problems. To face disease situations, she tends to look for support not only from health services or from official medicine, but also from the so-called popular medicine. Empowering mothers allows them to participate more fully in care decisions and to face

obstacles that can be found in this process[17].

In the case of speeches emerging in topic 1, it can be emphasized that, in some way, society, as regards health care, informs the population; However, this information is superficial and not always effective.

It can see in the speeches that mothers are unaware of phototherapy treatment. We believe that therapy ignorance is disturbing and generates nervousness to the mother, who witness their baby undergo an unknown treatment.

Phototherapy causes a strong impression in the mother, and all said they were concerned. The act of humanistic care proves to be an emotional support. Nursing, based on its technical competence, without losing the tenderness, must be docile and transmit to the mother the information they need to calm themselves down[13].

The discussion that emerges in the speech that involves the subject about believing or not in popular treatments for jaundice, is that culture is essential to incorporate the previous experiences, influence actions and thoughts of the present and pass the traditions for future members of the group, as was found found in this search. Older people of the family influence culturally and, due to the lack of the mothers' experience, many popular beliefs are part of the care provided to the kids[18], which was not evidenced in the first speech.

Some care, which are considered by the teams as alternative, are really recommended, such as sunbathing. This procedure is important for the NB, as well as helping in bone development, assists in jaundice reduction[19]. The same should be done with leaving the baby naked in the sun for five minutes a day, time that should be gradually increased up to about 15 minutes a day before 10 A.M. and after 16 P.M. It is important to emphasize that sun bath can help reducing jaundice, but it is not a treatment. If the mother perceives a very yellowish coloration of the skin, she should take the NB to be evaluated[18].

The use of alternative and complementary medicine is growing between adults and children. Many people use it concomitantly or alternate with conventional medicine. Home use of medicinal plants is one of the highlighted treatments of children's health.

Although not recommended, some practices are still part of everyday life of mothers when take care of their children, because they are based on experience, experimentation and evaluation of its use success on health issues[18]. It is known that the popular medicine has various treatments for jaundice, and they are widely used by newborns' mothers and their families.

It is essential that health professionals know the superstitions and popular practices, related to the health-disease process of the population, and become familiar with them, learning to deal with their values, beliefs and habits[18].

In 2006, the National Policy of Integrative and Complementary Practices in the Unified Health System (SUS) was approved, which proposes to incorporate and implement traditional Chinese medicine, acupuncture, homeopathy, herbal medicine and balneology social/crenotherapy. These facts show that it is not possible to ignore these treatments in the health service, because they are well known and used by the population.

Insecurity accompanies the mother from gestation, reflecting on fear in relation to the baby's health, which creates agitation and a sense of responsibility and concern for the well-being of the child[18]. The presentation of pathological complications that indicate hospitalization is a difficult situation, especially for the mother who, in some

cases, feels guilty for not being able to cure her child with home care[18].

In central idea 2, in DCS 1 and 2, mothers say they were very worried, nervous and shaken, not only because their babies were being exposed to a treatment new for them, but also because they had never seen or heard of this method or "yellowing".

The cultural and economic barriers, as well as ineffective therapies, often delay care. the teaching of all the skills should be supported to monitor jaundice, the signs of early neurotoxicity, the importance of breastfeeding, as well as the prevention of ineffective practices. Empowering mothers allows them to participate more fully in decision-making and face barriers to care.

CONCLUSION

In the face of the jaundice appearance and the possibility of treatment, it was found in the practice that mothers bring many popular knowledges in relation to this clinical condition, which make them nervous before the procedures to which their children are exposed.

Therefore, it is important the role of nursing and the health team along with these mothers, giving them all the necessary explanations about what is happening to their baby, such as manifestations and diagnosis and jaundice treatment.

Thus, it is essential to establish the communication of the health team with the mother, to clarify properly about the therapeutic that their child will be subjected to.

It is worth noting that, as a qualitative research, this study has as limitations the variability of the sample. However, this fact did not harm the intended results, as it was pointed out in the objectives and outlined in the method.

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CONTRIBUTIONS

All authors had equal contributions in the various stages of the research such as conception, design, data collection, data interpretation and final essay.

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