HOW WELL DO MOTHERS UNDERSTAND WHY THEIR NEWBORN IS HOSPITALIZED?

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ABSTRACT

INTRODUCTION: Maternal knowledge about serious infant illnesses has significant implications for care after discharge, particularly in countries with high infant mortality rates. No existing studies on this topic in low income countries were identified. The study sought to identify the level of maternal understanding about why a newborn was hospitalized and how mothers attributed blame for the illness.

MATERIAL AND METHODS: We conducted semi-structured interviews with mothers aged 18 and older who had infants hospitalized in a tertiary care facility in Universal College of Medical Sciences, Bhairahawa, Nepal and collected data on demographics, pregnancy and delivery, and beliefs about their infant's illness. Infant charts were abstracted to identify medical reasons for hospitalization for comparison with the mother's understanding, and levels of understanding were coded as 'none', 'partial' or 'full'.

RESULTS: One hundred and fifty three mothers were interviewed and their average age was 28. For 27%, this was their first pregnancy. Forty per cent of mothers had no understanding of why their infant was in the hospital and 28% had only partial understanding. One-third of the women reported blaming themselves for the child's illness. In multivariable analysis, demographic factors including maternal age, education, primiparous status, and urban vs rural residence did not predict maternal understanding or self-blame.

CONCLUSIONS: Sick newborns in low-income countries are at very high risk of adverse outcomes. Mothers who lack a clear understanding of why their infant is in the hospital might have difficulty communicating preferences about care, understanding the type of care that is being given, and recognizing future warning signs of illness. Such gaps in understanding could put the discharged infant at significant risk.

KEYWORDS:Developing countries; Infant health; Infant mortality; Patient-provider communication; Self-blame

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INTRODUCTION

It is not known how well mothers in low-income countries understand the reasons why their sick infant is hospitalized after delivery. Sick newborns are at greater risk of adverse outcomes both in hospital and after discharge.[1] However, mothers without clear understanding of why their infant is in the hospital might have difficulty communicating preferences about care, understanding the type of care that is being given, internalising the gravity of the situation, and recognizing future warning signs of illness after discharge.[2] Many hospitals in low-income countries struggle with heavy patient volumes, high acuity of patient illnesses, and inadequate numbers of trained healthcare providers.[3] The workload and severity of illnesses minimizes the time health-care providers can spend communicating with and educating parents of hospitalized infants. In addition, parents in low income nations have varying levels of education, might have minimal experience with hospital-based care, and might be unfamiliar with newborn illnesses.[4]

Cultural norms may also predispose parents to limit their questions and defer to health-care providers for decision-making.[5] Such a setting is ripe for misunderstandings, lack of awareness, and confusion on the part of parents whose infants are ill. While some research in high-income nations describes maternal self-blame when a child is ill, little is known about whether mothers in low-income countries blame themselves when their newborn is hospitalized and how they attribute the underlying cause of illness. Since hospitalization of a newborn is generally a stressful event for all parents and hospital experiences may affect care of the infant after discharge, it is important to understand how parents conceptualize the illness, their role in it, and their sense of culpability.This research is aimed to address some of these critical gaps in the literature. Using a hospital-based sample of mothers with hospitalized newborns, the study sought to (i) identify the degree to which mothers could articulate why their newborn was in the hospital; (ii) identify the degree of concordance between the mothers' reports of cause of admission and the infant's medical record; and (iii) explore maternal beliefs about self-blame for the infant's illness and hospitalization. Understanding parental perspectives about their hospitalized infants is an important step to enhancing support for parents and improving the health of high-risk newborns in low income nations. In Nepal, no such study is found till date.

MATERIALAND METHODS

The study was conducted from March to June 2015 at Universal College of Medical Sciences Teaching Hospital (UCMS), Bhairahawa, Nepal. UCMS is a tertiary care hospital affiliated with Tribhuvan University. UCMS contains a Mother and Baby Unit (MBU) which cares for approximately 3600 newborn infants, 1800 babies needing intensive care each year. The mothers aged >18 years with infants hospitalised in the MBU were interviewed. Interns and Residents identified patients who were on the unit, available for interviewing (not actively engaged in infant care), and willing to participate. Members of the team asked women if they were interested in participating in a short survey and obtained informed consent, either verbal or written based on maternal literacy. The team conducted semi-structured interviews with the mothers.

Women were asked questions consisting of a mix of open-ended questions and short-answer responses with follow-up probes, when appropriate. To assess maternal understanding of cause of hospitalization, interviewers asked 'Why did the doctors and nurses tell you that your baby is here?' If the mother reported that she had not been told anything, she was asked 'Why do you think your baby is here? What do you think is wrong?' Follow-up questioning enquired whether the mother believed what she was told was the real problem or if she believed something else or felt she was not being told the real answer. Data from the infant's chart was recorded, when available, to identify the medical reason for hospitalization for comparison with the mother's understanding. For the questions about self-blame, each mother was asked if she thought she had done something which might have made the infant sick. If yes, follow up questions sought to help the mother articulate what she might have done. Mothers were specifically asked whether evil spirits or “Saato” (a term used in Nepal to represent evil spirits) might have contributed to the sickness, as well as whether or not a\doctor or nurse had said something to make her feel she was to blame.

All responses from the mothers were reviewed and initial coding was conducted. The research team met regularly throughout the analysis phase to identify the important themes which emerged from the mothers' responses and potential relevant codes, which were assembled in a preliminary codebook. Subsequent study was focused on discussing, comparing and reconciling any incongruence in coding. The codebook was revised and all the maternal answers were revisited a final time to ensure consistency with the final set of codes.

We developed a rating system to evaluate the degree of concordance between maternal reports of why the infant was sick and the medical records. Maternal responses were grouped into three categories: (i) no understanding of the

medical reason (for example, the mother said 'I don't know' or 'The baby is sick'), (ii) partial understanding (for example, the mother said the newborn was premature but did not mention that it also had sepsis and jaundice), or (iii) the mother had a full or general understanding (for example, the mother indicated that the infant was born with a back problem and needed surgery when the medical diagnosis was spina bifida).

As the data included concise statements or summaries from the mother, summary statistics were calculated to identify how frequently different themes were raised. For the level of agreement between maternal understanding and chart data, bivariable analysis was undertaken using the x2 test to determine significant differences across descriptor variables, and then multinomial logistic regression was performed using maternal age, residence, level of education, and first vs other pregnancy. For the self-blame variable bivariable analysis was done using the x2 test (coding self-blame as yes or no) to compare self-blame with the descriptor variables (maternal age, residence, level of education, and first vs other pregnancy).Multivariable logistic analysis with selected variables was used to determine which factors were most strongly associated with maternal self-blame.

RESULTS

A total of 153 mothers with a newborn hospitalized in UCMS teaching hospital were interviewed (Table 1). Mean (SD) age was 28 (6) years, slightly more than one quarter had just completed their first pregnancy, and three-quarters had been pregnant before. Educational level varied: a third of women reported none or only primary education, 40% reported completing middle school, and a quarter had attended secondary school or higher.

Table 1: Demographic variables

Variables	n(%) Total= 153
Maternal age,mean [SD)	28(6) y
Residence	
Urban	103(67)
Rural	50(32)
Education	
None or primary level	53(35)
Middle school	61(40)
Secondary school or above	39 (25)
First pregnancy	42 (27)
Delivered in a hospital settin	146 (95)
Infant age at interview, mean (SD)	15 [18] days
Infant age at interview, range	1–47 days

Mothers were asked about the reason their infant was in the hospital . The most common answers were prematurity, infection and breathing problems (Table 2). While only 9% of mothers reported that they did not know or had not been told the reason, a large number described vague or non-specific reasons for hospitalization such as that the infant was sick, did not cry at birth or simply needed to be in hospital because of the level of care available there.

Table 2: Maternal belief about reason newborn was hospitalized (multiple answers allowed so total is >100%

	Maternal belief	n (%) Total n=153
1	Prematurity or small infant	27 (18)
2	Infection or fever	24 (16)
3	Breathing or respiratory problems	22 (14)
4	Jaundice	18 (12)
5	Other specific visible symptom	18 (12)
6	Infant is sick (non-specific)	19 (12)
7	Problems with eating/stooling/urination	14 (9)
8	I do not know or was not told	14 (9)
9	Congenital abnormalies	12 (8)
10	Infant did not cry	11 (7)
11	Sickness requiring hospital resource or procedure	9 (6)
12	Weakness	7 (5)
13	Complication from caesarean or vacuum delivery	5 (3)
14	Premature rupture of membranes	2 (1)

The study also compared mothers' understanding of her newborn's illness with the reason recorded in the medical chart; charts were available for 140 of the 153 cases (92%). Maternal understanding was categorized as none, partial or full (Fig. 1).

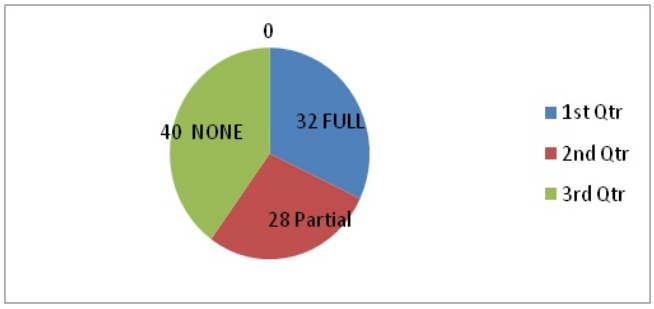

Figure 1: Level of agreement between maternal knowledgeof why the infant is hospitalized compared with chart documentation (in 140/153 cases for whom chart was available

Four in 10 mothers had no understanding of why their newborn had been hospitalized and three had only partial understanding. Only three in 10 appeared to have full understanding of the basic reason for hospitalization (Table 3). The team next evaluated maternal understanding using demographic covariates (maternal age, rural vs urban residence, maternal education, primiparous vs multiparous)

and days of hospitalization, but none of these variables was a significant predictor for maternal understanding.

Table 3: Medical chart diagnoses associated with infant admission (multiple answers allowed so total is 100%)

	Medical chart diagnoses	n (%) Total n=153
1	Sepsis or infection	55 (36)
2	Prematurity	40 (26)
3	Asphyxia	26 (17)
4	Respiratory distress	25 (16)
6	Low birthweight/growth-restricted	16 (11)
7	Congenital anomalies	15 (10)
8	Jaundice	14 (9)
9	Miscellaneous (e.g. abdominal distension, failure to cry, poor weight gain)	13 (9)
10	Premature rupture of membranes	12 (8)
11	Vomiting	4 (3)
12	Seizures	3 (2)
13	Meconium aspiration	3(2)

The analysis sought to identify maternal attribution of illness and to assess whether mothers blamed themselves for their infant's sickness. Two-thirds of women clearly stated that they had no role in their child's illness and did not blame themselves. Nearly a third of women reported self-blame for diverse reasons (Table 4).

Table 4: Maternal attribution of self-blame (total n=153) (multiple answers allowed so total is >100%)

	Maternal belief	n (%)
1	No, not at all (general)	102 (67)
2	No, not at all because God is in charge	1 (1)
3	Yes, no specific reason given	12 (8)
4	Yes, a health-care provider told me so	6 (4)
5	Yes, a family member told me so	4 (3)
6	Yes, because of medicine, herbs, or something I ate	3 (2)
7	Yes, because I was sick during pregnancy	5 (3)
8	Yes, because I did not take prenatal vitamins	1 (1)
9	Yes, because I fell when pregnant	2 (1)
10	Yes, because I performed strenuous work or worked too hard during pregnancy	4 (3)
11	Yes, because of marital or emotional problems	3 (2)
12	Yes, because of my delivery complications	3 (2)
13	Yes, because I did not feed the infant well or had breastfeeding or burping problems with the infant	3 (2)
14	Yes, because I travelled with the infant	1 (1%)
15	Yes, because I exposed the infant to cold or outdoors	4 (3%)
16	Yes, because of something I gave the infant to eat or take	2 (1%)
17	I do not know	4 (3%)

For example, 8% reported self blame but did not provide further explanation. Seven percent indicated that a health-care provider or family member had told them they were to blame. The remainder attributed the cause to behaviour or things they had done, or should not have done during pregnancy or after delivery.Three percent of women reported that they did not know whether they carried any blame for the illness. To assess the role of spiritual causes of illness, women were asked specifically whether they attributed their child's illness to evil spirits, but 93% of mothers denied this was a factor.

In bivariable analysis, self-blame was not significantly related to maternal age, rural vs urban residence or education. Multiparous women were significantly more likely than primiparous women to blame themselves. In multivariable logistic regression, none of the variables was significantly associated.

DISCUSSION

As far as we know, this is the first study in our country to evaluate parental understanding of why their sick infants are hospitalized. The findings show that 40% of mothers had no knowledge of the reason for their infant's hospitalization, and another 28% had only partial understanding. Just 32% of mothers demonstrated clear understanding of the reason, determined by comparing maternal reports with the infant's medical record. Newborns in general are a high-risk population, and those who are sufficiently sick to be hospitalized have high rates of morbidity and mortality. For example, 21% of infants in the baby unit in UCMS do not survive to discharge.[7] Substantial research in low income countries has demonstrated that parents often fail to recognize and seek treatment for 'red-flag' warning signs of serious illness in newborns.[4,8,9] Infants in the Neonatal Unit may be particularly vulnerable to recurrence of the illness or complication which led to admission, but parents who lack an understanding of why their child was admitted to the hospital are unlikely to detect early warnings signs or symptoms of disease after discharge.

The mothers in this study frequently identified a visible symptom (e.g. a sore on the umbilicus, abdominal distension or the baby not being able to open his eyes) as the reason for admission, regardless of whether it was the medical concern noted in the hospital chart. While few mothers specifically reported that they were not told the reason for admission, queries indicated that a far greater number had only a vague or erroneous understanding. This lack of knowledge raises important questions about communication regarding the child's illness.

A significant barrier to communication between mothers and health-care providers is the sheer number of patients treated by a small cadre of physicians and nurses. This problem is not unique to this study site but is faced by most hospitals in low income countries.[10] Nepal has an overall doctor patient ratio of about 1:17,000, with ratios better in urban areas than in rural

ones.[11] To put such a number in perspective, in the United States, the ratio is approximately 24:10,000.[12] The lack of personnel places substantial burdens on the medical staff who must care for an overwhelming number of patients with very limited resources.

There are also huge cultural differences globally in the amount of information patients and parents expect to be given by medical personnel as well as in the relationships between physicians and patients. Studies in South Africa and India have reported that families received little information from health-care providers about diagnoses or even causes of death.[13,14] In addition, many women have limited education and literacy, and might not know the right questions to ask about their child's illness. In low-resource nations, patient education is not always a significant part of prenatal and delivery care so women may be accustomed to having little information about their own health care.[10,15] Two articles from Nigeria discuss the role of physicians as all powerful and all-knowing, and a culture of providing limited information to patients, which might be accepted by patients and families.[16,17] While patients in Nepal value strong patient-provider relationships, particularly support from providers, not all place high value on communication.[18]

Physicians typically have very high social status in low-income countries, so it may be intimidating for a patient with limited education and social status to ask questions. Even in high-income countries, many parents lack information about their child's illnesses.[19] In addition, a woman may not be the primary decision-maker for her child, and this fact may limit her efforts to seek information and the physician's efforts to educate her. It was surprising to find that even when her infant had been hospitalized for a longer period, a mother's understanding of the reason for it was not improved..[20] However, given that this population was slightly better educated than the population of women as a whole, this further heightens concern about the lack of understanding of illness.

It is noteworthy that only 7% of women reported that evil spirits contributed to the infant's illness. It is quite common in this region of Nepal for women to consider pregnancy to be a vulnerable time when they are at greater risk of all sort of evil effect .[21] It is possible that such beliefs are more commonly held in rural areas and are less likely to be reported by patients in an urban hospital; it is also possible that more women held these views but did not feel comfortable admitting to them during the interview. Data in Nepal certainly indicate that many women who use spiritual healers or herbs do not report them to health-care providers during pregnancy.[21]

About a third of mothers blamed themselves for their child's illness. This figure is similar to studies in high-income countries which have assessed parental self-blame for neonatal illness.[22,23] Furthermore, some studies suggest that, rather than self-blame being problematic for parents, it might actually be an adaptive response. In studies in which parents attributed blame to their own behaviour or characteristics, they were less likely to be depressed; researchers have hypothesized that these parents might be more likely to feel that they had some control over prevention of the problem in a subsequent pregnancy.[22,23] In contrast, women in these studies who blamed other people (usually physicians) were more likely to be angry and depressed. It is not clear whether self-blame has different impacts in different cultural groups, and this deserves further study. In future research, the team will follow up with the mothers in this study to evaluate longer-term mental health outcomes and to test the effect of self-blame.

As in all studies, this research has a number of limitations. Firstly, for logistical reasons, the study obtained a convenience sample which might not represent all mothers of sick infants at this hospital. Secondly, the sample size was relatively small so results should be interpreted accordingly. Thirdly women perceived by the nurses to be more receptive to the study or who spoke Nepalese might have been recruited in higher numbers. Fourthly women may not have felt comfortable sharing all their beliefs, particularly if they held views which they thought would be stigmatized or dismissed in a health-care setting. Finally, this study was cross-sectional, and longitudinal studies are critically needed to identify how maternal knowledge during hospitalization affects post-birth outcomes.

Most mothers of sick infants in a tertiary hospital in Nepal had low levels of comprehension of why their infant was hospitalized, others having none or only partial understanding. Given that infants who survive to discharge generally will have higher health risks than the average newborn, this is concerning, and it is not clear whether parents will know what warning signs to watch for after discharge. Only about one-third of mothers blamed themselves for the child's illness and a very small proportion blamed evil spirits. These results generally raise significant concern about hospital communication of infants' medical conditions, and further work is needed to understand the barriers faced in educating parents about their newborn's illness.

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