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## **Impact of Ethics and Economics on End-of-Life Decisions in an Indian Neonatal Unit**

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# Impact of Ethics and Economics on End-of-Life Decisions in an Indian Neonatal Unit



**WHAT'S KNOWN ON THIS SUBJECT:** Mortality statistics and concern for a child's best interest in terms of dignity and quality of life are the most important factors when decision-makers set limits for treatment of preterm neonates in Western countries.



**WHAT THIS STUDY ADDS:** Facing severe resource scarcity, multiple outcomes external to the clinical welfare of the newborn influence our informants' decisions about treatment after preterm birth, and the providers have to adjust the gestational age limit for treatment thereafter.

## abstract

**OBJECTIVE:** The aim of this article was to describe how providers in an Indian NICU reach life-or-death treatment decisions.

**METHODS:** Qualitative in-depth interviews, field observations, and document analysis were conducted at an Indian nonprofit private tertiary institution that provided advanced neonatal care under conditions of resource scarcity.

**RESULTS:** Compared with American and European units with similar technical capabilities, the unit studied maintained a much higher threshold for treatment initiation and continuation (range: 28–32 completed gestational weeks). We observed that complex, interrelated socioeconomic reasons influenced specific treatment decisions. Providers desired to protect families and avoid a broad range of perceived harms: they were reluctant to risk outcomes with chronic disability; they openly factored scarcity of institutional resources; they were sensitive to local, culturally entrenched intrafamilial dynamics; they placed higher regard for “precious” infants; and they felt relatively powerless to prevent gender discrimination. Formal or regulatory guidelines were either lacking or not controlling.

**CONCLUSIONS:** In a tertiary-level academic Indian NICU, multiple factors external to predicted clinical survival of a preterm newborn influence treatment decisions. Providers adjust their decisions about withdrawing or withholding treatment on the basis of pragmatic considerations. Numerous issues related to resource scarcity are relevant, and providers prioritize outcomes that affect stakeholders other than the newborn. These findings may have implications for initiatives that seek to improve global neonatal health. *Pediatrics* 2009;124:e322–e328

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### KEY WORDS

ethics, infant, newborn, decision-making, social determinants of health, India

### ABBREVIATIONS

GA—gestational age

DAMA—discharged against medical advice

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In India, one third of the 26 million infants born annually have low birth weight, are preterm, or both, and 1.3 million die during the neonatal period.<sup>1,2</sup> The estimated need for intensive care beds in India is 72 000, with only 2000 currently in place.<sup>1</sup> Several basic, inexpensive interventions for improvement in outcomes have been described, but because advanced care is both expensive and labor intensive, there has been little interest in increasing the availability of technology-dependent neonatal therapies.<sup>3–5</sup> Only a small number of private or government hospitals provide intensive care for preterm neonates that could be considered comparable to the standard of care in the United States or Europe. Private demand for such care is increasing with rapid expansion in personal wealth, professional interest, and growing social awareness; however, in the absence of widespread insurance coverage, inequitable distribution of such cost-intensive health care remains prevalent.<sup>6</sup>

In reviewing worldwide published databases, we were unable to identify any prospective, in-depth study on how providers approach life-saving or life-ending decisions for potentially treatable newborns under conditions of obvious resource scarcity. Among the few published surveys on point, minimal attention is given to how socioeconomic factors affect clinical decision-making for preterm neonates.<sup>7–9</sup> Given India's disproportionate share of global neonatal mortality, such qualitative data are needed for full understanding of the scope of the challenge to improve survival. India's high neonatal mortality rate is the increasing subject of international scrutiny.<sup>10</sup> This article begins to fill a knowledge gap by providing a descriptive analysis of how providers in an Indian NICU reach life-or-death treatment decisions.

## METHODS

### Setting

The study institution requested anonymity for the purposes of this report. We therefore limit our description of the setting to the following: (1) the hospital enjoys a national reputation and has consistently been ranked as one of the “best” in the Indian popular press; (2) an academic faculty educates hundreds of students annually; (3) it is not-for-profit, religiously affiliated, private and provides tertiary-level neonatal intensive care (Table 1); (4) the hospital serves a heterogeneous regional urban and rural population from across the socioeconomic-religious strata that is reflective of the larger Indian demographic (most patients are Hindu and

are locally classified as lower middle class).

Patients generally pay out of pocket for hospital bills and medicines, but exceptions are common. According to hospital accountants, an average of 13% of families who receive neonatal services pay their entire bill. Services are subsidized by revenue redistribution from more profitable departments. Typical cost of care for preterm neonates who are born at approximately 28 weeks' gestational age (GA) and are in need of ventilation is between INR 40 000 and 80 000 (approximately US \$800–\$1600). The unit has a monthly operating budget of roughly INR 150 000 to 200 000 (approximately US \$3000–\$4000) to cover unpaid bills.

A government hospital in the region generally provides free care and typically serves the poorest in the region who are either unable or unwilling to go to private institutions. The government neonatal unit is incapable of providing mechanical ventilation and serves as an informal referral base for the studied institution.

### Data Sources

Primary data sources included (1) formal interviews with 23 key informants (Table 2); (2) field observations made

**TABLE 1** Description of the Department of Neonatology

Serves a local population of ~600 000
Treats, on average, ~2000 of 8000 neonates delivered in the hospital annually
~250 outborn neonates are additionally admitted annually
Relatives of outborn neonates are required to pay a registration fee before being admitted
Unit typically operates over official bed capacity (60 beds)
Level 3 unit (NICU)
15 beds and 8 ventilators (1 high-frequency ventilator)
Surfactant and inotropic agents available, no inhaled nitric oxide
Electronic cardiorespiratory monitoring equipment and limited number of infusion pumps
Nurse-to-infant ratio officially 1:2 or 1:3 but typically 1:4 or 1:5
Level 2 unit
35 beds (shares 6 incubators with level 3 unit, remainder are open cribs with room temperature set at 32°C)
Typical diagnoses include sepsis, asphyxia, congenital malformations, and prematurity not requiring mechanical ventilation
Limited electronic monitoring, oxygen availability, or intravenous drip usage
Nurse-to-infant ratio: 1:7 to 1:15
Level 1 unit
10 beds
Typical admissions include otherwise well neonates who are <1.8 kg, the departmental threshold for safe discharge
Nurse-to-infant ratio: 1:10

**TABLE 2** Formal Interviews

Principal investigator (Dr Miljeteig) conducted all formal interviews
Interview guide was revised as analyzed data suggested consistent themes
Twenty-three key informant interviews were audiotaped and transcribed
Formal informants included
6 doctors working in the neonatal department, including head of department
4 obstetricians, including head of department
Heads of nursing in neonatology and in delivery room
2 referral doctors from lower level hospitals
Doctors from hospital's development
pediatrics department, the in vitro fertilization clinic, the medical ICU, the neuro-ICU, and the casualty unit; a psychologist; and an accountant in administration

**TABLE 3** Field Observations and Documents Studied

Participation in daily morning rounds in 3 neonatal units and delivery room
Informal discussions with doctors after rounds
Observations during consultation time with families
Observations in follow-up infant clinics, high-risk antenatal clinics, meetings, and lectures
Visits to local referral hospitals, clinics, private pediatric practices, home visits, and neonatal unit in the nearby government hospital
Documents examined included
Registers from delivery room and neonatal departments
Mortality and morbidity statistics developed by obstetric and neonatal department for the years 2006 and 2007
Protocols and handbooks used in neonatal department

as a part of involvement in daily routines, informal conversations, attendance at meetings, and specific follow-up of cases (Table 3); and (3) analysis of key documents and statistics (Table 3).

### Data Collection

The study took place between January and April 2007. Interviews were conducted during 25 to 100 minutes and consisted of questions that elicited provider responses regarding treatment initiation or removal for preterm neonates (interview guide available on request). Field observations were systematically recorded by the primary investigator (Dr Miljeteig). Hospital documents were analyzed with approval by the institution. The project was accepted by the research ethics committee at the hospital and was approved by the Norwegian Social Science Data Services.

### Data Analysis

Analysis of all primary data was modeled on grounded theory by using an editing analysis style.<sup>11,12</sup> This process includes deriving conceptual themes from data sources rather than from a preconceived theoretical framework.<sup>11</sup> Distinct units of meaning were identi-

fied within all textual material (transcribed interviews, written field observations, and institutional documents) with the assistance of the software NVIVO 7 (QRS International, Victoria, Australia). Separate categorical codes were then assigned to each unit. These initial codes were then connected across thematic lines to create larger conceptual categories. Finally, content within these categories was integrated, refined, and given final classification.

## RESULTS

Brief excerpts from primary data sources are provided to support our descriptive results and conceptual analysis.

### Threshold for Initiating Treatment

A majority of informants stated that they would consider initiation of treatment if the GA were predicted to be at least 28 weeks (Table 4). No limit was observed to be absolute in practice, because case-specific considerations influenced treatment decisions: "Less than 28 weeks, we just do not give them any hope, unless they can afford treatment. But >30 to 32 weeks, we give them fairly good prognosis and see their attitude." (D).

**TABLE 4** Sampling of Provider Threshold for Initiating Treatment on the Basis of GA and Weight

Informants Directly Involved in Treatment Decision	Limit for GA	Weight, g
A	28	900–1000
B	27	900
C	28–32	1000
D	30–32	
E	28–29	1000
F	28	
G	28–30	1000
H	28	750
L	28–32	1000
O	30–32	1200
R	28–29	750
S	28	
T	28	800

Weight is not an independent criterion, but some informants reported evaluation of weight when the GA was very low.

Between 28 and 32 weeks' GA, families were often asked to participate in decisions concerning initiating of resuscitation. In soliciting family opinion, physicians counseled about anticipated financial cost of care, predicted prognosis, and expected length of hospital stay. After 32 weeks, physicians typically unilaterally initiated treatment and involved parents only if there were a perceived risk for long-term morbidity for the newborn.

### Classification of Provider Reasons to Support Treatment Decisions

The analysis generated the following conceptual classifications: clinical reasons, protective reasons, structural reasons, procedural reasons, compassionate reasons, formal reasons, and indirect reasons. Thematic overlap exists across these categories.

#### *Clinical Reasons: Provide an Intact Survival*

Physicians estimated local survival rate for neonates who were born past 26 weeks' GA to be >50% and beyond 28 weeks' GA to be >70%. Despite such favorable estimates, risk for disability was a key concern motivating treatment decisions: "In the department, we feel that we should only give productive children to the family; no handicap, need of treatment, tone abnormality, retinopathy, learning disability, need of be taken care of in special ways. If you give a diseased child, a compromised child, the family is . . . devastated." (B).

Providers understood "intact survival" to be absence of neurologic disability and absence of a need for costly treatment in the future. They noted a duty to avoid pushing treatment on a family when a neonate was likely to end up "a compromised child." Informants offered as partial justification for their practice the reality that India possesses an inadequate system of supporting children with disabilities, par-

ticularly with respect to rehabilitation, long-term treatment, and appropriate educational services, and the reality that many families are poorly prepared to take on such burdens: “As there is no social security system for these premature and the commitment from the family is not there in our society, we try to limit ourselves to the babies where it is likely to get better.” (A)

### *Protective Reasons: Avoiding Harm to the Family*

Directly related to clinical reasoning, providers expressed a complex set of duties to protect the family and the child from harmful external effects that were often at odds with one another. Informants rarely discussed neonates themselves in terms of perceived interest in receiving or avoiding potentially life-saving treatment and avoided framing the problem in terms of neonatal rights that are separate from those of families. They often expressed that any long-term protection of the child rested on the family's shoulders: “Over the child's rights are the child's belongings. The child belongs to the family.” (K)

Informants emphasized a protectionist concern for the family's financial well-being given the pervasive lack of health insurance. They felt a duty to prevent marginalized families from using their income and savings or from acquiring new debt for an infant who had a reasonable risk for dying or a need for long-term medical attention: “We try to not make a waste for the family; it is better for them to go for a new baby.” (O)

### *Structural Reasons: The Hospital's Resources*

Constraints in the neonatal department's financial and human resources influenced treatment deliberations. An observed part of provider responsibility included estimating a family's eco-

nomie status to inform a decision about whether to provide free treatment or demand payment: “We are withholding funds to make pragmatic decisions. Withhold the funds for patients who really need the money.” (G) Consistent with a desire to discharge essentially normal infants, informants articulated an obligation to use scarce department resources on neonates who were perceived to have a high chance of survival without chronic morbidity.

### *Procedural Reasons: Negotiating With Families to Keep Good Relations*

Informants noted that final treatment decisions often depended on gauging initial and ongoing family enthusiasm for care during hospitalization. Providers were observed routinely to include extended elder family members in treatment decisions, because young couples were often not viewed as the primary decision-makers for their own newborns. Providers noted that once a neonate was discharged, almost nothing could be done to ensure adequate follow-up and believed that because care decisions would eventually fall completely out of their hands, it made little sense to force treatment on unwilling families: “Their [the family's] motivation is the main factor we put weight on; therefore, we sometimes pay more attention to the family than the child itself.” (J)

### *Compassionate Reasons: A Precious Infant in a Motivated Family*

Informants reported that a history of infertility or recurrent losses influenced treatment decisions in a more aggressive direction. Advancing maternal age without previous reproductive success and/or use of in vitro fertilization prompted providers to relax self-imposed resuscitation thresholds that are based on GA: “We are more compassionate if we know their history of infertility.” (O)

Informants used such terms as “precious infant” or “precious pregnancy” in such situations and, notably, documented the same within official records in capital letters to raise staff awareness. Most parents who could afford in vitro fertilization could also afford the cost of neonatal intensive care; however, an inability to pay did not negatively influence provider treatment decisions in cases with a history of previous infertility: “...and then they [parents] will say: ‘We have come here with so much hope, they have told us that you will save the baby.’ So then we [providers] cannot bring up the financial aspect: ‘Just because you are poor, we cannot do anything.’” (H)

### *Formal Reasons: Guidelines, Consensus, or Law*

Informants did not identify any policy guidelines concerning when to initiate, withhold, or withdraw treatment for preterm neonates. Informants stated that they did not perceive Indian law and, more specific, the Indian Child Protection Act as relevant to guide treatment decisions for preterm neonates: “No, we do not have any national guidelines, because there is no national policy as to limit or how.” (F)

Junior providers stated in formal interviews that they learned about decision-making criteria through specific case management or through conversation with senior colleagues. A written protocol within the unit stated, “(For) infants weighing <2 kg or < 35 weeks' GA: All babies with signs of life should be transferred to the NICU and the further course of action should be decided in the nursery” (Manual, Department of Neonatology).

### *Indirect Reasons: Cultural Entrenchment of Gender Discrimination*

Informants emphasized that they never considered gender a reason to consider withdrawing treatment. In-



dian law prohibits prenatal gender selection, and, notably, at this institution, ultrasounds during pregnancy generally were not performed. Nevertheless, we observed that, after birth, gender was a regular concern for providers. Informants felt a strong duty to protect female newborns against culturally entrenched discrimination yet often felt powerless to do much to change long-standing prejudices: "So the gender bias is the biggest problem in this place. I feel so bad when I see a baby (girl) that is kicking around, having a good prognosis and the parents say that, 'No, no, no, we want to take this baby home,' and I know that the chance of survival (at home) is very small, but I have to accept." (L)

Informants reported the manifestation of gender bias in numerous ways: families were observed to be less interested in intensive care, in buying basic medicines, and coming to follow-up outpatient appointments after discharge when their infant was female. Informants reported that they had little to no recourse in such cases, and if they pressed too hard, they risked neonatal abandonment in the hospital without adequate state support to find suitable alternative placement.

Additional evidence to support these observations came from examination of hospital medical registers. We noted with some frequency the notation "DAMA" (discharged against medical advice). Typically in such cases, the physicians were optimistic about a newborn's prognosis, but the family would insist on taking the infant home before it was thought clinically safe. Family motivation for stopping care was often based on cost but also sometimes on newborn gender. Among the DAMA neonates, 60% were girls, whereas the female rate in the NICU was only 42%: "Then if they are having 3 girl children, and now the fourth, they will be ready to leave at any

stage. Let's say that the child is even 1.9 (kilos) and you just have to keep for 1 to 2 days, even for that they are not willing." (H)

Informants articulated protectionist concerns for mothers as well. They noted that many of these women were uneducated and were blamed by the husband's family members when a neonate was born preterm, resulting in the need for costly treatment. Informants also described how marginalized women were often perversely blamed when the newborn was female. They reported that such blame could result in eviction from the husband's home after hospital discharge and were accordingly apprehensive about pushing for treatment when unable to prevent out-of-hospital abuse of these women.

## DISCUSSION

We have described how providers who face significant resource constraints and operate within a particular context of poverty and complex sociocultural conditions approach specific treatment decisions regarding intensive neonatal care. We acknowledge that this sampling is from one institution in a large and remarkably diverse country, and, therefore, generalizations cannot be drawn. Nevertheless, we believe that a strength of this study is that the teaching institution described is well regarded within India, has a relative abundance of resources, and serves as a major regional referral center. We suspect that many of the social, cultural, and economic factors that influence provider treatment decisions here will be more magnified in hundreds of hospitals within India with fewer capabilities. Although we do not present descriptive data from the local governmental hospital, our key informants consistently reported that patients who could afford private clinical services avoided even free govern-

ment services out of concern for poor quality and inadequate resources.

These observations suggest how lack of social, legal, and economic security can converge to deny some at-risk neonates the ability to receive life-saving medical care. We believe that much more in-depth investigation is needed to substantiate this preliminary report. Our findings are particularly striking with respect to the influence of projected disability and gender on treatment decisions. The remarkably high standard for "intact survival" adopted by respondents reflects a more pervasive concern about the inadequacy of resources that are available in India to support both survivors with disabilities and their families. Under difficult circumstances, we observed a conscientious but highly variable pattern of decision-making that prioritized broadly defined, non-patient-centered outcomes. We observed little internal compulsion on the part of providers to act consistently (a justice concern) across newborns with similar predicted survival rates with intensive care. A range of externalities could motivate treatment decisions that are based on case-specific details.

These observed practices stand in dramatic contrast to what typically happens in North America and Europe.<sup>13–15</sup> Beyond 25 weeks' GA, most US-based providers agree that resuscitation and treatment should be initiated regardless of parental wishes.<sup>16–18</sup> The standard justification sounds in the professional commitment to act in the newborn's best interests.<sup>19–21</sup> A major ethical assumption involves a claim that the benefit of treatment to the newborn far outweighs any predicted burdens to the child.<sup>22</sup> Moreover, in relatively resource-rich settings such as the United States, the burden of survival on others (eg, family, society) is largely deemed less important (or

even irrelevant) to a patient-centered treatment calculus.<sup>23</sup>

Providers in our study cast their net of concern over a wider set of stakeholders. Under conditions of tangible scarcity, the harmful consequences to others mattered greatly to our informants and, we believe, pushed them to consider more heavily the downstream effects of treatment decisions on families and their own institution. The transparency with which these providers discussed the importance of both immediate and future cost of care relative to the value of newborn human life stands in distinction to practice in the United States and Europe, where clinicians generally consider open discussion of expenses taboo to guide clinical decision-making.<sup>24–27</sup> However controversial their approach may seem, providers at the study institution were observed to be exquisitely responsive to the conditions on the ground; they were as a group remarkably pragmatic decision-makers. As our observations hopefully suggest, they also did not lack reflective moral conscience.

Still, our study does not answer a harder set of questions. We do not have a full sense of the extent to which an observed preference to discharge infants with potential for future productivity might reflect an insidious discriminatory attitude toward those with

disabilities in India. We are also worried that even at an exemplary institution in India, some evidence suggests that female infants and disenfranchised women continue to experience marginalization.

The most serious limitation of our study is that no families were interviewed. Still, we believe that our observations introduce important issues for any comprehensive discussion about how to reduce global neonatal mortality and morbidity. India bears the world's largest proportional burden of neonatal death in 2009.<sup>2</sup> It is making progress, and recent state-sponsored efforts to scale up basic, cost-effective interventions to reduce the burden of preventable death in the rural areas are to be applauded.<sup>28</sup> One important strategy encouraged by local health ministries and international health organizations is to increase the number of institutional deliveries.<sup>29,30</sup> For otherwise well infants, such efforts should ultimately reduce the neonatal mortality rate.

We cannot entirely forget newborns who are born preterm (or any newborn) and in need of costly care. Our observations describe what is already taking place in one tertiary-level hospital that is capable of providing high-quality intensive care. With an increase in institutional deliveries, there likely will be an increase in the number

of infants who could benefit from costly care, who would have otherwise died “unnoticed” in the home.<sup>31</sup> We believe that it is time to start thinking more seriously about how we can meet the needs of these newborns equitably and fairly as well.<sup>32</sup>

## CONCLUSIONS

Facing resource scarcity, multiple factors external to the clinical outcome of the newborn influenced our informants' decisions about treatment after preterm birth. At least in the context studied, ethical discussions that might center on a newborn's best interest were replaced by a pragmatic concern for the consequences to families and the hospital. We hope that this article encourages a broader discussion regarding the socioeconomic determinants of newborn health.

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