







THE EXPERIENCE OF PHOTOTHERAPY IN MOTHERS OF NEWBORNS WITH NEONATAL JAUNDICE

VIVÊNCIA DE MÃES DE RECÉM-NASCIDOS COM ICTERÍCIA NEONATAL NA FOTOTERAPIA

EXPERIENCIA DE MADRES DE NIÑOS RECIÉN NACIDOS CON ICTERICIA NEONATAL EN FOTOTERAPIA

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ABSTRACT

Objective: to analyze the experience of mothers of newborns with neonatal jaundice undergoing treatment with phototherapy. **Method:** this is descriptive research with a qualitative approach carried out in a university hospital in the Northeast of Brazil. Data collection was carried out from March to August 2017, through semi-structured individual interviews, with 20 mothers of newborns diagnosed with jaundice and undergoing phototherapy in rooming-in. Data were analyzed using the content analysis technique proposed by Bardin. **Results:** From the analysis, three thematic categories emerged - understanding about jaundice and phototherapy, perception of maternal care in phototherapy, and support during phototherapy treatment. Social support, faith, playful activities, and optimism for recovery were elements identified as empowering mothers to cope with the treatment. On the other hand, the lack of knowledge about the therapy, the concern with the newborn's health status, the unknown environment with the postponement of going home, the isolation of the family, and the failure in communication with the team was highlighted as elements that weaken the process. **Conclusion:** it was concluded that mothers have a deficit of information about the child's therapy, which directly influences the hospitalization period, making it troubled and having an effect of insecurity in caring for the child, with the health team as the essential element in the transmission of information to insert the mother in the care of the newborn and strengthen ties between them.

Keywords: Mothers; Infant, Newborn; Jaundice, Neonatal; Phototherapy.

RESUMO

Objetivo: analisar a vivência de mães de recém-nascidos com icterícia neonatal submetidos ao tratamento com fototerapia. **Método:** trata-se de pesquisa descritiva com abordagem qualitativa realizada em um hospital universitário do Nordeste brasileiro. A coleta de dados foi realizada no período de março a agosto de 2017, por meio de entrevista individual semiestruturada, com 20 mães de recém-nascidos diagnosticados com icterícia e em fototerapia no alojamento conjunto. Os dados foram analisados mediante a técnica de análise de conteúdo proposta por Bardin. **Resultados:** da análise emergiram três categorias temáticas - compreensão sobre a icterícia e a fototerapia, percepção do cuidar materno na fototerapia e apoio durante o tratamento de fototerapia. O apoio social, a fé, as atividades lúdicas e o otimismo pela recuperação foram elementos identificados como potencializadores para o enfrentamento do tratamento pelas mães. Por outro lado, o desconhecimento sobre a terapêutica, a preocupação com o estado de saúde do recém-nascido, o ambiente desconhecido com adiamento da ida para casa, o isolamento da família e a falha na comunicação com a equipe foram destacados elementos que dificultam o processo como fragilizadores. **Conclusão:** concluiu-se que as mães possuem déficit de informações a respeito da terapêutica do filho, o que influencia diretamente no período de internação, tornando-o conturbado e tendo efeito de insegurança no cuidar do filho, sendo a equipe de saúde o elemento essencial na transmissão de informações para inserir a mãe no cuidado ao neonato e estreitar laços entre eles.

Palavras-chave: Mães; Recém-Nascido; Icterícia Neonatal; Fototerapia.

RESUMEN

Objetivo: analizar la experiencia de madres de recién nacidos con ictericia neonatal sometidos a tratamiento con fototerapia. **Método:** se trata de una investigación descriptiva con abordaje cualitativo realizada en un hospital universitario del Nordeste de Brasil. La recolección de datos se realizó de marzo a agosto de 2017, a través de entrevistas individuales semiestructuradas, con 20 madres de recién nacidos diagnosticados de ictericia y sometidos a fototerapia en alojamiento conjunto. Los datos se analizaron mediante la técnica de análisis de contenido propuesta por Bardin. **Resultados:** del análisis surgieron tres categorías temáticas: comprensión sobre ictericia y fototerapia, percepción del cuidado materno en fototerapia y apoyo durante el tratamiento con fototerapia. El apoyo social, la fe, las actividades lúdicas y el optimismo para la recuperación fueron elementos identificados como potenciadores de las madres para afrontar el tratamiento. Por otro lado, el desconocimiento de la terapia, la preocupación por el estado de salud del recién nacido, el ambiente desconocido con el aplazamiento del regreso a casa, el aislamiento de la familia y la falta de comunicación con el equipo fueron elementos que dificultan el proceso como debilitadores. **Conclusión:** se concluyó que las madres tienen un déficit de información sobre la terapia del niño, lo que influye directamente en el período de internación, volviéndolo problemático y teniendo un efecto de inseguridad en el cuidado del niño, siendo el equipo de salud el elemento fundamental en la transmisión de información para insertar a la madre en el cuidado del recién nacido y fortalecer los lazos entre ellos.

Palabras clave: Madres; Recién Nacido; Ictericia Neonatal; Fototerapia.

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INTRODUCTION

The arrival of a child is a milestone in a woman's life and, during pregnancy, she desired and idealized a healthy child that she will hold in her arms and take home. However, certain adverse circumstances postpone this contact and bring concerns, such as jaundice.¹

Neonatal jaundice is one of the events that delay discharge and family contact. This condition corresponds to expressed hyperbilirubinemia, being multifactorial and characterized by yellowing of the skin, nails, and other organs such as eyes, originating from accumulated bilirubin, as a product of hemoglobin degraded by the destruction of red blood cells.²⁻⁴

This disease affects around 60% of full-term newborns, those with 37 weeks of gestation or more, and 80% of pre-term babies, those under 37 weeks of gestation, presenting jaundice in the first days of life, evidenced by total serum levels of bilirubin above 5–7 mg/dL.⁵ Most of the time, it is physiological. However, in many situations, it can be pathological.³

Physiological is present 48 to 72 hours after birth, reaching a mean bilirubin peak of 6 mg/dL on the third day of life, not exceeding 12.9 mg/dL and declining in one week. The pathological appears in the first 24 hours and serum bilirubin rises above 13 mg/dL.^{2,3}

Data on the global burden of diseases reveal that severe jaundice affects 481,000 newborns annually, leaving 63,000 with moderate or severe long-term neurological impairment and causing 114,000 deaths. In Brazil, according to official systems, there were 1,008 deaths from neonatal jaundice in the last 10 years.^{6,7}

Phototherapy is the first-choice therapy, consisting of high-intensity light incidence on the skin, transforming the fat-soluble indirect bilirubin into a more water-soluble molecule, facilitating excretion, reducing levels of this substance, and preventing its passage through the central nervous system.³

Maternal understanding of the treatment depends on this exposure to fluorescent light and is important for the collaboration with therapy and obtaining a better result.⁸

The newborn's hospitalization is affected by emotions, feelings, conflicts, guilt, hope, and sadness not only for the parents but for the whole family,⁹ characterized as a strange environment, with apparatus of equipment and procedures, whose newborn remains being treated in the crib, undressed, with a blindfold or eye protection and irradiated with light.¹⁰

The literature reveals that, when experiencing the need for treatment with phototherapy, the mother may find the procedure frightening, revealing a range of feelings that depend on the perception of the unknown treatment, the risks, and the benefits. The team and the mother should establish efficient communication, clarifying about the therapy and conveying security.¹⁰

In this context, mothers in many situations feel uncomfortable with this therapy and even interfere in the process, removing the newborn from the crib during treatment. Therefore, we highlight the importance of being guided and included in the child care process during treatment with phototherapy. This applies to performing simple actions that can be encouraged, such as: removing the eye patch during breastfeeding; eye cleaning with saline solution; closing the eyelid before replacing the blindfold, and changing position.¹

Thus, considering the great epidemiological value of neonatal jaundice, the psychological conflict of mothers, the probability of non-cooperation in the treatment and the involvement or worsening, as well as the insufficiency of recent research, we highlight the need to study the experience of mothers in the phototherapy treatment of their NBs. Therefore, the following guiding question was raised: what is the experience of mothers of newborns with neonatal jaundice in their child's phototherapy treatment?

In this sense, this research aimed to analyze the experience of mothers of newborns with neonatal jaundice undergoing treatment with phototherapy.

METHOD

This is a descriptive study with a qualitative approach, developed by identifying, recording, and analyzing the characteristics, factors, or variables that relate to the phenomenon or process.¹¹

The study was carried out in the accommodation of a university hospital in Recife, capital of Pernambuco, Northeastern Brazil. For the sample, we used the saturation technique of answers, characterized by the non-inclusion of new participants after offering redundancy of answers.¹² This process resulted in 20 interviews, carried out by the same interviewer.

We chose as the investigated group, all mothers with newborns hospitalized in the sector, diagnosed with jaundice in the medical record, and undergoing phototherapy treatment for at least 24 hours. We excluded mothers whose children were in other units; who were not at the time of the interview; under 18 years old whose guardian

was not present; also, another companion of the newborn who was not the mother.

Data collection took place between March and August 2017, through a semi-structured script, consisting of 30 questions, divided into two stages: characterization of participants and perception of mothers.

There were 24 questions related to characterization such as sociodemographic, obstetric, and neonatal data. There were six open questions based on the guiding question of the study, including:

- What information do you have about the light bath (phototherapy) treatment that your child is taking? Did you already know about this treatment before this contact?
- Did you receive any guidance/information about the light bath treatment (phototherapy) that your child is undergoing? If yes, who was the professional? Talk about it.
- Tell me about your day(s) since your child was placed on light bath treatment (phototherapy) until now.
- Have you received any kind of support from the team in caring for your baby in the light bath (phototherapy)? If yes, which one(s)?
- Are there any difficulties regarding the care of your baby in the light bath (phototherapy)? Tell me about it.
- What has facilitated your baby's care in the light bath (phototherapy)?

Mothers were identified by the neonate's medical record and invited to participate. All accepted to participate. We conducted the interviews in a private room in the sector, providing privacy, and recorded with prior authorization, with an average duration of 20 minutes, and later transcribed in full by the researcher.

For anonymity, the fragments of each participant were coded by the letter "I" followed by a number in the order of participation, from 1 to 20, for example, I1 (Interviewee 1). At the end of the interviews, we clarified with them about the therapy, including the risks and benefits of the issue raised at the time.

To analyze the data, we used the content analysis technique proposed by Laurence Bardin, which comprises a set of communication analysis techniques. It is a set of communication analysis techniques aimed at obtaining, through systematic procedures and objectives of the description of the content, indicators that

allow inference of knowledge related to the conditions of production or reception of these messages.¹³ The technique consists of three phases: pre-analysis, exploration of the material, and treatment of the results obtained with the interpretation.¹³

The pre-analysis in this research consisted in the organization and development of an analysis plan that provided the opportunity for the systematic exploration of the documents selected for the study.¹³ In the second stage, we performed the exploration of the material for the transformation of the raw data into thematic content for understanding the text, consisting of the grouping and categorization of fragments of the subjects' speeches.¹³

Finally, in the third phase, the treatment of the data results was carried out. We could analyze the data through the inference, interpretation, and articulation of thematic contents obtained with the theoretical reference to answer the research question and the proposed objective.¹³

This research was developed after approval by the Research Ethics Committee of the Federal University of Pernambuco - UFPE.

RESULTS

The mothers participating in the study were of childbearing age, between 16 and 42 years old; self-declared brown; with a partner; who did not complete or reach high school; exercised varied activities with low remuneration or developed activities of the home; they lived in an urban area of the metropolitan region and had a low family income of one minimum wage.

They were multiparous, had prenatal care with six or more consultations, with 12 vaginal deliveries and eight cesarean sections. They had newborns who were exclusively breastfed, younger than 38 weeks of gestation, being seven preterm babies with low weight and 13 full-term babies with adequate weight. Ten of them had the same ABO Rh blood type as the mother - O+ and 10 had ABO or Rh incompatibility, one of the main causes for the development of jaundice.

In the analysis of the speeches of the study participants, three thematic categories emerged related to the experiences of mothers in phototherapy for newborns with neonatal jaundice: a) maternal understanding of jaundice and phototherapy; b) perception of maternal care in phototherapy; c) and support during phototherapy treatment; more detailed below.

Maternal understanding of jaundice and phototherapy

In this first category, we show how the mothers understand the topic. This category was formed from the following registration units: lack of understanding/lack of information by the team; superficial understanding of the treatment; search for information; and knowledge about the topic.

The registration unit lack of understanding/lack of information by the team emerged in the testimonies of interviewees 2 and 6:

Look, to be honest, some doctor came and said why he was, no. I overheard. I didn't have any more information and I also don't understand why he's taking [the treatment] (12).

What I said I heard it from doctors talking to each other, but not arriving like this and explaining to me. And if I didn't stay connected, I didn't know it was nothing, it's up to the child to give no information. It was a doctor who installed it, I think, she just installed it, and turned on the light there and didn't even say... so much so that she didn't even say where to stay with the baby correctly (16).

The superficial understanding of the treatment was highlighted in the interviewee's testimony 14:

It's because it's jaundice, right? It's good to do because it can harm his development. No, I've never heard of no. It's his little eyes that were yellow and would need this treatment (114).

In the testimony of interviewee 5, we observed the search for information:

In the beginning, I didn't know anything, but just as we have the internet to clear up doubts, then I cleared up the doubts. (15)

The knowledge registration unit on the topic emerged in the interviewee's testimony 6:

I know it's made a pigment in the skin; it makes it react in the child's body. And for this to happen, we, mothers, have to breastfeed a lot, because due to this pigment that the light releases from the baby's skin, it said that along with feeding, then it [the baby] will release it through the feces and the pee what the body is not able to do (16).

Perception of maternal care in phototherapy

This category shows the experiences of mothers accompanying their children in phototherapy and was formed from the following registration units: optimism/confidence in the treatment; anxiety about being discharged/homesick; concern about the devices used/treatment conditions; and maternal/postpartum health.

The optimism/confidence in the team's treatment unit emerged in the testimonies of interviewees 1 and 8:

That little by little he's getting better. It's much better (11).

I'm thinking it's good. The important thing is for her to get better and she's already better (18).

The unit of recording anxiety about discharge/homesickness emerged from the testimony of interviewee 5:

Then it's tiring, people who are mothers want to be at home [crying], but as it's for their good, we have to do it... So, it's just the anxiety of going home. Because no one likes to be in here, no (15).

The concern with the devices used/treatment conditions emerged in the testimonies of interviewees 3, 11, 13, and 17:

I feel very sorry for him. [...] I'm afraid of this thing of him taking off his glasses and staying a long time, he can go blind. It's all day just looking and telling everyone (117).

It hasn't been very good. He doesn't sleep well. With light, he doesn't sleep. It keeps waking up. It's too hot for him (13).

[...] Only the cold when it hits, he is shivering. Anguish, terrible (113).

Ah! Difficult! The bad thing is at night he doesn't want to stay here. He cries a lot, then she said she can't let him cry a lot, we have to take it, nursing it, give it a little breast, then put it on again (111).

The postpartum maternal health registration unit was highlighted in the testimony of interviewee 12:

It's difficult because we're operated. Then we get up all the time, it bothers him a little, but of course, it's for his good (112).

Support during phototherapy treatment

This category shows the support experiences of mothers accompanying their children in phototherapy, which was formed from the following registration units: team support, support from caregivers/colleagues in the ward, support in faith/beliefs, and support in recreational activities.

The team support registration unit emerged in the testimonies of interviewees 4, 5, and 18:

They said I was nervous, so I could be patient that this was a phase and it would pass. I liked the treatment of the people here and they are very attentive to him (I4).

The doctor said that it could either be because of the blood type of the mother and father or because he was born prematurely. She explained that she has a business in zone A B C zone 1 2 3, which is head, body and legs and arms, there is 1 number that explains which region is more present. Then she also explained that it's more on her chest, legs, and head. The team is very attentive, I have nothing to complain about (I5).

Then a nurse said that it would be good for her because it was very yellow, that something there doesn't work properly. The nurse, a little lady who came to install the device, was the one who spoke. The doctor said that she would need something changed there. That she was born yellow and this color was to change, which was already on her face and body. [...]. They say it is not to put any clothes on her (I18).

The support of caregivers/companions in the ward was highlighted in the testimonies of interviewees 4 and 5:

I had my companions, but I was alone for three days and I had the companion of others as well (I4).

OK. She goes straight there. She asks, takes, looks [team]. She helps, looks at the girl, gives a bath [companion]. Each one helps the other when they need it [infirmery colleagues] (I7).

The faith/beliefs support in the registration unit appeared in the testimony of the interviewee 4:

Sticking with God and praying has helped and strengthened me and the words people give me too (I4).

The registration unit support in playful activities emerged from the testimony of the interviewee 5:

I liked some storytellers, I wanted them to come back because we left the world that we were worried about and paid attention to the beautiful story. The handicrafts that the girls have, help [Crafts University's extension projects with mothers] (I5).

DISCUSSION

Despite its positive effects, phototherapy is not a risk-free treatment and several side effects can be observed such as increased heart rate, seizures, hypocalcemia, changes in metabolism, thrombocytopenia, increased leukocytes, DNA damage, alteration in the functioning of the immune system, hyperthermia, softening of the stool and skin rash.¹⁴

Thus, because of the normally prolonged time of treatment and possible side effects, we need to adopt measures aimed at protecting newborns, such as education and information for the main caregiver – in our case, the mother. In this sense, analyzing how the mothers understand jaundice and phototherapy is a key issue in the qualification of treatment and care, with a focus on reducing side effects and preventing sequelae.

The testimonies of the mothers evidenced the lack of knowledge and superficial knowledge on the topic, expressed, above all, in the reduction of the clinical condition to yellowing of the skin, with no deepening and a better understanding of the process, noting superficiality in the symptoms of jaundice.¹⁵

Such lack of knowledge represents a weakening factor in the process of acceptance and cooperation for the treatment, as the lack of knowledge about the disease leads the mother to minimize jaundice and treat it as a simple change in skin color and phototherapy as any treatment.⁸ Thus, we should give the correct guidelines and with the appropriate language, as the use of technical language often does not reach the individuals to whom one wants to convey messages, requiring the most everyday language. With this, professionals should seek to facilitate understanding, seeking allies for treatment, and providing better care.

Considering that the Nursing team has contact with the mother-child binomial 24 hours a day and they are usually the professionals responsible for installing and maintaining phototherapy care, we highlight the importance of maintaining communication between Nursing and caregivers. Thus, Nursing professionals should take a leading role in the actions of information to caregivers,

as the statements also revealed the mother's longing for information about the child's condition and treatment, a condition that seems to be associated with a lack of guidance.

Corroborating our study, we identified a similar situation in a survey carried out in a regional hospital in the Federal District, which also evidenced the maternal concern to seek more content on the topic.¹⁶

With the popularization of internet access, this became an important tool for the dissemination of knowledge in the health area – having been cited as a source of research by the interviewees. However, the quality of health information available on the most diverse non-certified websites cannot be guaranteed and can sometimes lead patients to inaccurate information, as they cannot differentiate the credible contents from those presented in portals without scientific support.¹⁷

Therefore, we emphasized the need to establish effective communication between the health team and the newborns' caregivers/companions, clarifying possible doubts and communicating technically correct, up-to-date information and in a language compatible with the level of understanding of individuals. Thus, they can understand the importance and reason of phototherapy treatment, as well as its consequences and benefits, and work in a way to share the responsibility for care, transforming previously exclusively technical actions into more humanized actions with bonding and respect for all knowledge involved in the care process.

The second empirical category that emerged from the mothers' statements is related to the perception of maternal care in phototherapy, which addressed the positive and negative perceptions revealed in the statements.

Regarding the positive perception, this is important in coping with the treatment since the treatment of the newborn does not depend only on the care of health professionals, but also on the care, attention, and affection it may receive from the caregivers. This reality is in agreement with a study carried out with mothers in a federal hospital in Rio de Janeiro, which highlighted the importance of maternal trust and understanding for the success of treatment.¹⁸

On the other hand, the negative perception associated with phototherapy treatment also emerged from the mothers' testimonies, demonstrating that accompanying a child hospitalized in phototherapy can be confusing, especially due to the use of eye protection - glasses, and the treatment may interfere with the union between mother

and child, compromise the bond and generate emotional imbalance.¹⁶

Therefore, mothers should receive specialized technical and emotional support, with a differentiated and empathetic approach, qualifying the care of their baby, facilitating the course of treatment, and strengthening the professional bond between mother and family.

Although the use of eye protection - glasses - is cited by mothers as a generator of emotional concern/discomfort, this resource is essential for the treatment, considering the possibility, albeit remote, that exposure to phototherapy light may trigger retinal degeneration. Therefore, the proper use of eye protection is essential.⁵

However, given the benefits of eye-to-eye contact between mother and newborn - which aims to spread the baby's real identity with vision stimulation - and is also gratifying to the mother, it is important to guide the removal of eye protection during breastfeeding and daily care, to strengthen the visual bond.⁵

Another highlight in the testimonies is related to the mothers' concern with maintaining the baby's adequate body temperature, either because they think that the baby's exposure to light from phototherapy is too hot or because they think that the little clothing necessary for the treatment can expose the newborn into the cold. This finding reinforces the results of similar research carried out with mothers in a maternity hospital in João Pessoa, Paraíba, which also registered maternal concern with the baby's temperature in phototherapy.¹⁵

Therefore, the team should be aware of the care related to the maintenance of the appropriate distance between the light source and the newborn, avoiding heating and burns.⁸ It is also important to constantly check the temperature to detect signs of hypo- or hyperthermia and to maintain vigilance for signs of dehydration and skin dryness.³ Therefore, giving clear information about this care to mothers brings tranquility and collaboration in the treatment.

The baby's crying was reported as a reason for concern by the mothers during the treatment. This was also a finding in another study carried out with mothers in a hospital in Recife, Pernambuco, in which the child's crying was mentioned as a reason for maternal anguish and non-cooperation with the treatment.¹

Another important aspect was homesickness/anxiety for hospital discharge, referring to the house as a refuge, the place where they feel at ease and rest with family support. The hospital is indeed a not-so-welcoming environment for mothers, given the difficulties faced with the

attempt to maintain privacy, the absence of choice – whether for accommodation, food – as well as the diversity of standards to be followed. Also, there is the absence of a family support network, which is often restricted to just one companion. This reality was also verified in a survey conducted with mothers in a hospital in Recife, Pernambuco, in which mothers reported anxiety about being discharged, wishing to return to their homes and family life.¹

Finally, the situation of postpartum recovery was also mentioned as a negative factor for the care of newborns under phototherapy, as the puerperium is a period of fragility, of recognition of oneself and the baby who arrived, in which it can be accompanied by a crisis that causes anguish, doubts, fear, and uncertainties, requiring humanized care by the health team and support from the support network.¹⁹

The third empirical category deals with the support experiences of mothers accompanying their children in phototherapy, and the statements were sent to the support of the team, caregivers/companions in the ward, faith/beliefs, and the playful activities developed.

Support in phototherapy treatment was evidenced in the statements, with the representations listed being an important part of the social support network for the individual in society. In this context, one of the aspects linked to the care of women and children during childbirth and puerperium refers to the social support network of these families, reported in a study that family appears in 61.5% of cases and family groups, neighbors, and friends in 12.3% to support the care of women and children during the delivery and postpartum period.²⁰

Considering that the wards of the institution under study are, on average, made up of four beds, caregivers and mothers who share end up forming a support network that promotes mutual help and exchange of experiences and strengthens a network of trust and strong and integrated support.²⁰

On the other hand, family support works as a care cycle in which family members take care of the mother, who takes care of the child. However, the separation of home and family breaks this cycle, being a weakening factor faced during therapy.¹

In this scenario of weakening family support and living with conflicting and distressing feelings and thoughts, the testimonies revealed that some mothers resort to faith/beliefs as a form of support, nurturing/strength, begging God for the restoration of their children's health. By faith, they are likely to reach acceptance of the situation.

Thus, in a moment full of unresolved questions and mixed feelings, events of mental escape, distraction, and entertainment are extremely important, such as playful activities, which reveal motivational instruments and build knowledge and skills in a relaxed way.²¹ We noticed that the extension activities developed in the sector with storytellers and handicrafts are understood by mothers as important support during the treatment process.

The support of the team was another point that emerged from the testimonies under study, seen as crucial for the establishment of a sensitive dialogue and qualified listening for the mothers, creating a space to resolve doubts about the treatment.¹⁸ However, there was a predominance of testimonies that evidence the lack of this type of support, even highlighting indignation because some professionals go through the ward and use the baby's clinical case as an example for the discussion, ignoring the mother and not having the establishment of dialogue and/or transmission of information.

Such a situation is inconceivable for a university hospital, and it is urgent to transform the technical moment of the clinical visit into a moment of health education, giving other contours to the situation and making it less cold and more humanized, as well as more inclusive, making the caregiver/mother participate in the process.

In this same context, a qualitative study carried out in a tertiary federal hospital in Rio de Janeiro with mothers also highlighted the absence of this support system and highlighted the inconsistency in the health care provided by the team.¹⁸ Thus, providing constant guidance in simple language from beginning to the end of treatment can solve some questions asked by mothers. The information provided should explain the treatment and daily care to be given to the newborn. Thus, the team must interact with the mother, seeking to support her and guide her on the various aspects that encompass care for the newborn.¹⁰

CONCLUSION

The objectives raised were, at first, achieved, since the methodological approach used allowed us to understand that the maternal experience with her newborn in phototherapy encompasses a series of factors, which permeate the understanding of the topic, the perception of care, and the support experienced to face this experience.

Thus, there was the identification of contributing elements to the treatment in the maternal perception, which is potentiating, such as social support, faith, playful activities, and optimism for recovery. Elements that hinder the process were also highlighted, which are weakening: the lack of knowledge about the therapy, the concern with the health status of the newborn, the unknown environment that leads to frustration due to the postponement of going home, the isolation of the family and the failure to communicate with the team.

We conclude that mothers have a deficit of information about the child's therapy, which contributes to a period of difficult hospitalization experience, with the effect of insecurity in caring for the child in that circumstance. In this scenario, the health team, especially Nursing, which spends 24 hours in daily care, must act as an essential element in the transmission of information/guidance to the mothers, seeking to include them in the child's care and strengthening the ties between them.

We identified that there are few recent studies on the theme, which confirms the relevance of this study. In addition, conducting the interviews allowed the researcher to resolve the mothers' doubts and anxieties, which was very productive.

Finally, although this study is aimed at analyzing the experiences of mothers of newborns in phototherapy at a public hospital, we need to review maternal and child health policies in the country to improve care for them. Therefore, we should conduct further studies to verify the experience and perceptions of professionals who assist this audience, in addition to comparing the findings with other public and private institutions.

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