ABSTRACT

Objectives: to analyze the maternal perception about phototherapy and to describe the mothers' evaluation of an educational tool in the same theme. Method: descriptive study with a qualitative approach. 30 mothers participated, after signing the Term of Free and Informed Consent. The interviews were then submitted to the Content Analysis Technique in the Thematic Analysis modality. After collecting the data, we identified the need for an educational material, which was elaborated and evaluated. Results: limited knowledge regarding treatment was perceived. Regarding the educational material, there was satisfaction and its recommendation by 100% of the mothers. Conclusion: mothers do not feel secure with the information they receive from health professionals, which compromises their confidence and their contribution to therapy. There was a high relevance of the use of an educational tool that meets the real needs of the mothers. Descriptors: Nursing; Newborn; Phototherapy; Health Education.

RESUMO

Objetivos: analisar a percepção materna sobre fototerapia e descrever a avaliação das mães sobre uma ferramenta educativa na mesma temática. Método: estudo descritivo, com abordagem qualitativa. Participaram 30 mães, depois de firmado o Termo de Consentimento Livre e Esclarecido. Realizaram-se as entrevistas, em seguida, submetidas à Técnica de Análise de Conteúdo na modalidade Análise Temática. Após coletados os dados, identificou-se a necessidade de um material educativo, o qual foi elaborado e avaliado. Resultados: percebeu-se conhecimento limitado em relação ao tratamento. Quanto ao material educativo, houve a satisfação e sua recomendação por 100% das mães. Conclusão: as mães não se sentem seguras com as informações que recebem dos profissionais de saúde, o que compromete a sua confiança e sua contribuição diante da terapêutica. Verificou-se elevada relevância do uso de uma ferramenta educativa que atenda às necessidades reais das mães. Descriptores: Enfermagem; Recém-Nascido; Fototerapia; Educação em Saúde.

Dans cette étude descriptive qualitative, une équipe de chercheurs a recueilli des informations auprès de 30 mères, après leur consentement libre et éclairé. Les interviews ont été soumises à une technique d'analyse du contenu en analyse thématisée. Après collecte des données, une nécessité pour un matériel éducatif a été identifiée, qui a ensuite été élaboré et évalué. Les résultats ont montré une connaissance limitée sur le traitement. En ce qui concerne le matériel éducatif, il a été perçu comme satisfaisant et recommandé par 100% des mères. La conclusion est que les mères ne se sentent pas sûres avec les informations reçues des professionnels de santé, ce qui compromet leur confiance et leur contribution à la thérapie. Il y a eu une haute pertinence de l'utilisation d'un outil éducatif qui répond à leurs besoins réels. Descripteurs: Enseignement à la santé; Nouveau-né; Phototherapie; Éducation en santé.
INTRODUCTION

One of the most common problems in the neonatal period and one of the reasons for hospital admission is jaundice, and about 60% of term newborns (NBs) can develop it in their first week of life.1 According to a retrospective analysis, of records of mothers of newborns hospitalized in the Neonatal Intensive Care Unit, this was the clinical condition that most affected the term and preterm newborns (87.3%). Phototherapy was the prevalent treatment, applied in 85.4% of affected patients.2

The disease is caused when there is overproduction or decreased excretion of bilirubin due to hepatic immaturity (hyperbilirubinemia). 3 Bilirubin is usually eliminated from the body by hepatic conjugation with glucuronic and eliminated in bile in the form of bilirubin glucuronides. Jaundice consists of a deficiency in the conjugation of bilirubin and, when not bound to albumin, becomes liposoluble, which prevents its adequate excretion.4

Physiological jaundice is one that arises 48-72 hours after birth, is usually associated with the adaptation of the newborn to extraterine life and is characterized by an increase in blood bilirubin from 6-8mg/dl to a maximum level of 12mg/dl.3

Pathological jaundice is the most serious clinical condition that arises in the first 24 hours in some NBs and presents levels of blood bilirubin above 17mg/dl, with extreme values up to 30 mg/dl or more, depending on the population that is affected. If not treated correctly, it can progress to acute bilirubin encephalopathy and brain injury, which may lead to chronicity, permanent neurologic sequelae (kenicterus), or death.5

The most indicated treatment for jaundice is phototherapy, a therapeutic modality used for the treatment of various dermatological diseases.3

Phototherapy management requires some care, such as eye protection, checking for weight gain and/or loss, checking vital signs, water balance, observing overheating and taking care not to use oils or ointments due to the risk of burns.6 However, it is understood that the nurse must go beyond technical care, also committing herself to the education and health knowledge of the mothers and/or caregivers of the newborn.

Health education is an activity that seeks to contribute to the critical awareness of the individual and to the change in health practices through empowerment and information.7 In this context, it can be seen that Nursing can use this resource in the treatment of children with jaundice to help parents and families cope with this situation, which in most cases is unexpected and traumatic.3

Due to the high incidence of cases of neonatal jaundice, together with the perception of the anguish of the mothers in the hospitalization process, this study sought to help in the acquisition and improvement of knowledge regarding phototherapy, encouraging the participation of parents in the treatment of their children and clarifying the doubts regarding it.

In view of this context, the following questions arose: what is the maternal perception about phototherapy and the role of Nursing in this process?

OBJECTIVES

- To analyze the maternal perception about phototherapy.
- To describe the mothers’ assessment of an educational material developed by the authors.

MÉTHODO

A descriptive study with a qualitative approach to the development of educational material << Guidelines on phototherapy: you keeping an eye on your baby >> and is based on the theoretical and pedagogical framework of Paulo Freire’s problematization.8

The study was carried out at a regional hospital in the Federal District, from December 2014 to April 2015. Participants were 30 randomly chosen mothers, 15 in the interviews and 15 in the evaluation of the educational material, according to the following inclusion criteria: having a child hospitalized in the maternity hospital in phototherapy, knowing how to read and write and wanting to participate in the study. The project was approved by the Research Ethics Committee of the Health Science Teaching and Research Foundation - FEPECS (protocol number 1127/2010), CAAE 24633313.4.0000.5553, as well as the Free and Informed Consent Form was signed with the mothers before the data collection.

The data was obtained through interviews, with open questions, in a previously elaborated script, guided by the following questions: What do you know about phototherapy (light bath)? Do you know why your child is undergoing treatment? What is the treatment for, in your opinion? What do you feel and how has your experience been, seeing your child taking a light bath? What did
the Nursing team advise you about the disease and the treatment? Do you feel secure in how the treatment is performed? How can you cooperate in caring for your child during phototherapy? What are your biggest questions regarding the treatment of phototherapy? Would you like to have educational material on the subject? The interviews were recorded, the mothers, named with flower names to guarantee anonymity, and then the speeches were transcribed and analyzed, leading to the emergence of the following categories: knowledge and feelings of the mothers in relation to the phototherapeutic treatment; orientation of the Nursing team.

The analysis of the qualitative data began with the pre-analysis, where the floating reading of the interviews was carried out, with the objective of acquiring the central ideas of the speeches through an exhaustive contact with the material. Subsequently, the corpus was constituted, where the interviews were grouped according to the common characteristics they presented; finally, hypotheses and objectives were formulated and reformulated, and the exploratory phase was resumed, having as a parameter the exhaustive reading of the material and the initial inquiries. The second stage of the thematic analysis was the exploration of the material, where categorization was carried out, which consists in reducing the text to meaningful words and expressions.9

As a methodological reference, for the elaboration of the educational material, the five steps proposed by Reberte and collaborators (2012): 1) Systematization of content were adapted; 2) Choice / Creation of illustrations; 3) Content composition; 4) Validation of the material by professionals and 5) Validation of the material by the mothers. Steps four and five, relative to content validation, were not performed at this stage of the study due to the research execution time. However, an evaluation of the material by the mothers was carried out.

In the content systematization stage, the mothers' learning needs were questioned. Thus, for the educational material to reflect the learning needs, an individual survey of maternal doubts regarding phototherapy was performed. After the participation of the mothers, the pertinent literature on health and education was used.

In the second step, choosing/creating the illustrations, a graphic design specialist created the layout for the educational material, using graphic and original drawings.

In the composition phase of the content, the educational material was structured in the form of questions and answers, as a strategy to stimulate the user's interest in the content and allow it to address the exact point of their doubt.

In the educational material, the following criteria were evaluated in question format: is the cover attractive? Do you think the topics described are important? Is the content size in the topics appropriate? Is the text easy to read? Can the brochure help you better understand what phototherapy is? Do you think the booklet can be delivered to mothers as an educational guideline before the blood test? Would you recommend this brochure to other mothers? Therefore, for each item described, the respondent pointed to a concept on a Likert scale of the five options (I strongly disagree, disagree, agree, strongly agree and do not know). In addition, there was a field for suggestions...

RESULTS

In this stage of the research, the qualitative approach of the study, with the statements grouped in its categories, and the descriptive part of the construction, with the applicability of the educational material on phototherapy, are encompassed.

The first category refers to the knowledge and feelings of mothers regarding phototherapy and the second category describes the role of Nursing in the process of health education.

♦ Category 1: Knowledge and feelings of mothers regarding phototherapeutic treatment

The mother, when conditioned to extend her hospitalization due to the phototherapeutic treatment of the child, undergoes a process of adaptation and compliance. At that moment, the insecurity is present, which affects the maternal emotional state, as observed in the comments:

I've cried a lot (cries), I've suffered a lot to leave her [...] It's bad to see her like this in the crib, it's strange. (Daisy)

Very tragic, we never want to see this with our child because it's very bad. He gets upset, he does not like it. God knows how much I've suffered with him here. (Hibiscus)

Phototherapy can cause such bad feelings, hence the importance of the mother being well informed about her child's treatment. However, in practice, this was not observed: Because he has jaundice, which is the yellowing that causes something in the liver, that's because I researched it myself, I went after it to know what it was. (Dahilia).
In Dalia’s speech, it is noticed that she presents more information not because she was guided by the team, but because she sought, on her own, subsidies to solve her doubts.

For mothers, having their child hospitalized and undergoing phototherapy can be extremely confusing, mainly due to the use of ocular occlusion. Treatment may interfere with mother-child bonding, which may compromise the bond and generate an emotional imbalance. Eye protection was one of the problems reported in the study:

[…]We get scared, cover their little eyes, there’s that feeling that looks like he’s blind. At the time they put it on I started to cry, I was despaired and then we get used to it because we put it in our head that it is for their good. (Iris).

Thus, in the face of possible intercurrences, it is indispensable that the parents be properly guided by the team. According to Sunflower, the guidelines received are related to eye protection and length of stay in phototherapy, but nevertheless, they seem ambiguous and unclear.

The most that I could do was not to leave him long out of the light […] to protect the little eyes and to always remove all the clothes. (Sunflower)

In this way, it is understood that, although mothers have little or no knowledge regarding the disease and treatment, they receive information, even superficial, from some important care that will favor the discharge of the newborn. It is possible to notice that the professionals pass on basic knowledge, which is not enough to clarify the main doubts identified in this study.

Through the analysis of all the speeches, the lack of physio-pathological information provided in relation to the disease and the maternal ignorance about them are evident.

♦ Category 2: Nursing team orientation

Most mothers report not receiving enough information, and when they receive it, they are unequal.

The bad thing is because when we receive the news that they will receive a light bath, the problem is that each one says one thing, they say that our child will stay in a place that cannot come out for anything, each one says something. So we do not have information. (Jasmin).

It was observed that insufficient information and lack of knowledge regarding therapy are directly related to maternal insecurity:

I do not feel safe because I do not know anything, nobody tells me anything […]. (Orchid)

The team does not provide many details related to jaundice and phototherapy. It is believed that due to the lack of time due to work overload or even because they believe that the mothers do not have enough knowledge related to the therapy, they do not adequately clarify the maternal doubts.

Basically, she explained to me that she had to stay in phototherapy not to get a more serious illness and she has to take this bath of light […]. (Bromeliad)

Often, even the team shows insecurity to mothers, which makes coping with the situation even more complicated:

When I came to the room and the girl put this crib here, I stayed a long time without placing my daughter in it because I was afraid and also it was not turned on, I did not know how to put her there, understood? I was afraid she would get a shock because the lady herself was afraid of being shocked, so I told her: ‘If you’re scared, can you imagine if I’m going to put my daughter there?’ […] I imagine if something happens to my daughter and there is a problem […] It would be great to have something to inform us. (Daisy)

The majority of mothers, need only to understand the environment and treatment of their child and the team must be able to transmit information to the family so that they can join in and collaborate with the treatment. Therefore, it is possible to observe that mothers do not receive the information they would like, which seems to help them decrease trust in the team and their cooperation with treatment. Faced with the lack of educational materials available in the databases on this subject and from the maternal need, there was the construction of educational material with the aim of minimizing the maternal doubts related to phototherapy. The following is the layout of the material:
The evaluation of the educational material (Figure 2) saw the participation of 15 mothers, aged between 14 and 37 years old, all of them literate, with the majority having a high school education (53.3%). Among them, 93.3% had full-term children and 6.6%, preterm infants. In relation to the profession, the majority were housewives - 66.6%.
<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
<th>Suggestion</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Is the cover attractive?</strong></td>
<td>1</td>
<td>6.6</td>
<td>2</td>
<td>13.3</td>
<td>8</td>
</tr>
<tr>
<td><strong>Do you think the topics described are important?</strong></td>
<td>0</td>
<td>0.0</td>
<td>0</td>
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<td>8</td>
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<tr>
<td><strong>Is the content size in the topics appropriate?</strong></td>
<td>0</td>
<td>0.0</td>
<td>0</td>
<td>0.0</td>
<td>11</td>
</tr>
<tr>
<td><strong>Is the text easy to read?</strong></td>
<td>0</td>
<td>0.0</td>
<td>1</td>
<td>6.6</td>
<td>8</td>
</tr>
<tr>
<td><strong>Can the leaflet help you to better understand phototherapy?</strong></td>
<td>0</td>
<td>0.0</td>
<td>0</td>
<td>0.0</td>
<td>5</td>
</tr>
<tr>
<td><strong>Do you think the booklet can be given to mothers as an educational guidance before the blood test?</strong></td>
<td>0</td>
<td>0.0</td>
<td>0</td>
<td>0.0</td>
<td>5</td>
</tr>
<tr>
<td><strong>Would you recommend this brochure to other mothers?</strong></td>
<td>0</td>
<td>0.0</td>
<td>0</td>
<td>0.0</td>
<td>3</td>
</tr>
</tbody>
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Figure 2. Data regarding the evaluation of the educational material by the mothers of the study. Brasilia (DF), Brazil, 2015.

Regarding the information received about phototherapy, 53.3% received some explanation from the professionals and the remaining 46.6% did not receive any type of information. In the evaluation of the material, 79.9% of the patients were satisfied with the design presented, but three participants strongly disagreed (6.6%) or only disagreed (13.3%). The only suggestion put forward in the question was that the cover could have more colors to attract the audience. The suggestion was adhered to for material improvement.

Regarding the importance of the topics described and if the content size is adequate, 100% satisfaction of the participants was verified, that is, 53.3% agreed and 46.6% strongly agreed on the importance of the contents, and 73.3% agreed and 26.6% strongly agreed with the text size. Thus, there was a positive view of the study participants regarding the material.

Regarding the ease of reading the booklet, 93.3% of the participants were satisfied, since 53.3% agreed that it is easy to understand and 40% strongly agreed. However, one participant disagreed with this statement.

The mothers of the study showed great satisfaction with the presented material, 33.3% agree, and 66.6% strongly agree that it can help them better understand phototherapy and that it can be given to other mothers as an educational orientation before the blood test. Of these, 20% agree and 80% strongly agree that they would recommend it to other mothers. That is, 100% of the interviewed mothers were approved.

In this way, it is possible to verify that there was a general satisfaction, the relevance of having an explanatory content in relation to the phototherapy treatment being understood by the mothers, facilitating the understanding of the diagnosis and the interventions performed by the professionals.

As a further suggestion, a mother suggested that there should be a pair of glasses for each newborn, a proposal that is being considered for future research.

DISCUSSION

When constructing educational material, one should consider the population profile, what it intends to inform and what are their expectations, so that they can actually modify a reality. In the holistic perspective of care, one believes in the need to seek other strategies as support for joy and well-being in the hospital environment, such as health education actions.
A study carried out with ten mothers of newborns under phototherapy at the neonatal inpatient unit of a public maternity hospital in Fortaleza, Brazil, corroborates this study, reporting that the lack of therapeutics presented as a crucial factor in the disturbance and nervousness of the mothers when seeing their child undergoing treatment that is unknown to them.13

Another study carried out in a hospital in Minas Gerais, Brazil, with the participation of six mothers, affirms that, besides the lack of information, the main discomfort reported by the mothers is eye protection, which was pointed out as the cause of the participants' suffering due to the direct eye contact.14 Anxiety also presented by survey respondents.

Thus, more detailed guidance on therapy is needed to help the family cope with this unique process in their combination of various feelings.

Faced with this moment of fragility, it becomes unique and propitious for the professional to inform, support and guide, in a clear and objective way, in order to offer differentiated emotional support to the patient.1 The information provided, as reported by the mothers, does not seem to calm them, much less heal their doubts. It is imperative that there is a reflection and awareness of professionals regarding the importance of family inclusion in phototherapy and the sensitivity to understand that although the treatment, in its conception, is simple and daily, it can be threatening and difficult for the family.

When the family is inserted, together with the staff, in the care of children, they feel safer and more confident about the hospitalization. And so that they can participate actively in the process, it is necessary to have the presence of welcoming environments, permanent education of the team and appreciation of the participation of the family in their care and education. These factors approximate and improve safety in coping, which is not observed in the selected maternal speech.15

The right of parents to participate directly in the diagnosis, treatment and prognosis and to receive information regarding the procedures to which their children are submitted is guaranteed by law. This is what addresses the Rights of the Hospitalized Child and Adolescent.16

There are problems in the care of newborns with neonatal jaundice related to the failure in team-family communication. Dialogue is usually focused only on the implementation of treatment and not on maternal guidance.

Effective Nursing actions are necessary towards the family and the NB, supported by the communication between the team and the NB.

The use of instructional and printed materials, including educational manuals and folders, can be an efficient instrument for interaction between the health team and users for clarifying technical aspects, standardizing the guidelines to be given and providing the client with an objective way of acquiring knowledge.

In addition, educational actions bring different visions to the work of professionals who develop their practice. In this logic, educational actions can transform an environment considered by many as cold and technical, as the hospital, in a more humanized and transforming place of the reality in which one lives, offering instruments that favor the very change of conceptions that have long been rooted.17

Thus, educational materials collaborate to acquire knowledge and bring professionals closer to the patient. To do so, the text should be easy to read and should have illustrations that motivate and solve the main doubts.17 However, it should be emphasized that the level of schooling can directly influence the understanding of texts of educational materials. Patients with low educational levels and with little access to information tend to classify educational materials with lower scores due to language.17

CONCLUSION

Mothers have little knowledge and are not adequately oriented regarding the pathophysiology and care required during phototherapy and, when they are, they are informed in a more superficial way.

Educational materials are important learning tools that can be incorporated into day-to-day nursing. In general, the study material had a positive result by maternal evaluation, with recommendations for its reproduction to other mothers. In this way, it is understood that, through its content, the family can feel inserted in the treatment.

REFERENCES

2. Araújo IRB, Oliveira LLS, Santos TMGG, Moraes SDS. Nursing care of the newborns.


Ivo RS, Ribeiro LM, Leon CGRMP de et al.

Maternal perception and construction...