Barriers to neonatal care in developing countries: Parents’ and providers’ perceptions

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Aim: Hospital care and advanced medical technologies for sick neonates are increasingly available, but not always readily accessible, in many countries. We characterised parents’ and providers’ perceptions of barriers to neonatal care in developing countries.

Methods: We interviewed parents whose infant was hospitalised within the first month of life in Cambodia, Malaysia, Laos and Vietnam, asking about perceived barriers to obtaining newborn care. We also surveyed health-care providers about perceived barriers to providing care.

Results: We interviewed 198 parents and 212 newborn care providers (physicians, nurses, midwives, paediatric and nursing trainees). Most families paid all costs of newborn care, which they reported as a hardship. Although newborn care is accessible, 39% reported that hospitals are too distant; almost 20% did not know where to obtain care. Parents cited lack of cleanliness (46%), poor availability of medications (42%) or services (36%), staff friendliness (42%), poor infant outcome (45%), poor communications with staff (44%) and costs of care (34%) as significant problems during prior newborn care. Providers cited lack of equipment (74%), lack of staff training (61%) and poor infrastructure (51%) as barriers to providing neonatal care. Providers identified distance to hospital, lack of transportation, care costs and low parental education as barriers for families.

Conclusions: Improving cleanliness, staff friendliness and communication with parents may diminish some barriers to neonatal care in developing countries. Costs of newborn care, hospital infrastructure, distance to hospital, staffing shortages, limited staff training and limited access to medications pose more difficult barriers to remedy.

Key words: barrier; developing country; health-care access; low-resource country.

What is already known on this topic

1 Improved technology can improve neonatal outcomes in resource-limited countries where access is feasible.
2 Providers in many developing countries may have insufficient training and experience to utilise new methods of neonatal intensive care.
3 Parents’ perceived barriers to care may limit access to or effectiveness of neonatal intensive care techniques.

What this paper adds

1 Parents in these four Southeast Asian sites perceive deficiencies in neonatal intensive care unit conditions and practices that are amenable to low-cost improvement measures.
2 Providers in these four Southeast Asian sites perceive limitations in equipment, training and infrastructure as barriers to care and limitations to their ability to provide higher level of care. These barriers will be more difficult to remedy with low-cost improvements.
3 Perceived barriers differ by site suggesting that hospital quality improvement efforts should begin with an analysis of barriers to care relevant to practice in differing locales.

Many technical innovations that can improve neonatal health outcomes are increasingly available in low-resource countries.1-5 However, they are often not easily available in centres that lack technology, provider experience or economic means to implement and sustain interventions routinely utilised in the developed world.6-7 Parents’ perceptions of barriers to care also adversely impact the effectiveness of neonatal care programs developed for low-income countries.6-10

We interviewed parents regarding their prior experiences and perceptions of potential barriers to accessing newborn care locally. We surveyed newborn care providers’ perception of barriers to providing care and those that they believe families
experience locally. Local data from parents and providers could facilitate implementation of neonatal care programs that are feasible, inexpensive, relevant to local conditions and acceptable to families. The goal of this study was to inform future efforts to reduce barriers to newborn care and improve health-care delivery in low-resource countries.

Methods

This project involved collaboration between the University of California San Francisco and four hospitals in Southeast Asia: the National Hospital of Pediatrics (NHP) in Hanoi, Vietnam, International Medical University and Tuanku Jaafar Hospital, Seremban, Malaysia, Angkor Hospital for Children (AHC) in Siem Reap, Cambodia and the Mother and Child Health Hospital in Vientiane, Lao PDR. These sites have established roles in regional neonatal health care for extensive portions of each country. The NHP in Hanoi is the largest neonatal intensive care unit (NICU) in Vietnam, serving as a referral centre for lower-level health centres (commune stations, district hospitals or provincial hospitals) in most provinces in northern Vietnam where few lower-level centres have the capacity for neonatal intensive care. Tuanku Jaafar Hospital is an urban teaching hospital associated with International Medical University; it has a large and well-equipped NICU serving as a NICU referral centre for central Malaysia. AHC in Siem Reap, Cambodia is a private hospital with a paediatric intensive care referral centre for most of northwestern Cambodia where alternate sources of neonatal care are scarce or rudimentary. The Mother and Child Health Hospital is a teaching hospital in Vientiane, Lao PDR; it has a small NICU that is increasingly utilised as a perinatal referral centre for surrounding under-resourced districts.

Parent interviews

We developed a parent survey questions in collaboration with local physicians. Survey questions asked parents about prior newborn care experience, perceptions of barriers to obtaining newborn care and basic demographics. They were pre-tested for face and content validity, clarity, ease of administration and sensitivity to family and local cultural backgrounds. Consent forms, informational letters and surveys were translated prior to implementation. Site directors or research assistants identified eligible parents, gave the parents an explanatory information letter and requested written informed consent to participate. We interviewed consenting parents whose infants were hospitalised either at birth or within the first month of life at each centre. Multiparous women were asked about experience in seeking care for their prior infants, while primiparous mothers were asked about their experience during the pregnancy and delivery of their current infant. We asked the number of prior infants delivered at a range of birthing sites, rather than the specific sites at which their prior infant had been born. Bilingual and medically trained assistants (paediatric residents and nurses) used standardised questionnaires for 20-min face-to-face to interviews in their preferred language (Vietnamese, Khmer, Malay or Lao). For illiterate or semi-literate parents, the letters were explained in the family’s primary language. A small monetary incentive or gift was given on completion of the interview.

Institutional reviews boards at the University of California, San Francisco and at each participating hospital approved the study.

Provider survey

Staff and trainees providing newborn care at participating centres were eligible. Local site directors gave eligible providers an introductory letter explaining the study and assuring confidentiality. As permitted by each institutional review board, providers did not provide written informed consent; return of a completed survey was taken as implicit consent. Survey questions had been reviewed for relevance to local practice by site directors, translated (into Vietnamese, Khmer, Malay and Lao) and back-translated into English to ensure linguistic accuracy. Surveys were administered in English or the provider’s primary language, as preferred. At each site, approximately 50 newborn care providers (physicians, nurses, midwives and paediatric and nursing trainees) were surveyed about barriers to providing neonatal care and barriers that parents experience in seeking care locally. The survey took approximately 20 min to complete. A small monetary incentive was given to providers who completed the survey.

Interview and survey data were entered into an Excel database and were analysed using True Epistat (Richardson, TX, USA). Univariate frequencies were tabulated for categorical variables, and summary statistics calculated for numeric variables.

Results

Parent interviews

Study personnel interviewed 198 parents; three parents refused participation because of time constraints. While either parent was eligible, in 85% of cases, only the mother was interviewed. Demographic characteristics differed between sites, reflecting significant differences in socio-economic factors, residence, education and literacy (Table 1). Women in Siem Reap represented a more rural, less educated and higher health risk group. Overall, mothers had a mean age of 29 years, and a mean of 9 years of education; 116 of the mothers were multiparous. About 20% of families lived in cities, except in Vientiane (76%). Just over half (52%) of the multiparous mothers, 100% in Vientiane, had delivered their last infant in a hospital. Women identified cost (60%), distance to hospital (24%), family obligations (26%) and local culture (25%) as influencing their choice of delivery site (data not shown); 20% reported that they had no choice in delivery site. The majority (>85%) at all sites had an attendant at their last delivery (physician, midwife or traditional birth attendant). Overall, 7% of multiparous women had experienced a prior neonatal death. Over 50% of women reporting a prior neonatal death had not sought medical care, nor did they know the cause of death.

Table 2 shows economic and health-care access factors that families identified as barriers to obtaining newborn care locally. A majority (61%) paid all medical costs for their children; 70% reported that this represented a significant hardship. A small but significant number across all sites also reported feeling unable to provide basic needs for their children. The proportion perceiving
that newborn care costs too much differed significantly between sites: half of parents in Hanoi and Siem Reap, as compared to 10% in Seremban and Vientiane. As a measure of added opportunity costs for families, parents reported that they could stay with a hospitalised child only up to 9–13 days due to loss of income or family care needs. Families reported that newborn care overall is difficult to obtain (22%), too far from home (39%) or too costly (34%). Additionally, 17% reported not knowing where to get newborn care locally. Many (33%) reported problems with prior newborn hospital care.

Figure 1 shows parents’ experiences of prior newborn care, showing low levels of satisfaction with care across all sites.

Many of the problems explaining low levels of satisfaction can be attributed to economics or hospital infrastructure problems (lack of services, lack of medications, long waiting time, costs). Diminished satisfaction can also be attributed to provider and hospital personnel practices (staff demeanour, lack of cleanliness, lack of privacy, poor communication). In Hanoi, the three most common issues were medication availability, hospital cleanliness and long waiting times. In Siem Reap, parents cited infant outcomes, newborn care costs and staff demeanour. In Seremban, waiting time was the most common issue. In Vientiane, fewer parents cited problems with prior care, most commonly citing long waiting time as problematic.

Table 1  Demographic characteristics of parents and providers at each site

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Hanoi</th>
<th>Siem Reap</th>
<th>Seremban</th>
<th>Vientiane</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents interviewed</td>
<td>n = 48</td>
<td>n = 41</td>
<td>n = 59</td>
<td>n = 50</td>
</tr>
<tr>
<td>Age (mean ± SD), years</td>
<td>27 ± 5</td>
<td>28.6 ± 6</td>
<td>29.4 ± 6</td>
<td>29.0 ± 8</td>
</tr>
<tr>
<td>Education, years</td>
<td>10.3 ± 2</td>
<td>4.4 ± 4</td>
<td>10.5 ± 3</td>
<td>10.2 ± 5</td>
</tr>
<tr>
<td>Residence:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>City</td>
<td>22%</td>
<td>18%</td>
<td>20%</td>
<td>76%</td>
</tr>
<tr>
<td>Town</td>
<td>17%</td>
<td>13%</td>
<td>61%</td>
<td>22%</td>
</tr>
<tr>
<td>Village</td>
<td>57%</td>
<td>70%</td>
<td>19%</td>
<td>2%</td>
</tr>
<tr>
<td>Last infant delivered in hospital</td>
<td>62%</td>
<td>46%</td>
<td>49%</td>
<td>100%</td>
</tr>
<tr>
<td>Mother had choice for delivery site</td>
<td>85%</td>
<td>81%</td>
<td>78%</td>
<td>76%</td>
</tr>
<tr>
<td>Skilled attendant at delivery</td>
<td>88%</td>
<td>85%</td>
<td>97%</td>
<td>94%</td>
</tr>
<tr>
<td>Previous death of infant (1st month of life)</td>
<td>5%</td>
<td>18%</td>
<td>2%</td>
<td>0</td>
</tr>
<tr>
<td>Parents feel unable to provide for basic needs of child</td>
<td>7%</td>
<td>15%</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>Providers surveyed</td>
<td>n = 63</td>
<td>n = 47</td>
<td>n = 57</td>
<td>n = 45</td>
</tr>
<tr>
<td>Female</td>
<td>58%</td>
<td>46%</td>
<td>39%</td>
<td>39%</td>
</tr>
<tr>
<td>Male</td>
<td>5%</td>
<td>11%</td>
<td>6%</td>
<td>6%</td>
</tr>
<tr>
<td>Age (mean ± SD), years</td>
<td>33 ± 9</td>
<td>33 ± 8</td>
<td>35 ± 9</td>
<td>33 ± 8</td>
</tr>
<tr>
<td>Training:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physician</td>
<td>21</td>
<td>9</td>
<td>24</td>
<td>19</td>
</tr>
<tr>
<td>Resident</td>
<td>1</td>
<td>9</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Medical student</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Nurse</td>
<td>32</td>
<td>20</td>
<td>29</td>
<td>9</td>
</tr>
<tr>
<td>Midwife</td>
<td>4</td>
<td>8</td>
<td>–</td>
<td>9</td>
</tr>
</tbody>
</table>

Table 2  Economic considerations and non-economic factors parents perceive as barriers when they seek hospital care for their children in each region

<table>
<thead>
<tr>
<th>Economic factors</th>
<th>Hanoi</th>
<th>Siem Reap</th>
<th>Seremban</th>
<th>Vientiane</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents pay all costs of child’s medical care</td>
<td>54%</td>
<td>58%</td>
<td>69%</td>
<td>90%</td>
</tr>
<tr>
<td>Hard or impossible for parents to pay for hospital care</td>
<td>75%</td>
<td>88%</td>
<td>53%</td>
<td>44%</td>
</tr>
<tr>
<td>Days parents can afford to stay away from home/work</td>
<td>9 days</td>
<td>13 days</td>
<td>10 days</td>
<td>13 days</td>
</tr>
<tr>
<td>Newborn care costs too much</td>
<td>53%</td>
<td>56%</td>
<td>7%</td>
<td>10%</td>
</tr>
<tr>
<td>Access factors</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents do not know where to get hospital care for infants in their area</td>
<td>35%</td>
<td>20%</td>
<td>7%</td>
<td>8%</td>
</tr>
<tr>
<td>Hospital is too far from home</td>
<td>52%</td>
<td>49%</td>
<td>27%</td>
<td>38%</td>
</tr>
<tr>
<td>Newborn care is difficult to obtain</td>
<td>0%</td>
<td>56%</td>
<td>14%</td>
<td>4%</td>
</tr>
<tr>
<td>Experienced problem(s) with past newborn hospital care</td>
<td>52%</td>
<td>17%</td>
<td>14%</td>
<td>2%</td>
</tr>
</tbody>
</table>
Provider surveys

Overall, 212 providers returned completed surveys (Table 1). Differences in training reflect staffing patterns across sites. The majority of providers were female, with an average age of 33 years. A larger number of providers were male in Siem Reap than in other sites, reflective of the hospital’s overall staff demographics. Forty-two per cent of respondents were physicians, and an equal percent were nurses. Medical students and midwives made up approximately 4–5% of those surveyed.

Providers identified both economic and non-economic factors that they believed impede parents’ ability to obtain newborn care (Table 3). Family support and family demands were less commonly cited in Vietnam than in other sites. Less frequently cited, but still significant, barriers included religious beliefs and family pessimism regarding outcome. In Hanoi, a smaller proportion of providers felt that parents’ reliance on tradition healers was a barrier to obtaining care. Compared to other sites, a smaller proportion of proportion of providers in Siem Reap felt that parents’ religious beliefs were a barrier to obtaining care.

Across all sites, the majority of providers reported that lack of training and equipment impeded their ability to provide newborn care in the hospital where they practice (Fig. 2). Inadequate infrastructure was the next most commonly barrier, cited by a majority of providers in Hanoi and Seremban, the two most technically sophisticated sites. Hospital economic constraints and providers’ religious beliefs were cited by a minority of providers across all sites.

Providers believed that lack of equipment and staff training and care costs to families and society are reasons that they should not provide more aggressive care for sick infants in their institution (Fig. 3). In Hanoi, where the neonatal unit routinely cares for 50% more patients than allocated beds and staffing, the majority of providers cited lack of equipment and nursing staff as impediments to providing higher-level newborn care. Compared with providers at other sites, many more Vientiane providers cited concerns for resource utilisation as a barrier to providing higher-level care.

Discussion

Access to care

Parents and providers identified similar economic barriers to newborn care, including costs of care, distance, lack of transport and loss of work. In all sites, the majority of parents cited...
economic issues, even in Seremban and Hanoi which have higher economic indices, and in Vientiane where three-quarters of the parents reside in Vientiane. In all centres, most parents reported paying all medical costs for newborn care; notably, Vietnam has subsequently mandated universal child health coverage, and medical costs at AHC are supported by funding from a non-governmental organisation. Unexpectedly, over 40% of parents in each site found it difficult or impossible to pay for hospital care. Although Malaysia and Lao PDR are, respectively, the most and least economically developed of the four sites, very few parents in both Seremban and Vientiane perceived that the costs of newborn care were too high. We did not verify whether they had been unable to pay their infant’s medical bills.

Providers in Hanoi much less commonly cited loss of work as a barrier to parents seeking care, which seems at odds with the shorter duration Hanoi parents reported they could be away from family or work. Compared to Hanoi and Siem Reap, a larger number of providers in Seremban and Vientiane cited costs of care, consistent with the higher percentage of parents who reported paying all newborn care costs, but in contrast to the low percentage who felt that newborn care costs too much. In all sites, providers were more likely than parents to perceive that distance to the hospital posed a barrier to accessing care.

Providers additionally identified non-economic factors as barriers impeding parents’ access to newborn care locally, including poor family education, lack of support for families whose child is hospitalised, families’ reliance on traditional healers and religious beliefs. That these factors were not cited as barriers by parents likely reflects their faith in traditional therapies and religious beliefs as support mechanisms. The reality that neonatal care in these countries is often unable to achieve favourable outcomes in critically ill newborns might explain why parents cited expected poor outcome as a barrier to seeking care and also why providers perceived parents as pessimistic.

**Quality of care**

Poor staff training (medical and nursing) and lack of equipment are the most important factors that providers cite as inhibiting their ability to provide neonatal care. The low proportion of providers citing lack of nursing staffing in Siem Reap reflects the high prestige of nursing at AHC and throughout post-civil war Cambodia. The low proportion of providers in Hanoi citing medical training as a barrier to providing care is likely related to pre-existing comprehensive neonatal capacity-training curricula at the NHP, while the higher proportion of providers in Siem Reap and Vientiane is likely related to recent implementation of
higher-level newborn care in those sites. To a lesser extent, providers in these sites perceive that health-care costs to families and society are reasons that they should not offer more aggressive levels of care for sick newborns in their hospital.

**Solutions**

As half of neonatal deaths worldwide occur following home births, increasing access to and the quality of neonatal care should be a priority to reduce neonatal mortality rates. However, improved perinatal morbidity and mortality cannot be expected unless programs can increase parents’ care-seeking. Decrease delays in recognition of illness, facilitate more timely referrals for care and improve access to quality care at all levels. Identifying barriers amenable to change is an important first step in developing locally feasible and affordable programs that could improve health-care access and neonatal outcomes.

Economic restrictions seen in low- and middle-resource countries can be difficult to overcome without substantially increased health-care expenditures and systematic changes in health-care delivery. However, where health-care resources are severely restricted, low-cost alternatives to improving health-care access and technical capacity have been proven affordable and cost-effective: A primary goal should be to build capacity at local health centres, district clinics and birthing centres, enabling more women to seek care nearer to their homes and families, something they generally prefer. Another way to improve access to life-saving interventions would be to develop locally produced, low-tech equipment that is affordable and simple to distribute, use and maintain.

Failure to seek or delays in accessing care increase neonatal morbidity and mortality. In particular, in poor communities where care-seeking is less common. In India, less than 5% of newborns with a major illness were seen for medical care outside the home. In rural India, only 31% of newborns with serious illnesses were taken to a care provider, and half of these were non-medical or traditional providers. In some studies, only 10–20% of newborns without a skilled attendant were taken to a care provider during their illness. Additionally, lower castes or rural families were less likely to seek medical care. Earlier recognition of illness by parents or birth attendants would increase early referrals and potentially facilitate earlier treatment when morbidity and mortality could still be reduced. Our study findings highlight an ongoing need to determine the extent to which health outcomes improve after the implementation of community education and outreach programs designed to augment parents’ care-seeking.

Simple home and community education programs and even brief antenatal education can reduce neonatal illness. These data point to the importance of the need to diminish the extent to which parents feel barred from or delay accessing higher-level care in developing countries.

Seven per cent of multiparous mothers had experienced a prior neonatal death; yet, over half had neither sought medical care nor did they know the cause of death. In our study, providers cited parents’ pessimism about efficacy of care as impeding their willingness to seek care, a finding reported and disputed previously. Parents cited concerns for neonatal outcomes as a barrier to care. These two findings may be differing, but related, reflections of low-resource health-care systems where a larger proportion of sick newborns inevitably die. Reliance on traditional healers could also delay higher-level care for sick infants and help explain the high incidence of a prior neonatal death.

Many deliveries in low-resource countries still occur at home without a skilled attendant. Skilled attendance and institutional delivery rates are lowest in countries with the highest neonatal mortality rates; more than 50% of neonatal deaths occur following home births without a skilled attendant. In contrast to other low- and middle-resource countries, the majority of women in our study had a skilled attendant present at delivery, and the home-delivery rate was low (0–54%). Notably, in Vientiane where all multiparous women had delivered their prior infants in hospital, none of the mothers reported the loss of a prior newborn.

In our study, providers identified inadequate provider training as a barrier to providing higher-level care. Health education for hospital and community providers may help improve health-care delivery in low-resource settings, although capacity-building programs are costly and difficult to sustain. Educational programs to improve midwives’ and birth attendants’ skills in safely managing normal deliveries, recognising perinatal complications and making timely referrals for higher-level care could improve neonatal morbidity and mortality.

**Limitations**

We interviewed parents already receiving care in regional referral centres; our results likely under-represent the difficulties faced by parents in large regions in each country where little skilled neonatal care is available. We interviewed multiparous and primiparous mothers, which introduces some heterogeneity, but also improves generalisability, of our results. Literacy, in particular health literacy, varied among centres, with many women at AHC unable to read or write. Even though we used medically trained, bilingual interpreters, questions may have been interpreted differently across sites. It is conceivable that in these countries, some families would not feel comfortable in identifying barriers when interviewed by local providers. We also interviewed only families who had already accessed medical care. Families who did not seek medical care would likely face additional barriers. For these reasons, we may have underestimated perceived barriers to care in these developing countries.

**Summary**

Health-care costs, opportunity costs of obtaining care and limitations in services and medications are challenging issues to remedy in low-resource developing countries. Non-economic factors may be more amenable to quality improvement initiatives. Improvements in facility cleanliness, patient privacy, staff treatment of families and communication with parents represent low-cost methods by which low-resource hospitals might...
begin to break down barriers to care. Educating parents on where and how to access care and empowering them to recog-
nise neonatal illness would increase care-seeking behaviours. 
More widespread education of family members, non-medical
community members and traditional birth attendants would be 
an added method to trigger earlier recognition of illness, hasten
parents’ willingness to access care and decrease delays in referral
for care.

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