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# Parental Understanding and Care-Seeking Practices for Neonatal Jaundice: A Qualitative Study

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## ABSTRACT

**Background:** Neonatal jaundice (NNJ) is a condition characterized by yellow discoloration of the skin and sclera due to elevated serum bilirubin levels in newborns. While it is often physiological and self-limiting, untreated cases may progress to severe hyperbilirubinemia, leading to complications such as kernicterus and long-term neurological impairment. Despite the availability of effective treatment, delays in care-seeking remain prevalent, often influenced by gaps in parental knowledge and socio-cultural beliefs. Therefore, this study aimed to explore parents' understanding of NNJ and examine the factors shaping their care-seeking practices.

**Methods:** A qualitative descriptive study was conducted at Kota Bharu, Kelantan. Twenty parents whose infants were diagnosed with NNJ were purposively sampled and interviewed using semi-structured guides. Interviews were conducted face-to-face or via telephone, audio-recorded, and transcribed verbatim. Data were analysed using thematic analysis.

**Results:** Three major themes emerged: (1) *Parental Perception and Understanding of NNJ*, (2) *Care-Seeking Practices for NNJ* and (3) *Influences on Response to NNJ*. Parents commonly recognized NNJ by yellowing of the skin and sclera but often underestimated its seriousness, perceiving it as a harmless condition or relying on past experiences. Care-seeking behaviours reflected a dual pathway: while many sought prompts medical care when symptoms worsened, others initially turned to traditional remedies such as herbal baths and sun exposure. Family members, previous experiences, and emotional responses strongly shaped parental decisions, with fears of hospitalization, invasive procedures, and childcare disruptions contributing to delays.

**Conclusion:** Parental responses to NNJ were shaped by limited knowledge, cultural practices, family influence, and emotional concerns. Strengthening antenatal and postnatal education, providing clear and culturally sensitive health communication are essential to promoting timely care-seeking and reducing the risk of NNJ-related complications.

**Keywords:** Neonatal jaundice; Parental perception; Care-seeking behaviour; Cultural beliefs; Qualitative study, Malaysia

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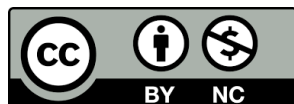
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## INTRODUCTION

Neonatal jaundice (NNJ), characterized by yellow discoloration of the skin and sclera due to elevated bilirubin levels, is one of the most common neonatal conditions worldwide. While most cases are physiological and resolve without intervention, some can progress to severe hyperbilirubinemia, risking kernicterus and long-term neurological damage if untreated (1). Despite the availability of effective treatments such as phototherapy, studies have shown that delays in seeking care remain a significant barrier to successful management, particularly in low- and middle-income countries (2). Parental recognition of symptoms, perception of illness severity, and response behaviours are critical in the timely treatment of NNJ.

In Malaysia, where traditional beliefs often intersect with biomedical understanding, it is essential to investigate how parents interpret jaundice and what influences their decisions regarding care. Ministry of Health (MOH) Clinical Practice Guideline (CPG) was standardized diagnosis and treatment, and sun exposure is not recommended for jaundice management. This study explores parents' understanding and care-seeking behaviours for NNJ and identifies the factors shaping their responses.

Neonatal jaundice prevention is important in the first week of life, especially in sub-Saharan Africa with the highest global burden of neonatal mortality (3). Early detection and timely initiation of treatment are widely recognized as the most effective strategies to prevent neonatal jaundice (NNJ) from progressing to severe hyperbilirubinemia and its associated complications. The 2022 American Academy of Paediatrics (AAP) guidelines emphasize universal bilirubin screening prior to hospital discharge and updated thresholds for phototherapy and exchange transfusion to reduce the risk of kernicterus (4). Similarly, maternal education interventions have been shown to significantly decrease delayed care-seeking, thereby lowering the incidence of acute bilirubin encephalopathy (2). Clinical evidence consistently highlights that when NNJ is identified early and managed promptly, serious outcomes such as irreversible neurological impairment are largely preventable (5,6).

Although neonatal jaundice (NNJ) is a common condition with established treatment guidelines, limited evidence in Malaysia has specifically examined how parents understand and respond to this condition. Existing local studies suggest gaps in parental knowledge and a continued reliance on traditional practices, which may contribute to delayed care-seeking. However, there is insufficient in-depth exploration of how cultural, social, and health system factors collectively shape parental decision-making. Therefore, this study aims to explore parental understanding and care-seeking practices for neonatal jaundice in the Malaysian context, focusing on the cultural, social, and health system factors that shape their responses. By uncovering parental perspectives, the findings may help identify gaps in awareness, improve health education, and guide strategies to reduce preventable complications of NNJ.

## METHODS

### Study Design

This study employed a generic qualitative descriptive design to explore parents' understanding of neonatal jaundice (NNJ) and the factors influencing their care-seeking practices. This approach was selected due to its appropriateness in capturing, contextual insights into decision-making (7). The generic qualitative research design assisted the researcher to gain an understanding of how parents perceive neonatal jaundice and their care seeking practice of their child with neonatal jaundice through this exploration as to what the parents's understanding, tough and actions regarding the handling of her baby in jaundice. This study was conducted in Kota Bharu due to the high incidence of neonatal jaundice reported in Pasir Puteh, Kelantan. As a report in previous study determinants of NNJ among neonates in Pasir Puteh Kelantan, found that among 1154 newborn who underwent postnatal follow-up, 727 (63%) develop NNJ and required further treatment (8). The rising case trend highlighted the need to examine parental understanding and care-seeking practices within this local setting to better inform targeted interventions.

### Participants and Sampling

Participants were recruited using purposive sampling, which is a widely used strategy in qualitative research for selecting individuals

who can provide in-depth and relevant information (9). The inclusion criteria were: (i) parents ages above 18 years old, (ii) primigravida or multigravida, (iii) parents whose newborns had been diagnosed with NNJ and (iv) Malaysian by nationality. Sample size was guided by the principle of data saturation. Data saturation was defined as the point at which no new information, themes, or insights emerged from the interviews, and further data collection was unlikely to add significant value (10). In this study, saturation was reached after several interviews when responses became repetitive, but recruitment was continued until 20 participants to ensure diversity and richness of perspectives.

### **Data Collection**

Data were collected through semi-structured interviews as the primary method of data collection. This approach was chosen for its flexibility, allowing in-depth exploration of issues based on participants' responses. Face-to-face interviews were conducted to facilitate rich, detailed accounts of parents' perceptions while ensuring privacy and confidentiality.

The semi-structured interview guide was developed in alignment with the study objectives and covered several key domains. Opening questions explored parents' general understanding of neonatal jaundice and their overall experiences. Core questions examined parental knowledge of causes and signs, perceived severity, sources of information, and actions taken upon recognizing symptoms. Particular emphasis was placed on care-seeking behavior, including when and why parents sought medical care, factors influencing their decisions, and the use of traditional or home remedies. Probing questions were used to further explore cultural beliefs, family influences, and experiences with healthcare services to gain a comprehensive understanding of the parental decision-making process.

Each interview lasted between 30 to 60 minutes for each selected participants in private room and specific time mutually agreed upon by the selected participants and researcher. A total of 18 participants were able to be interviewed face to face, whilst 2 participants agreed interviewed via telephone.

### **Data Analysis**

Interview transcripts were analysed using thematic analysis following Braun and Clarke's (11), six-phase framework: (a) familiarization with the data, (b) generation of initial codes, (c) searching for themes, (d) reviewing and refining themes, (e) defining and naming themes, and (f) producing the report. Thematic analysis was selected because of its flexibility and its suitability for capturing both explicit and underlying ideas within participants' narratives, thus allowing for a comprehensive understanding of the phenomenon under study (12). This approach ensures transparency and rigor in the analytic process, while also enabling researchers to remain closely connected to participants' voices and contextual meanings (13). The analysis aimed to generate new insights into parental knowledge, beliefs, and care-seeking practices regarding NNJ.

### **Ethical Considerations**

Ethical approval was obtained from Kulliyah of Nursing Post Graduate Research Committee (KNPGRC) and the IIUM Research Ethics Committee (IREC). Informed consent was obtained from all participants prior to data collection, with assurances of confidentiality, voluntary participation, and the right to withdraw at any time without penalty.

### **Trustworthiness**

To ensure the trustworthiness of the study, several strategies were applied following established qualitative research criteria. Credibility was strengthened through prolonged engagement with participants and iterative review of the interview transcripts to ensure accurate representation of their perspectives (12). Dependability was maintained by keeping a detailed audit trail that documented all methodological decisions and data analysis processes, enabling transparency and consistency (14). Confirmability was enhanced through reflexive journaling and peer debriefing, which minimized researcher bias and allowed for critical reflection on the analytic process (15). Transferability was supported by providing thick descriptions of the study context and participants, allowing readers to assess the applicability of findings to other settings (14,16). Collectively, these strategies strengthened the rigor and trustworthiness of the study findings.

**RESULTS**

**Sociodemographic Characteristic of Parents**

**Table 1** presents the sociodemographic characteristics of the 20 parents who participated in this study.

**Table 1:** Sociodemographic Characteristic of Parents

Demographic characteristic	Frequency (f)	Percentage (%)
Age		
21-30	10	50
31-45	10	50
Race		
Malay	20	100
Level of education		
Secondary school	5	25
University	15	75
Employment status		
Housewife	6	30
Working	14	70
Parity		
Primiparous	6	30
Multiparous	13	65
Husband	1	5
Mode of interview		
Online	2	10
Face to face	18	90

**Thematic Findings**

The finding is presented based on the thematic analysis of interview with 20 parents (19 mothers and 1 father). Three major themes were emerged including (a) Parental Perception and Understanding of NNJ, (b) Care-Seeking Practices for NNJ, and (b) Influences on Response to NNJ. Each theme comprised several subthemes, as outlined below.

**Theme 1: Parental Perception and Understandings of NNJ**

Parents generally recognized NNJ by the yellowing of the skin and sclera, but their knowledge of its causes, severity, and treatment was often incomplete. Many normalized the condition, believing it to be a harmless part of infancy, while others underestimated its seriousness based on past experiences or limited antenatal information. Their perceptions were shaped by personal observation, partial advice from healthcare providers, and cultural interpretations. For instance, many parents had a basic understanding that NNJ causes yellowing of the baby’s skin. However, several expressed confusion or incomplete knowledge about the causes, severity, and treatment:

*“I don’t really know much about this... but I’ve heard people mention ‘yellow fever’. I think it’s the same as jaundice... people say it’s just a common condition in newborn babies... so I don’t really know much about it.”*

*(Participant 8)*

Some assumed NNJ was a normal and harmless condition:

*“At the time, I only had a limited understanding. The nurse had explained it during my pregnancy, but I didn’t fully grasp the information. I assumed jaundice was something normal, that all babies experienced it. I wasn’t aware of how serious it could become if not treated early.”*

*(Participant 17)*

Others underestimated its severity based on past experience:

*“My first child had a bit of jaundice too, but it went away on its own. The second child had no issues. But with this baby, the jaundice seemed to get worse. I thought it would go away like with his older brother... that’s why I wanted to wait and see first... but it turned out the jaundice was hard to reduce.”*

*(Participant 7)*

In terms recognition of jaundice in their child, the parents commonly relied on visual observation, particularly of the skin and sclera. However, inconsistent presentation sometimes delayed care seeking:

*"I started noticing that the baby looked yellow on the third day after birth. At that time, the skin began to appear yellowish, especially on the face and chest. I was quite worried too, but the nurse at the clinic mentioned that mild jaundice is common in newborns."*

(Participant 19)

Similarly, another mother explained that her main method of recognition was by checking the baby's overall skin colour and the whites of the eyes, which often heightened her level of worry:

*"Usually, I look at my child's skin colour. If it looks yellow, especially on the face, chest, and sometimes the hands, I start to worry. The whites of the eyes also turn yellow."*

(Participant 18)

In summary, parents were familiar with the visible signs of NNJ but lacked depth of understanding which leading to misconceptions that influenced their responses. These beliefs would directly influence their next step whether seeking medical help or turning to traditional practices.

## Theme 2: Care-Seeking Practices for NNJ

The findings shown that the care-seeking behaviours of the parents reflected a mix of hospital visits and reliance on traditional remedies. While many parents sought medical care when symptoms worsened, others initially tried herbal baths or sun exposure, often influenced by family advice or cultural norms. These practices coexisted, with some parents alternating between traditional and formal approaches depending on perceived illness severity.

Most of the parents in this study sought formal medical care when symptoms worsened, particularly when babies showed poor feeding, excessive sleepiness, or worsening jaundice:

*"The nurse here said... you have to breastfeed frequently if you don't want your baby to develop jaundice after going home... don't just let the baby sleep all the time... if there's any*

*change in the baby's skin colour, quickly bring them to the clinic for a blood test."*

(Participant 27)

Another parent shared how worsening symptoms, such as refusal to breastfeed and excessive sleepiness, prompted her to seek hospital care without delay.

*"I immediately took my baby to the hospital after noticing that my baby didn't want to breastfeed, was inactive, and was sleeping most of the time... I became worried when I saw the skin turning more yellow."*

(Participant 2)

Despite the use of formal healthcare, traditional remedies remained a common first response. Practices such as herbal baths and early morning sun exposure were often attempted before seeking medical care, usually based on advice from relatives or prior family experience:

*"I only knew about using herbal baths with roots and leaves... because my sister had done it before. She was the one who suggested I bathe my baby with that too. So I tried bathing my baby with the herbal mixture every morning... but I felt like there wasn't much change."*

(Participant 29)

Similarly, another parent explained that they combined early morning sun exposure with herbal water baths, yet the baby's jaundice symptoms persisted.

*"We immediately started sunbathing the baby in the early morning... and bathed the baby with boiled herbal water that we bought from a Chinese traditional medicine shop. We tried bathing the baby for about two days... my wife also breastfed the baby frequently... but we still noticed yellowing in the baby's eyes."*

(Participant 20)

Overall, care-seeking was shaped by a balance between trust in healthcare services and the persistence of cultural remedies. Beyond individual knowledge and practices, parents' decisions were also heavily shaped by external influences, including family members, past experiences, and emotional factors, which played a decisive role in when and how care was sought.

## Theme 3: Influences on Response to NNJ

This finding revealed that the decision-making was rarely individual, with spouses and extended family members strongly shaping parental actions. Fathers' involvement varied, while elders often encouraged traditional practices. For example, family input often guided how mothers responded to jaundice. In some cases, encouragement from elders pushed parents to seek medical care

*"My husband didn't know much about this illness either... so he left all the decision to me. Both of us were too afraid to go to the hospital. But after I called my mother, came from the village and immediately urged me to go to the clinic only then did I gather the courage."*

(Participant 10)

In other cases, spouse was proactive role:

*"My husband would immediately take the baby to the hospital if the baby developed jaundice... he's worried that the condition might get worse if treatment is delayed."*

(Participant 1)

Past experiences strongly shaped parental behaviour. For instance, a mother with previous experiences with neonatal jaundice explained how her previous experiences influenced her decision-making and treatment approach:

*"My first child had a bit of jaundice too, but it went away on its own. The second child had no issues. But with this baby, the jaundice seemed to get worse. I thought it would go away like with his older brother... that's why I wanted to wait and see first... but it turned out the jaundice was hard to reduce."*

(Participant 7)

While some mothers felt confident in managing NNJ due to previous positive experiences, others particularly those who had faced stressful hospital admissions were hesitant to return to formal care.

*"My second child also got jaundice... I was worried then... afraid of having to be admitted again... remembering my first experience, I didn't feel like taking my second child to the hospital... so I tried those herbal baths first at that time."*

(Participant 12)

In addition to family influence and past experiences, parents' emotional reactions

played a crucial role. Fear of medical procedures, anxiety about hospitalization, and concerns about managing other children at home were key reasons for delaying care. For example, a mother described her worry about painful procedures and potential complications if she brought her baby to the hospital:

*"I thought my baby might get pricked many times, or that it could get worse... at that time I was really scared to bring the baby to the hospital... afraid of the needles... that's why I waited first."*

(Participant 17)

Despite of fear of medical procedures, other parents were also concerned about the practical challenges of hospitalization, such as childcare responsibilities at home.

*"I was afraid that if we went to the hospital, the doctor would ask to admit the baby... and the baby would have to stay there for who knows how long. My husband works far away, so who would look after my other children at home?"*

(Participant 6)

In short, family dynamics, past experiences, and emotional fears played a central role in how parents responded to NNJ.

## DISCUSSION

This study highlights the multifaceted nature of parental care-seeking behaviours for NNJ. While many parents recognized visible signs of jaundice, their understanding of the condition's seriousness varied. Misconceptions and normalization of symptoms were significant barriers to prompt medical attention. Three key themes emerged: (a) Parental perception and understanding of NNJ, (b) Care-seeking practices, and (c) Influences on response to NNJ. These findings highlight the complex interplay between knowledge, cultural beliefs, prior experiences, and social influences in determining parental actions. Although most participants recognised jaundice by visible yellowing of the skin and sclera, their understanding of its causes, potential complications, and need for timely treatment was often limited or inaccurate.

Most parents in this study demonstrated limited knowledge about the condition, with many associating jaundices with common or non-serious symptoms. Several participants

admitted they had never encountered the condition before and were confused upon receiving the diagnosis. In supporting this, Alinaitwe et al. (17) showed similar finding, previous lack of information and misconceptions, mothers depend on trial -and-error method such as sun exposure or dietary changes. Others study revealed that parental knowledge regarding neonatal jaundice was generally limited. While most parents were able to recognize the visible signs of jaundice, such as yellowing of the skin and eyes, their understanding of the underlying causes, potential complications, and appropriate treatment options was insufficient. Misconceptions were common, with some parents perceiving jaundice as a minor or self-limiting condition that could be managed through traditional remedies or sun exposure, rather than seeking timely medical attention. This gap in knowledge has also been reported in other studies, which highlight that inadequate awareness among parents often contributes to delayed care-seeking and increases the risk of severe outcomes, including kernicterus (18,19,20). These findings align closely with this study, where parents were generally familiar with NNJ but lacked detailed understanding of its causes, warning signs, and the urgency of appropriate treatment. Most parents in this study demonstrated limited knowledge about the condition, with many associating jaundices with common or non-serious symptoms.

The finding in this study shows that many mothers received limited or no information about neonatal jaundice during their antenatal visits or classes. While some were given brief explanations, most felt the information was insufficient to prepare them for recognizing and managing jaundice in their newborns. This finding was consistent with previous studies. For example, Olatunde et al. (3) highlighted significant gaps in antenatal education on neonatal jaundice. Their studies revealed that many mothers reported only brief or superficial exposure to the topic during pregnancy, which contributed to limited awareness and inadequate preparedness for recognizing or managing NNJ. Similarly, in China, knowledge gaps were evident, with low recognition of abnormal early jaundice, limited understanding of diagnostic methods, and minimal proactive health information-seeking among mothers (21).

Parental care-seeking behaviours for neonatal jaundice (NNJ) in Asia reveal similar patterns of misconceptions, cultural influence, and delays in timely healthcare access. In this current study, many parents still practice traditional remedies instead of hospital treatment as a first action. Furthermore, a study involving the development of a herbal bath soap using *Averrhoa bilimbi* and *FlosLoniceræ*, plants commonly featured in Traditional Chinese Medicine demonstrates the cultural embedding of herbal intervention for jaundice in Malaysian contexts (22). Similar study in Vietnam was consisting with this study. Maternal awareness of the severity of neonatal jaundice was generally low, which often contributed to delays in seeking appropriate care. Cultural practices such as keeping newborns in dark rooms to protect them from perceived harm and reliance on traditional remedies were reported to hinder early recognition and timely treatment of jaundice (23,24). In Bangladesh, neonatal complications including jaundice were often attributed to parental negligence or spiritual causes, leading families to prefer traditional healers and local practitioners rather than formal healthcare services (25).

Decision-making about NNJ care was rarely made by mothers alone. Spouses, mothers-in-law, and extended family members played a significant role in shaping parental responses. In many cases, mothers followed traditional practices based on advice from elders or family expectations. This often influenced whether professional care was sought early or delayed. This finding very similar in study by Do et al, (24), that reported that decision regarding treatment were rarely made by mother alone, instead often share among grandmother, aunts or the broader family network. Decision-making was strongly shaped by spousal and extended family input, previous personal experiences, and emotional responses such as fear and anxiety. This finding mirrors those of Alhassan et al., (26) who noted that fear of invasive interventions can deter parents from seeking care.

Mothers' previous experiences with neonatal jaundice and their underlying beliefs significantly influenced their decision-making and treatment approach in this study. For some mothers, having dealt with jaundice in earlier children gave them confidence in managing the condition through regular breastfeeding and close monitoring. Ezaka et al, (27) reported that mothers with a history

of caring for jaundiced infant had greater chances of possessing good knowledge of NNJ. Traditional beliefs and cultural practices significantly influenced mothers' initial response to neonatal jaundice. Many relied on advice from elders or their own experience with previous children, often prioritizing home remedies such as herbal baths and sun exposure before seeking formal medical care. Goli et al, (28) similarly found that many mothers relied first on home remedies or advice from relatives due to past positive experiences with traditional methods. This reliance led to delays in seeking hospital treatment, sometimes until the baby's condition worsened.

Taken together, the findings highlight that parental care-seeking for NNJ is shaped not only by knowledge but also by cultural traditions, family influences, and emotional experiences. While parents were generally aware of jaundice as a condition, limited depth of knowledge, inadequate antenatal education, and reliance on traditional remedies often delayed appropriate care. Family dynamics and prior experiences played a decisive role, while emotional fears created additional barriers. Strengthening antenatal education, incorporating culturally sensitive health promotion, and engaging family members not just mothers are essential to improving timely recognition and treatment of NNJ. Without these interventions, preventable complications of jaundice will persist despite the availability of effective treatments.

## CONCLUSION

This study demonstrates that parental responses to NNJ are shaped by their level of understanding, recognition of symptoms, previous experiences, family influence, and cultural beliefs. While most parents could identify the visible signs of NNJ, many held misconceptions about its causes, severity, and management. These knowledge gaps, combined with reliance on traditional remedies and emotional barriers often delayed timely medical intervention. The findings highlight the need for targeted and culturally sensitive health education that goes beyond superficial awareness to provide practical guidance on early recognition, risks, and appropriate management of NNJ. Antenatal and postnatal care should integrate clear, consistent messages for both mothers and fathers, while also engaging extended family members who play influential roles in

decision-making. By addressing misinformation, promoting early detection, and reducing fears related to hospital care, healthcare providers can strengthen parental confidence and encourage prompt care-seeking. Ultimately, enhancing parental understanding and fostering timely care-seeking behaviour will contribute significantly to the reduction of NNJ-related morbidity and mortality in Malaysia.

## LIMITATION

This study has several limitations that should be considered when interpreting its findings. First, the study was conducted within a specific geographic setting, which may limit the transferability of its findings to other regions in Malaysia with differing socio-cultural contexts. Second, participant recruitment was undertaken primarily through healthcare facilities, and during the study period only mothers were permitted to visit their infants in the ward. Consequently, the perspectives of fathers were underrepresented, potentially limiting the breadth of parental viewpoints captured. Third, as the data relied on self-reported experiences, there remains a risk of recall bias and social desirability bias influencing the responses. Finally, given the sensitivity of cultural beliefs and traditional practices surrounding the management of NNJ, it is possible that some participants chose not to fully disclose certain practices, thereby limiting the completeness of the data. Despite these limitations, the study provides valuable insights into the factors shaping parental understanding and care-seeking behaviours for NNJ and emphasise the importance of culturally sensitive health education and family involvement in neonatal care.

## CONFLICT OF INTEREST

The authors declare no conflict of interest.

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## AUTHOR CONTRIBUTIONS

**RR@H:** Involved in data collection, initial data entry, and drafting of the manuscript, especially the results and discussion sections.

**LSP:** Contributed to the conception and design of the study, supervised all stages of the research, guided the analysis and interpretation, and led the writing and critical revision of the manuscript.

**SHAH:** Contributed to study design, data analysis, and critical revision of the manuscript for intellectual content.

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