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# Motherly challenges when facing neonatal phototherapy treatment: a descriptive study

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## ABSTRACT

**Aim:** To expose the challenges faced by mothers of newborn babies who are submitted to phototherapy treatment in a rooming-in setting. **Methods:** A descriptive study, using a qualitative approach, conducted by interviewing 10 mothers whose babies experienced neonatal phototherapy while rooming-in between the months of June and October of 2014 in a public health institution in the city of Rio de Janeiro. Bardin's Content Analysis was used for analysis. **Results:** Three analytical categories emerged: *Mothers' feelings and reactions towards phototherapy treatment*; *The lack of knowledge when facing a new reality* and *The healthcare team as a support network for the mothers.* **Discussion:** Despite the simplicity of phototherapy treatment, it makes the mothers feel negative emotions such as anguish, sadness and guilt. **Conclusion:** The nursing staff must be prepared to hear and guide the mothers throughout phototherapy, taking into consideration that it is a negative experience during the newborn hospitalization.

**Descriptors:** Infant, Newborn; Hyperbilirubinemia; Phototherapy; Neonatal Nursing.



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## INTRODUCTION

Neonatal hyperbilirubinemia, commonly known as jaundice, is a clinical finding of multiple etiologies[1,2]. Caused by an elevated level of bilirubin in the blood, the condition is characterized by its yellow-orange pigmentation of the skin, sclera and other body tissues[1,3]. It results from an insufficient maturity of the pathways of the liver combined with the breakdown of the newborn baby's (NB) erythrocytes[4,3]. It is estimated that about 60% of fullterm newborns (FTNB) and about 80% of preterm newborns (PTNB) show some degree of hyperbilirubinemia during the first days of their lives[5].

Jaundice can be classified as physiologic or pathologic. However, in half of the cases its source is physiological and normally presents itself in a soft manner and with spontaneous regression. When the spontaneous regression does not occur or when pathological jaundice is suspected, the NB is submitted to treatment such as phototherapy[1,3]. Phototherapy uses fluorescent and halogen lighting equipment in order to expel bilirubin in urine and feces through the mechanisms of photo isomerization and photo oxidation [1,6]. It is a non-invasive method of high impact that diminishes levels of plasmatic bilirubin, regardless of the NB maturity [7].

Phototherapy treatment, when performed in rooming-in care units (RI), commonly adopts equipment such as the bili light and bili spot, taking into consideration that, in the Brazilian reality, up-to-date equipment is rarely used in neonatal intensive care due to its increased handling complexity and because of the exposure of healthcare professionals to its adverse effects, such as dizziness and nausea[6]. For families, especially mothers who accompany their children in RI, this is an unexpected situation, as the majority of NB babies receive basic health care, the use of state-of-the-art technologies being unusual in this context. In this room, the emphasis is on guiding and motivating mothers towards providing care for their newborn children in order to prepare the mother for hospital discharge as well as to strengthen the pair bonding between mother and child.

Given that, this research aims to expose the challenges faced by mothers of NB babies who were submitted to phototherapy while in a RI setting.

## METHODS

This is a descriptive study with a qualitative approach[8,9]. The study was held in a RI setting of a tertiary-level, child-friendly, federal public hospital, also specialized in the treatment of high-risk newborn infants, located in the city of Rio de Janeiro.

The study setting has 19 beds divided into twin cabins, allowing a usual crib to be placed by the puerpera's bedside. In this sector NB infants receive care directly from their mothers under the supervision of the nursing staff. Whenever a NB baby needs phototherapy, the nursing staff seek to accommodate this pair in a single cabin.

Data collection took place between June and October of 2014, involving 10 mothers of NB infants that were being submitted to phototherapy treatment. These mothers agreed to take part in the research by signing the Free and Clarified Consent Term (FCCT). Mothers who were not physically and/or psychologically healthy at the moment of data collection were excluded from the study.

A guide for a semi-structured interview, composed of two parts, was used for data collection. The first part of the interview consisted of sociodemographic- and obstetric-related questions [10]. The second part comprised the guiding questions of the interview: how did you feel

when you found out your child would have to undergo phototherapy treatment? How do you feel witnessing your infant's daily routine while in phototherapy treatment? The statements were recorded and subsequently transcribed.

Data collection ended when the "saturation point" was reached in the statements[1]. In order to guarantee their anonymity, the participants were identified through numbers following the order in which the interviews took place - for instance, participant 1.

Bardin's Content Analysis, more specifically Thematic Analysis, was used to elucidate the statements[12]. Three analytical categories were created: *Feelings and reactions of mothers towards the treatment*; *The lack of knowledge facing a new reality* and *The healthcare team as a support network for the mothers*.

After the categorization, the scientific literature was examined. In order to do so, a review of the scientific research was carried out using the following databases: Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS) (Latin-American and Caribbean Health Sciences Literature Database), Medical Literature Analysis and Retrieval System Online (MEDLINE), Scientific Electronic Library Online (SciELO) and Base de Dados de Enfermagem (BDENF) (Brazilian Nursing Database).

This research was conducted according to ethical rules established by Resolution nº 466/2012 of Conselho Nacional de Saúde (CNS) (National Health Council)[13]. The project was approved by the institution's Research Ethics Committee under the number 819.980/2014.

## RESULTS

The average age of the group of 10 mothers was 32.7 years old, with a standard deviation (SD) of ±12.7. Concerning the number of pregnancies, four were primiparous and six multiparous. As for the type of birth, five experienced vaginal deliveries. Regarding the maternal level of education, one mother had a postgraduate degree, seven had completed secondary school, one had an incomplete secondary school degree and one had completed elementary school. It was noted all participants had more than six prenatal consultations.

The average NB's gestational age (GA) was 38.6 with a standard deviation (SD) of ± 2.5. At the moment of the interview, the NBs were between two and seven days of chronological age, with a standard deviation of ± 2.5.

Only one mother was watching her infant undergo the treatment for the second time.

*Category 1: Feelings and reactions of mothers towards phototherapy treatment*

This category accounted for 44.9% of the recording units (RU), representing 163 RU of 368 RU and nine meaning units (MU).

For the mothers, their reactions towards phototherapy treatment represent mixed and ambivalent feelings. Since it is an uncontrollable situation for them, it causes pain, sadness, concern, guilt and a feeling of postponement regarding the return to their homes. These feelings become apparent in the following statements:

> [...] but phototherapy itself is just too painful [...] (Interview 2)

> [...] Oh, it's horrible! Seeing him, like that, crying. I just cried. And then I asked if I could hold him and, at first, they told me not to [...] He cries, I cry. Yesterday I broke down, I held his hand and cried so, so hard (cries). It's awful... (cries) And I have another daughter,


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> it's very hard to be between the two of them [...] (Interview 3)

> […] Oh, I was sad! Oh, I was concerned! Oh, I kept thinking if it was my fault, blaming myself, that was it, but now it's over. Now I'm dealing better with it [...] (Interview 5)

However, they can still preserve feelings of hope and resilience:

> [...] Oh, feeling that she would get well soon and wouldn't need to be in treatment for too long. I wasn't too depressed, I was thinking the treatment was going to work, everything will be all right, better, positive thinking! [...] (Interview 9)

*Category 2: The lack of knowledge facing a new reality*

This category is composed of three MU and five RU, as follows: doubt, (lack of) knowledge, lack of instruction regarding treatment, "caught off guard" and lack of clarity in the information provided, totalling 151 RU, which represent 41.03% of the category.

When experiencing this situation, women tend to create thoughts permeated with fantasy about their infants' health condition, regarding both treatment and pathology. Having so many doubts and fears could be a consequence of a failure in the communication process between the mothers and the healthcare team. These doubts are exemplified in the statements below:

> [...] I don't know if it's burning, if it could do any damage to his skin, if it burns, if he is going to be burnt [...] I wonder if he is going to get darker on only one side of his body? Especially that tiny mattress; I wonder if it is comfortable, or is it too hard? I keep thinking 'is it hurting?' [...] (Interview 2)

> [...] Honestly, for a person like me, completely unaware about the treatment, they could explain it in a clearer language, tell me what it is. I don't know if it's a virus, if it's some bacteria, what this Jaundice thing is (laughs). Honestly, the reason he is there, I don't know, you know? [...] (Interview 7)

The women's lack of knowledge regarding the treatment their infants are undergoing awaken in them thoughts embedded in cultural experiences and popular knowledge:

> [...] well, of what I learnt from my older relatives, when they're born like that, yellowish, giving them a sunbath and offering Beggar's Tick tea to drink does the trick, right? So I thought it was normal. [...] But I didn't know it was that severe, that there were a lot of consequences involved [...] You don't understand and you don't know and you're given the news like that, which is very frightening, you become so scared [...] On the first day [...] my girl just couldn't stop pooping. And I got desperate, asked 'is it possible she is in pain? Is she fussy?' [...] (Interview 10)

*Category 3: The healthcare team as a support network for the mothers*

This category was expressed by an RU (the healthcare team support), totalling 54 RU, or 16.67%, of the category. Most mothers describe having received support from the healthcare

team while their infants were undergoing phototherapy treatment.

> [...] There was always someone reinforcing care... Nurses, paediatricians… They came by to deliver a medication and would start to explain [...] (Interview 1)

> [...] They helped me at first with the provision of care for my child, giving me instructions and also explanations. The doctor was clear about what I had to do, how I had to do it, so all the staff came and were very attentive. I had support from the nurses during the day, daytime and nighttime, all the time, all my questions were answered [...] (Interview 8)

Meanwhile, some mothers pointed out the absence of this support system and highlighted the inconsistency in the healthcare provided by part of the healthcare team, as follows:

> [...] well, we don't know who we should be asking questions to. Some nurses are really nice when we question them, others not so much [...] Not all of them give you the liberty to ask questions, so you end up being supported by your family [...] (Interview 3)

> [...] I didn't know how to explain it to him (to the father), I just told him: 'look, she (the doctor) told me our baby has to do this thing because her skin is turning yellow [...] That's pretty much all I could tell him. And then I asked, asked for a doctor to come talk to him, as he wanted to understand [...] You seek information, you want information, you want to feel safe, [...] I didn't know the hospital performed these procedures, that the baby was looked after like that [...] (Interview 10)

The nursing staff spends most of its time taking care of the mother and child pair and is more involved in these families' daily lives. Consequently, the nursing staff, in addition to other categories, can be crucial for guaranteeing a sensitive dialogue and listening to the mothers in order to create room for solving doubts regarding phototherapy treatment.

When these mothers are given voice, it can be noticed that they bring propositions that could guide nursing actions in daily practice:

> [...] a support group would be nice to explain the daily routine. It's hard, because you're caught off guard. I had my prenatal care here, so up until the ultrasound examination everything was going well [...] They explained it to me here that my blood type wasn't compatible with my husband's and that's why she would have to undergo phototherapy [...] (Interview 4)

## DISCUSSION

The statements above indicate that mothers report negative feelings about the experience of their infants undergoing phototherapy treatment, since it is an uncontrollable situation for them.

In light of the challenges faced, the certainty that the treatment outcome will be best for their child overcomes the feelings of sorrow that permeate the mothers' daily lives.

The treatment makes these women scared and stressed, as they find themselves in a fragile


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and insecure position regarding their child's health. This is made clear by the ambivalent feelings such as guilt and feeling responsible for the infant's "suffering"; yet at the same time they also show feelings of hope and resignation[14].

Although phototherapy treatment is very common for healthcare professionals and a part of the RI routine, it must be considered that, for the mothers, it presents itself as something unusual, unfamiliar and, most of the time, frightening. Having a child undergo phototherapy treatment requires specific care, such as keeping the NB child naked under the lighting for as long as possible and protecting the infant's eyes using an appropriate blindfold. The care mentioned above caused complaints from the mothers, besides some expected collateral effects such as tanning of the skin and diarrhea. All of these factors may bring up feelings of sadness and anxiety because they do not fully understand and comprehend the therapeutic proposal[15].

The adaptation process of these mothers seems to be influenced by external aspects such as social, cultural and familiar. Their life stories and former experiences reflect in emotions and behaviors that vary from person to person. These are complemented by the healthcare quality provided by the healthcare team and the way it allows mothers to express their emotions[16].

Being near the NB baby and by his/her side during the recovery process are aspects that promote resilience when mothers face adverse conditions, making them stronger and able to overcome negative emotions.

Providing continuous guidance in easy-to--understand language from the beginning to the end of the treatment could solve some of the questions being asked by the mothers. The information provided must explain what phototherapy treatment is and the daily care the NB baby is going to face throughout the treatment, drawing the attention of the mother to the fact that she will be limited in holding, dressing or making eye contact with her child[17].

Communication enhances the interaction between healthcare professionals and family members, providing a humanization of the health assistance, reducing feelings such as anguish and unworthiness towards the treatment. Quality assistance is not limited to technical procedures, but also includes human relationships and communication, including the understanding of non-verbal messages and respecting individualities[18,19].

Most healthcare actions have focused on hard and soft-hard technologies, overlapping relational and soft technologies. Sometimes complex technology can be an obstructive factor for individualized healthcare, for a greater engagement of the healthcare team and for humanized assistance[20].

In this study setting, the participants seemed fragile, lonely and sensitive, sharing this moment with other mothers and demanding increased attention from the healthcare team. The demonstration of affection, respect, understanding, attention, restoring collective caring and proactive listening focused on the mothers' needs and expectations could make the difference. This behavior change may serve as an incentive for changing practices in healthcare, in which clinical knowledge is related to the patients' needs[21,22].

Strengthening the use of soft technologies and listening proactively are challenges faced daily by the neonatal nursing staff. However, these are essential for guaranteeing the patient's independence and for respecting his/her condition as a co-participant in the therapeutic process. Regarding neonatal healthcare, the mother (or person responsible) mediates the thoughts of the healthcare team and what she believes is best for the infant, which, in this case, is her child. Thus, giving the mothers voice is an essential

tool for guaranteeing their self-assurance and adherence to the therapeutic proposal.

Being able to recognize not only the needs of the NB baby who is undergoing phototherapy treatment, but also the questionings and expectations of the mother, could be the tool to intensify the strength she seeks to face a moment of emotional fragility due to her child's health.

## CONCLUSION

This research revealed challenges faced by mothers while their children undergo phototherapy treatment. It led to a better understanding of the feelings experienced daily by them. The statements evidenced fear, doubts, sadness, worries and lack of knowledge about the pathology.

Healthcare professionals pointed to effective communication as an aspect to remember during the therapeutic process. It is also an essential tool for implementing individualized patient care and fortifying the support network families need when going through a difficult period of time in their lives.

The limitation of the study was the fact that it was conducted in only one health facility, requiring further investigations in order to make findings more generalizable.

Finally, phototherapy treatment emerged as a complex experience in the life of these mothers, showing that it should be further analyzed through other studies, which may lead to improvements in neonatal nursing actions.

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