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# OVERCOMING VOIDS IN COMMUNICATION AND DECISION MAKING AMONGST CARETAKERS AND HEALTHCARE PROVIDERS IN THE NICU

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#### ABSTRACT

**Introduction:** Parents' need for communication, is not always met by the NICU staff, and when parents feel dissatisfied with their communication with the staff, their stress and anxiety increase and they find it more difficult to establish a close relationship to their child. This study focuses on the deficiencies and obstacles faced by the primary care takers of the neonates admitted in the NICU and the treating doctors.

Materials and methods: The aim of the study was to identify issues leading to discordant relationship between the caretakers of the patient and health care providers in the NICU.A time bound observational study was done over a period of 38 days at the neonatal intensive care unit of A.J. Institute of Medical Sciences, Mangalore. Parents as well as doctors rated their experiences of communication and stay in the NICU through a questionnaire delineating good interpersonal relations between the doctor and the patient.

**Results:** A convenience sample of 47 caretakers and 25 doctors agreed to participate in the study. Data collected from the caretakers consisted of 72 completely filled questionnaires. Significant problem areas for the caretakers were found to be regarding the visitation timings in NICU and their involvement in decision making while amongst the doctors it was found to be the lack of security and non-availability of a social worker.

**Conclusion:** Our study shows that there are many areas in which we can improve ourselves in order to avoid discordant relationship between doctors and patients.

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## **INTRODUCTION**

The health care system today is complicated, competitive and market-driven. Hospitals in our country are facing many challenges to define and measure quality in terms of "customer satisfaction". Patient satisfaction, which could be defined as the perception of the patients' needs and expectations being met by the care providers, is rapidly becoming a primary indicator for evaluation and comparison of quality in health care plans.

Parents' need for communication, is not always met by the NICU staff, and when parents feel dissatisfied with their communication with the staff, their stress and anxiety increase and they find it more difficult to establish a close relationship to their child.

Incidents of violence against doctors in the Indian subcontinent have increased in the last few years. Most doctors in India are concerned about their safety at work. More than 75% of doctors face violence during their practice. Almost half of the violent incidents occur in critical care units.

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Majority of the issues arise due to lack of communication between the caretakers/parents and the doctors. There has been a recent call for more research on trust in the health care system, which the authors argue, is required to 'understand, protect and restore' public trust in the health care system.<sup>1</sup>

This study focuses on the deficiencies and obstacles faced by the primary care takers of the neonates admitted in the NICU and the treating doctors.

## **MATERIALS AND METHODS**

The aim of the study was to identify issues leading to discordant relationship between the caretakers of the patient and health care providers in the NICU. The main objectives included studying the pattern of parental behaviour when their infant is admitted in the NICU, understanding the caretaker's perception of adequate health care support and finding the obstacles faced by the health care providers in providing optimal health care. From this, we hoped to promote and develop a cordial relationship between the caretakers and health care providers.

## Study Design

Parents as well as doctors rated their experiences of communication and stay in the NICU through a questionnaire. The questions in the questionnaire were based on articles<sup>2,3</sup>

delineating good interpersonal relations between the doctor and the patient. The questionnaire was further approved by a psychologist and a neonatal intensivist. The questions were divided into 4 domains for the patients namely: interpersonal relationship, parental involvement in treatment, competency of treating doctors and services by hospital. For the treating doctors, questions were in 4 domains namely: Interpersonal relationship, parental involvement in treatment, background of the caregivers and services by the system. They were

## Setting

A time bound observational study was done over a period of 38 days at the neonatal intensive care unit of A.J. Institute of Medical Sciences, Mangalore which treats around 2500-3000 newborns per year including extreme preterms and critically ill infants referred from neighbouring hospitals. During morning working hours, 4-5 doctors including 1 neonatal intensivist, 1-2 pediatric consultants and 2-3 pediatric residents work at the NICU in the form of 2 12 hour shifts. From 6 p.m. to 8 a.m., 1-2 residents who are on-call in house will attend to the NICU patients.

#### **Participants**

Parents of NICU patients were invited to participate in the study towards the end of the newborn's NICU stay, a day prior to being shifted to ward/discharged. Either parents or concerned caretakers of same family were given the possibility of filling in the questionnaire. An informed consent was obtained from all those who agreed to participate.

Doctors invited to participate in the study included consultants in the Department of Pediatrics as well as the residents working in the NICU.

## Data collection

Parents were asked to complete the questionnaire consisting of 22 questions about their experiences of communication with doctors and their overall experience in the hospital. Similarly, consultant paediatricians, residents and intensivists treating patients admitted to NICU were given a questionnaire consisting of 19 questions about their experience in counselling the caretakers and managing NICU babies. Initially the questionnaire collected demographic data of parents and doctors. The questionnaire for the parents also asked questions about the educational status and occupation of the parents filling the form.

### Statistical analysis

Data was tabulated using the SPSS version 22.0.0.0 software and paired data were analysed using chi square tests. A p value ≤0.05 was considered to be statistically significant.

### **RESULTS**

A convenience sample of 47 caretakers and 25 doctors agreed to participate in the study. Data collected from the caretakers consisted of 71 completely filled questionnaires. Demographic data collected included gender, age, education and occupation of the caretakers. The mean age was found to be 31.24 years with a standard deviation of 6.52. The data collected as depicted in Table 1 showed no significant differences (p value = 0.37, 0.5, 0.08) in the gender, age and education status of the caretakers, while it was found that all the mothers considered were homemakers (p = 0.001). Table 2 and 3 show the caretaker's and the doctor's perception based on the

questionnaire provided to them. It revealed that although the doctors encouraged an environment to bond with their baby (p = 0.45, 0.55), the caretakers have satisfactorily explained about the visitation timings (p = 0.03). The caretakers felt that their doctors were competent enough to handle their newborn and were satisfied with the counselling by the treating doctors. Doctors felt they involve the parents in the decision making of their baby as required. The doctors questionnaire mainly revealed a lack of presence of social worker during their counselling sessions and a lack of security as their main concerns.

Table 1 Patient characteristics

Characteristics	N	Percentage (%)
Gender		
Male	20	43.4
Female	27	56.6
Age		
20 – 29 years	22	47.8
30 - 39 years	23	48.9
40 – 49 years	2	3.3
Education		
Graduate or post graduate	8	17.3
Intermediate or post high school diploma	14	30.4
High school certificate	20	43.4
Middle school certificate	8	8.9
Occupation		
Profession	4	8.6
Semi-profession	6	13
Clerical/Shop owner	8	17.3
Semi-skilled worker	7	13.3
Unemployed/Homemaker	22	47.8

Table 2 Caretaker's Perception

	Positive Response % (n)	Satisfactory Response % (n)	Negative Response % (n)	p value			
D	Domain 1 – Interpersonal Relationship						
Clarity of neonate's condition	68 (32)	32 (15)		0.9			
Written consent	63.8 (30)	36 (17)		0.54			
Empathy of doctors	65.9 (31)	34 (16)		0.46			
Domain 2 – Parental Involvement							
Encouragement to	46.8 (22)	48.9 (23)	4.25 (2)	0.45			
bond with the baby	51 (24)	48.9 (23)	4.25 (2)	0.55			
Restriction of visitation	40.4 (19)	59.5 (28)		0.05			
Domain 3 – Competency Of Doctors							
Competency of doctors	78.7(37)	21 .2(10)		0.05			
Counselling skills	85.1 (40)	14.89 (7)		0.04			
Accesibility of doctors	55.3 (26)	44.6 (21)		0.74			
Domain 4 – Services By The System							
Overcharging	27.6 (13)	65.95 (31)	6.3 (3)	0.09			
Transparency of expenditure	46.8 (22)	53 (25)		0.80			

Table 3 Doctor's perception

	Positive Response % (n	Satisfactory ) Response % (n) l	Negative Response % (	p n) value				
Response % (n) Response % (n) Response % (n) value  Domain 1 - Interpersonal Relationship								
Respect of caregivers	36 (9)	64 (16)		0.89				
Need for daily counseling	84 (21)	12 (3)	4(1)	0.95				
Domain 2 - Parental Involvement								
Involvement in decision-making	40 (10)	60 (15)		0.05				
Restriction of visitation	8 (2)	88 (22)	4(1)	0.03				
Domain 3 - Competency Of Doctors								
Internet influence	56 (14)	52 (13)	12 (3)	0.70				
Influence of	56 (14)	44 (11)		0.88				

educational						
background						
Domain 4 - Services By The System						
Availability of social worker	12 (3)	32 (8)	56 (14)	0.05		
Lack of security	80 (20)	16 (4)	4(1)	0.05		
Involvement in expenditure	44 (11)	44 (11)	12 (3)	0.89		

#### DISCUSSION

There has been a recent call for more research on trust in the health care system, which the authors argue, is required to 'understand, protect and restore' public trust in the health care system. The current medical care environment is complex, including the rise of consumerism, increasing litigations, high-pressure marketing, easy access to medical information via internet, and poor access to reliable healthcare causing overcrowding in many medical centres. The interaction between anxious patients and busy doctors can lead to a lack of concordance and other communication gaps. Exposure to media reports of medical negligence can further erode the public trust in medicine as an institution, a trust that is declining during the last decade.

Studies show that when parents' integration into the unit was facilitated, the felt safer, gained control over the situation and were more connected to the infant.<sup>5</sup> Several studies have shown that patients prefer flexible visiting strategies. Open visiting hours realise the families' needs and have a positive impact on the patients, improve patient satisfaction and may even reduce the stay in hospital.<sup>6</sup>

Patient trust increases uptake of, engagement with and optimal outcomes from healthcare services and is therefore central to health practice, policy and planning. Most survey shows that although most parents were able to communicate to neonatal staff about their worries, there was much variation in counselling services and emotional support provided by doctors. Provision of competent care in a calm and reassuring manner as well as clear communication and careful explanations geared to parental comprehension capability may reduce parental anxiety. 8

Physicians have been found to discourage patients from voicing their concerns and expectations as well as requests for more information. This negative influence of the doctors' behavior and the resultant nature of the doctor-patient communication deterred patients from asserting their need for information and explanations. Patients can feel disempowered and may be unable to achieve their health goals. Lack of sufficient explanation results in poor patient understanding, and a lack of consensus between doctor and patient may lead to therapeutic failure. 9,10 Surveys tell us that patients want physicians who can skillfully diagnose and treat their sicknesses as well as communicate with them effectively. 9

In a study done by Astbury and Yu, more than 70% stated that understaffing/ overwork and the sudden death/relapse of an infant were highly stressful. Close in importance to these were nurse/ doctor conflict, priorities of care, and the condition of outborn infants. 40% or less found ambivalence to parents, insecurity regarding competence/knowledge. Our study however revealed that the caretakers believed their doctor would handle their newborn carefully and were competent enough to deal with their newborn but were not easily accessible.

A doctor's communication and interpersonal skills with patients form the crux of practice of medicine with the ultimate goal of achieving the best outcome and patient satisfaction. Most complaints about doctors are related to issues of communication, not clinical competency. Our study reveals that most of the doctors feel the reason for the lack of good interpersonal relationship is that the caretakers don't always treat them with respect, decision makers are not present during counselling and they find themselves being intimidated by the political influence of caretakers. Surprisingly a significant percentage of doctors find daily counselling stressful.

NICE quality standards for neonatal care identifies the importance of parents being involved in decision making. Parents should be encouraged and supported to participate in their baby's care at the earliest opportunity. Our study showed doctors would not always involve the caretakers in the decision making process.

A study by Chourasia et al showed no statistical significance in respect to education level of parents. However, another study showed that lesser educated and uneducated parents were found to have higher stress.8 Doctors in our study felt that the educational status of the caretakers almost always affect their quality of treatment and counselling. In a study done by Benita Cox, 65.1% of the total respondents indicated that the Internetinformed patient is a challenge to the doctor's authority. Potentially, this has major consequences for the doctor–patient relationship. Traditionally, the doctor's superior medical knowledge and the authority to select and sanction the use of resources in treatment have been central to the dynamic of the doctor-patient relationship. However, as the balance in ownership of clinical information changes, the decisionmaking role of doctors may come under increasing scrutiny by patients. 13

The staff must use their communication skills to understand and support the parents in their emotional crisis in the NICU. The hospitals on their behalf need to understand the parents' emotional state and modify their policies regarding restriction of visitation, financial transparencies and overall quality of services.

Communication between parents and their baby's principal medical care providers is important in the neonatal intensive care unit (NICU) setting. The parents of infants admitted in the NICU often find themselves in a situation of extreme emotional strain and crisis. Being separated from their child is painful and as the hospital environment is unfamiliar, the parents are dependent on doctors and nurses to be able to cope with their situation and familiarize themselves with the care of their child. Good communication between parents and staff is therefore an essential part of the support offered to parents in the NICU. <sup>13</sup>

Limitations of the study were that a larger sample size is required in order to determine statistical significance over a longer period of time and it needs to be implemented in multiple centres in order to analyse similar patterns of behaviour across various centres.

## **CONCLUSION**

To conclude, the doctor-patient relationship continues to be more in the realm of art rather than science. No measurement tool can capture every nuance of this complex relationship. Few evidence-based standards exist regarding the doctor-patient relationship. Most descriptions of the core dimensions of the doctor-patient relationship come primarily from conceptual analysis-even in this, consensus is lacking - and not from empirical research. Emanuel and Dubler have suggested that the ideal doctor-patient relationship consists of the six C's: Choice, competence, communication, compassion, continuity, and (no) conflict of interest. However, the challenge is to operationalize as specific measures these six C's.<sup>4</sup> Research clearly demonstrates that effective communication is indispensible to successful diagnosis and treatment.<sup>9</sup>

Our study showed that the caretakers were satisfied with the visitation policies, competency of the doctors and the counselling process. However, they were unhappy with their involvement in the decision making regarding their child's treatment. The doctors found thatthe presence of a social worker during the time of counselling was necessary, which was lacking during our study period. Another aspect that needs to be focused on is the lack of security of doctors at all times in the hospitals.

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