

# What Do Mothers know about Neonatal Jaundice? Knowledge, Attitude and Practice of Mothers in Malaysia

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## INTRODUCTION

Neonatal jaundice is a common condition affecting newborn babies. Two thirds of human neonates develop clinically evident indirect hyperbilirubinaemia in the first few days of life making it the most common clinical condition in the newborn requiring evaluation and management.<sup>1</sup> A survey of government hospitals and health centres under the Ministry of Health, Malaysia in 1998 found that 75% of newborns were jaundiced in first week of life.<sup>2</sup> Quality assurance program has shown that in Ministry of Health, Malaysia facilities, an average of 23.9% (Peninsular Malaysia), 21.2% (Sabah) and 23% (Sarawak) of total live births respectively was diagnosed as hyperbilirubinaemia from 1993 to 1997.<sup>2</sup> Therefore the burden of this condition is significant in our local population. Although a large majority of neonatal jaundice cases recover without sequelae, complications do occur in a minority that is acute bilirubin encephalopathy and kernicterus.

Reemergence of kernicterus had been reported in many countries. Stanley Ip *et al* with the American Academic of Pediatrics Subcommittee on Hyperbilirubinemia review in 2004 found that a total of 123 cases of kernicterus were reported and published.<sup>3</sup> Based on a summary of multiple case reports that spanned more than 30 years, it was concluded that kernicterus, although infrequent, had at least 10% mortality and at least 70% long-term morbidity.<sup>3</sup> Hyperbilirubinemia and kernicterus are reemerging as prominent clinical concerns hypothesized to be secondary to increased breast-feeding rates, early hospital discharges and overall lack of concern for the potential impact of severe hyperbilirubinemia on healthy term newborns.<sup>4</sup> The current practice of discharging mothers and infants 24 to 48 hours following birth, however, results in bilirubin levels peaking at home rather than in the hospital, thus shifting the primary responsibility for early detection and treatment of neonatal jaundice to the postpartum mother.<sup>5</sup> Prompt and effective intervention during the early phases of acute bilirubin encephalopathy can prevent chronic complications of bilirubin toxicity. Therefore it is important for all mothers to have adequate knowledge of neonatal jaundice, its important health implications, complications, treatments and methods of detection so that appropriate treatment is sought early.

Previous studies have shown inadequate knowledge of neonatal jaundice among mothers and community health

workers.<sup>6-9</sup> However these studies were done in different groups of people and in other countries. Some studies in Iran have indicated that many complications in neonates are due to lack of attention, self-treatment, use of inappropriate medicine and lack of confidence on new medications.<sup>8</sup> Studies have also shown that many mothers used medicinal herbs and traditional remedies as treatment for neonatal jaundice.<sup>8,9</sup> It is believed that such practices are also rampant in Malaysia. It would be useful to gain insight on the knowledge and practice of mothers in Malaysia. Therefore this study was designed to assess maternal knowledge and practice on various aspects of neonatal jaundice including recognition, causes, complications, treatment, prevention and to identify maternal factors that influence knowledge of neonatal jaundice. The information obtained can be used to assist health care practitioners in designing educational programs to improve maternal knowledge of neonatal jaundice.

## MATERIALS AND METHODS

### Sample

In this cross-sectional observational study, all mothers whose babies were aged from birth to 28 days of life and admitted to Ward 3D of Hospital Teluk Intan for neonatal jaundice were consecutively enrolled in this study from 1st March to 31st May 2008. Mothers who refused to give consent, did not room in with their babies, mothers who were health care workers and mothers of babies who were previously admitted to this hospital or other hospitals with the diagnosis of neonatal jaundice were excluded from the study. Neonatal factors that required exclusion from the study were babies with conjugated jaundice (direct hyperbilirubinaemia), secondary causes of jaundice and babies readmitted to the hospital.

### Procedure and Measures

Informed consent was obtained prior to enrollment. Data was collected via a self administered questionnaire. Once enrolled in the study, mothers were given a questionnaire form by a doctor in the ward to be filled up. The questionnaire was in English or Malay. Missing information was retrieved by a doctor directly asking the mother concerned. Illiterate mothers were asked directly for the information required. To facilitate understanding of the questionnaire by Chinese or Indian parents who were unable to read either English or Malay, the questionnaire was read out in Chinese or Tamil

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**Table I: Survey responses on person who noted jaundice in baby and action taken by mothers**

Person who noted jaundice and maternal action	Number (Percent)
Person who noted jaundice in baby	
Mother	16 (8.1%)
Relative	6 (3.0%)
Health nurse	159 (80.3%)
Others	16 (8.1%)
Missing info	1 (0.5%)
Action taken if baby is jaundice	
Go to a health worker (including nurses or doctors)	165 (83.3%)
Consult relatives	4 (2.0%)
Go to a traditional healer	1 (0.5%)
Place under sun	22 (11.2%)
Missing info	6 (3%)

**Table III: Mean knowledge score according to maternal factors**

Maternal factors	Mean Knowledge Score Mean (standard deviation)	P value
Mother's age	17.66 (2.97)	0.64
Ethnicity		
Malay	17.90 (2.92)	0.006
Chinese	17.35 (2.65)	
India	16.23 (2.71)	
Others	14.43 (4.20)	
Education		
Primary school or None	16.32 (3.41)	0.067
Secondary school	17.73 (2.98)	
Tertiary school	18.03 (2.56)	
Family Income		
<1000	17.48 (3.15)	0.682
1000-2999	17.74 (2.96)	
3000 and above	18.04 (2.52)	
Parity		
1	17.22 (2.89)	0.741
2-5	17.74 (3.10)	
>5	17.75 (2.93)	
Previous child with jaundice		
Yes	17.99 (3.11)	0.124
No	17.30 (2.92)	
Education by health care workers		
Yes	17.78 (3.13)	0.344
No	17.78 (3.13)	
Home visits by health staff		
Yes	17.56 (3.06)	0.945
No	17.52 (2.68)	

P significant at <0.05

**Table II: Survey responses on mother's knowledge of neonatal jaundice**

Maternal knowledge	Number of mothers answering correctly (Percent)
Checking baby for presence of jaundice	
Skin	188 (95.4%)
Eye	179 (90.9%)
Palms and soles	109 (56.2%)
Urine	100 (51.5%)
Faeces	108 (56.0%)
Causes of neonatal jaundice	
Breast feeding	142 (72.4%)
Breast milk	60 (30.9%)
Prematurity	92 (47.7%)
Infection	108 (55.7%)
Herbal medicine	97 (50.0%)
G6PD deficiency	84 (43.5%)
Complications of neonatal jaundice	
Kernicterus	141 (71.2%)
Fits	115 (58.1%)
Mental retardation	161 (81.3%)
Deafness	85 (42.9%)
Death	131 (66.2%)
Physical handicap	108 (54.5%)
Effective treatment for NNJ	
Phototherapy	186 (93.9%)
ET*	90 (45.5%)
Both	87 (43.9%)
Knows method of prevention	
Yes	18 (9.1%)
No	113 (57.1%)
Unanswered	67 (33.8%)

\*ET – exchange transfusion

respectively by a native speaker. Communication between participants was prohibited when filling up the questionnaire. Any doubts regarding the questionnaire could be clarified with the doctor in charge. Doctors involved in retrieving missing information or reading out the questionnaire to mothers unable to read the questionnaire were trained for this purpose.

The questionnaire consisted of 20 questions investigating knowledge, attitude and practice of mothers relating to neonatal jaundice (of indirect hyperbilirubinaemia type) as well as socio-demographic data. The questionnaire contained a full range of response options designed to identify the mother's knowledge, attitude and practice on neonatal jaundice. The first part of the questionnaire obtained socio-demographic data of the participants including age, ethnicity, parity, educational level and occupation. Question 19 is specifically aimed to determine the attitude and practice of mothers with respect to neonatal jaundice. Question 14 to 18 were designed to assess knowledge of mothers regarding recognition, causes, complications, treatment and prevention of neonatal jaundice. Question 14 to 17 had multiple correct answers. Each correct answer was given 1 mark. Wrong answers or no answer were not given any marks. The marks obtained for each question were totaled to give a maximum

score of 33 while the minimum was 0. The questionnaire was pilot tested on health care workers and 20 mothers to determine any difficulties or errors in the questionnaire. A copy of the questionnaire is in Appendix 1.

This study had received ethics approval from Ministry of Health Malaysia Research & Ethics Committee. (NMRR-08-326-1481)

#### Analysis

A sample size of 104 mothers was required to detect a difference of 5 in knowledge score between groups, with 90% power and a p value of less than 0.05 was regarded as statistically significant.

Data was analyzed using Statistical Package for the Social Sciences (SPSS) programme version 13. Descriptive analysis of percentage, mean and standard deviations were used. Statistical analysis was carried out using univariate analysis of variance and general linear model to compare means and identify factors influencing knowledge of mothers in various aspects of neonatal jaundice namely method of checking for jaundice, causes, complications, treatment and prevention.

## RESULTS

A total of 198 mothers (response rate 83.2%) consented to participate in the questionnaire out of 238 eligible mothers. 5 refuse to give consent for undisclosed reasons, 18 were not approached to participate in the study due to oversight by the attending doctor, 4 could not answer the questionnaire and could not understand any of the interpreters due to language barrier and 13 mothers were not rooming in with their babies.

#### General Characteristics of study population

More than half (59.1%) of the mothers were aged between 25 to 34 years old. The mean ages of mothers were  $29.1 \pm 5.6$  years. Most of the mothers were Malays (75.3%) followed by Chinese (14.6%), Indians (6.6%) and others 3.5% and this reflected the socio-demographics of the area where this study was conducted.

A large proportion of the mothers were multiparous with 61.6% having 2 to 5 children and 8.1% having more than 5 children. More than half of the mothers surveyed (55.6%) did not have previous children with neonatal jaundice. Most mothers were educated with at least secondary school education (85.3%) with 14.6% having tertiary school education. Approximately half of the mothers were housewives (53.0%) while 40.4% were working with more than two thirds of those mothers working being in the private sector. The mean family income among majority of mothers was less than RM3000 (83.3%).

An admirable proportion of mothers surveyed were breast feeding exclusively (81.8%) with 3 mothers (1.5%) bottle feeding only while the rest (16.7%) mothers gave breast feeding and bottle feeding to their babies. Almost all mothers have heard of neonatal jaundice (94.9%) but only around half (57.6%) were educated on neonatal jaundice by health staff despite a high percentage (85.9%) being visited at home by health staff.

Most mothers had informed the nearest health clinic regarding the birth of their babies (87.9%) as it was a normal practice in Malaysia. Although most mothers will bring their babies to a health care worker if noted jaundice (83.3%), a large proportion (11.2%) mothers will place their babies under the sun if jaundiced. Only 16 (8.1%) mothers noted jaundice in their babies. Most (80.3%) depended on a health nurse to detect jaundice in their babies. (Table I)

The findings on mother's knowledge of neonatal jaundice are shown in Table II. On questioning mothers of methods of checking a baby for presence of jaundice, 103 (52.0%) chose all three correct options namely a - by looking at skin, b - by looking at eyes and c - by looking at palms or soles. Only one mother was not able to identify a single correct method of looking for jaundice. However about half of mothers who identified all three correct methods wrongly thought that looking at urine or stools of babies were correct methods of detecting NNJ.

Only 16 (8.1%) of mothers were able to identify all the correct causes namely breast feeding, breast milk, prematurity, infection in blood, herbal medicine and G6PD deficiency. On the other hand, 103 mothers (52.0%) erroneously chose their food intake as a cause of neonatal jaundice while 71 (35.9%) thought that neonatal jaundice was inherited from mothers. 48 (24.2%) and 71 (35.9%) mothers respectively wrongly chose drugs and conditions during pregnancy as causes of neonatal jaundice. Three mothers were able to suggest an additional cause of neonatal jaundice namely mothers with blood group O and difference between blood group of mothers and babies.

Regarding complications of neonatal jaundice, 44 (22.2%) mothers were able to identify all six complications of NNJ namely kernicterus, convulsions, mental retardation, deafness, death and physical handicap. Most mothers (93.9%) knew that phototherapy was an effective treatment for NNJ while 87 (43.9%) mothers mentioned both photo therapy and exchange transfusion. However 144 (72.7%), 111 (56.1%), 33 (16.7%), 55 (27.8%) and 28 (14.1%) erroneously thought that sunlight, goat's milk, drugs, herbal medicine and traditional healer respectively were effective treatment for neonatal jaundice. Very few mothers knew methods of preventing jaundice in their babies. One third left this question unanswered. There were twelve mothers who suggested putting babies under sunlight while eight suggested traditional medicine or traditional methods. Nine suggested phototherapy or ultraviolet light. Two suggested goat's milk, one suggested healthy diet while another two suggested avoiding spicy food. There was one mother who suggested a dangerous method of pressing the baby's chest. Only twenty three mothers suggested a correct method of prevention which is breast feeding frequently. (Table II)

From table III, it can be seen that the mean knowledge score of mothers is 17.58 out of 33 with standard deviation 3.01. The minimum score of the valid responses is 8 while the maximum is 24 out of total of 191 valid responses. Using univariate analysis of variance it is found that mean knowledge score has no relationship with age, family income, parity, having previous children with neonatal jaundice, education of mothers by health staff and home

visits by health staff. Only ethnicity has a significant association with mean knowledge score of mothers. (Table III) However if we include all variables into general linear model, no variable is significant.

## DISCUSSION

This study reveals that participants have some knowledge on various aspects of neonatal jaundice. However there are still many misconceptions on neonatal jaundice. All but one mother seemed to know methods of detecting jaundice theoretically but only 8.1% of mothers were able to recognize jaundice in their own babies. Most mothers (80.3%) relied on health nurses to detect jaundice in their babies. About a tenth of mothers intended to place their babies under the sun if noted to be jaundiced. This is dangerous as not only will it delay treatment but prolonged sun exposure may cause harm to babies.<sup>10</sup> Misconceptions on benefits of sunning babies have been revealed in other studies. A study by Harrison *et al* showed that thirty-six per cent of post-partum mothers were in favour of using sunlight to treat neonatal jaundice.<sup>11</sup> What is more worrying is that in most cases, advice to mothers to sun their baby had been given by a midwife/nurse (41%) or a doctor/paediatrician (28%). Another survey done in Singapore also showed that 50.5% of parents thought that putting babies under the sun helps to prevent jaundice.<sup>6</sup>

There is still inadequate knowledge of causes of neonatal jaundice similar to other studies.<sup>8</sup> Most mothers still mistakenly attributed neonatal jaundice to food, drugs and conditions during pregnancy or inheritance from the mother. There were only 84 (42.4%) mothers who knew that G6PD (glucose-6-phosphate dehydrogenase) deficiency is a cause of neonatal jaundice despite the high prevalence of G6PD deficiency in our Malaysian population. However this is better than in Singapore where a recent study done among prospective first-time parents mainly indicated only 15.1% of those surveyed knew that G6PD deficiency is an important cause of neonatal jaundice while 69% have never heard of G6PD.<sup>6</sup>

Neonatal jaundice is a common condition that can lead to severe complications namely its long-term neurodevelopmental consequences (kernicterus). In Malaysia quality assurance program of Ministry of Health has revealed incidence of kernicterus to be 0.032% among cases of neonatal hyperbilirubinaemia.<sup>2</sup> However the incidence of kernicterus may not reflect the true situation due to under reporting. Only 44 (22.2%) of mothers were able to identify all six complications namely kernicterus, convulsions, mental retardation, deafness, death and physical handicap. Fortunately most mothers could identify at least one complication and only 2 mothers thought that there were no complications of neonatal jaundice. Lack of knowledge of complications of NNJ could lead to mothers mistakenly thinking that neonatal jaundice is not dangerous and influence their action taken.

Effective treatment of severe neonatal jaundice includes phototherapy and exchange transfusion. There is a degree of morbidity and mortality associated with exchange transfusions, mortality ranging from 0.4 - 10.6%, and

morbidity ranging from 6.7 - 20.4%.<sup>12</sup> A vast majority of mothers (93.9%) knew that phototherapy was an effective treatment. However a large proportion erroneously thought that sunlight, goat's milk, drugs, herbal medicine and traditional healer respectively were also effective treatment for neonatal jaundice. This is worrying as this implies that mothers may choose an ineffective treatment for their babies afflicted with neonatal jaundice. Only twenty three mothers were able to suggest a method of prevention of neonatal jaundice which is breast feeding frequently while some suggested unproven and even dangerous methods such as putting babies under sunlight, traditional medicine, traditional methods, goat's milk, healthy diet, avoiding spicy food and pressing the baby's chest.

The mean knowledge score of mothers on neonatal jaundice had no relationship with age, ethnicity, family income, parity, having previous children with neonatal jaundice, education of mothers by health staff and home visits by health staff. Surprisingly there was no relationship between mother's age, parity and having previous children with neonatal jaundice with maternal knowledge of neonatal jaundice. This is in contrast to a study in Iran that showed maternal knowledge on neonatal jaundice had a significant association with history of neonatal jaundice, mother's age and child's birth rank.<sup>8</sup> there was also no relationship between ethnicity, family income, education and home visits by health staff with maternal knowledge of neonatal jaundice. This could be due to inadequate knowledge of health staff themselves in neonatal jaundice or the methods of imparting their knowledge may have been ineffective. A study done in Nigeria shows that primary health care workers may have inadequate knowledge and misconceptions on neonatal jaundice.<sup>13</sup> So far no study has been done among primary health care workers in Malaysia and it would be interesting to look into this aspect.

We recognised that there were some limitations to our study. There was a selection bias as the sample mothers surveyed included only mothers with babies admitted for idiopathic neonatal jaundice and rooming in with their babies and may not reflect true knowledge of all mothers. A number of foreign-language speaking mothers were not included as they could not understand English, Malay, Chinese or Tamil which are the main languages used in Malaysia and no interpreters could be found for them. The study was also limited by the design of the questions which only have yes or no answers that could lead to guessing of answers by mothers.

## CONCLUSION

In conclusion this study did not reveal any factor that could affect maternal knowledge of neonatal jaundice. However there are still a lot of misconceptions regarding neonatal jaundice among mothers even though they have been educated by health staff. Therefore it is important that more emphasis is made on educating mothers on this common but potentially serious condition. Perhaps the knowledge of health staff or methods that health staff used to convey information to mothers should be looked into. We would like to propose another study to assess health staff knowledge on various aspects of neonatal jaundice.

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