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Understanding Demand for Healthcare Among Families of High-risk Newborns

By: Taha Ibrahim Siddiqui,Nayana Nair,Diane Coffey

'Low birthweight and prematurity' is now the most common cause of child death in India. Apart from improving publicly provided newborn care, we need to communicate to families how vulnerable their babies are and how important appropriate care is to their survival.

One December morning in a village in Uttar Pradesh, Khushi started having labour pains three weeks before her baby's expected date of delivery. She and her husband Shivam rushed to a large government hospital in the district capital, where Khushi was admitted to the labour and delivery unit. After what felt like an eternity to Shivam, the nurse emerged with the news that Khushi had given birth to a girl baby who weighed only 1,500 grams.

Healthcare providers consider babies weighing less than 2,500 grams as 'low birthweight' (LBW) and those weighing less than 1,800 grams 'very low birthweight' (VLBW). According to government guidelines, when a VLBW baby is born in a public facility, she should be assessed and treated by a Special Newborn Care Unit (SNCU), and her parents should receive training from the nurses about how to care for the baby at home. Khushi and Shivam's baby needed these services.

Despite the baby's poor condition, Shivam knew that their family could not afford for him to be away from home for long. It was the planting season and he needed to sow the rabi crop. The nurses asked whether he could leave Khusbhoo and the baby in the hospital. Despite initial hesitation, he was willing. Khusbhoo, however, was scared. Navigating the hospital by herself seemed daunting. What if she could not understand what the staff expected of her? Who would bring food for her? Who would look after the baby when she needed to take a bath or use the washroom?

Khushi and Shivam are not alone in facing such a dilemma. The Million Deaths Study (2017) found that prematurity and low birthweight is the leading cause of child death in India (Fadel et al. 2017). An important reason why prematurity and low birthweight contribute to so many child deaths is a shortage of appropriate care for such babies. Rural public healthcare systems face several challenges in delivering services, including lack of space (Kumar et al. 2020), lack of medicines and supplies (Raut-Marathe et al. 2015), and high rates of absenteeism among staff (Banerjee et al. 2004).

There is a shortage of appropriate healthcare for premature and low birth weight babies. It is also important to address the fact that many families do not seek care, even when it is available.

However, even when appropriate care for premature and low birthweight babies is available in public hospitals, parents like Khushi and Shivam may face significant barriers to taking advantage of it. We, the authors, have the privilege of supporting a dedicated group of nurses and doctors who provide care to premature and low birthweight newborns in rural Uttar Pradesh, and counselling and training to their families. Among the most important skills that they teach families are how to provide kangaroo mother care (KMC), which involves holding the baby skin to skin on the mother's chest for extended periods of time, and how to provide breast milk to babies who initially struggle to breastfeed.

As part of this experience, we have come to understand that in addition to the supply-side challenges described above, premature and LBW babies face important challenges when their families do not demand healthcare (Ministry of Health and Family Welfare 2014). Given this context, it becomes pertinent for health workers to re-imagine their roles. They should focus not only on providing high-quality care but also on educating families about the benefits of appropriate care for their babies and the risks of caring for a low birthweight or pre-term newborn in the same way they might care for a full-term, normal weight newborn.

Popular misconceptions

Premature and low birthweight babies face unique health challenges in the first days and weeks after birth. With less body fat than full-term, normal weight babies, they are less able to regulate their body temperatures, putting them at risk of hypothermia. Many premature babies have not developed the sucking and swallowing reflexes they need to breastfeed. They may need to be fed by cup, spoon, or feeding tube.

They may have trouble breathing. Many would benefit from special medicines, machines, and constant skin to skin contact with their mother, which 'reminds' them to breathe. They are also at a higher risk of infection than babies who are born full term and at a normal weight. For all these reasons, receiving timely and appropriate health care promotes their survival.

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Unfortunately, parents in rural Uttar Pradesh often underestimate the complications their low birthweight or premature baby may face. Prior research documents that birthweight may not even be perceived as the key indicator of newborn health that it is (Darmstadt et al. 2008). We have often heard family members say, "*Haadh hai, maas chadh jayega*," which translates to "The bones are there, the muscles will come."

Parents may be unconcerned about their child's low birthweight if they know of a neighbour or a relative whose small baby survived. Often families do not think low birthweight is a concern and do not understand the need to weigh and measure the growth of the babies. In the days after birth, families tend to be more concerned about the appearance of the newborn than the weight.

In much of rural north India, healthcare workers may be too busy or too culturally distant from the families they serve to bridge this information gap. One thing that is special about the nurses who we work with is that they take time to explain the specific problems that vulnerable babies face in terms that families can understand. For instance, when interacting with families from villages, the nurses avoid medical and English terms, such as 'prematurity'. Instead, they might compare a baby born early to picking an unripe mango.

They explain the benefits of the baby staying in the hospital until she has been discharged (rather than leaving against medical advice) and the benefits of continuing the types of care they learn in the hospital at home. For example, the nurses explain how keeping the baby skin-to-skin on the mother's chest mimics the womb's environment and helps the baby grow, much like how placing an unripe mango in a warm environment helps it ripen. Counselling that is individually tailored to both the baby's needs and to the family's background improves communication and increases the adoption of evidence-based practices.

Importance of nursing

Another barrier to care-seeking amongst the families of premature and low birthweight infants is families' perception of what constitutes 'good' medical care. One of the nurses who we work with shared the story of a father whose baby needed to be fed by a cup because she was too weak to feed from the breast. The father said, "*Dawai sui to chalti nahi hai yahan, doodh hi to pilana hai to ghar pe hi pila lenge*." This means, "The baby isn't getting any kind of medicine or injection here, if she only needs to be fed milk, well, we can feed breast milk at home as well."

We have heard similar statements from many parents who perceive only those medical treatments prescribed by doctors, such as oxygen therapy or antibiotic injections, to be worth the difficulties and costs of staying in the hospital. They are less likely to see the value of the care, training, and monitoring provided by nurses. Yet, nurses play an essential role in the survival of low birthweight and premature babies.

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In this case, it would take several days for a nurse to show the mother and other caregivers how to express breast milk and cup-feed using safe techniques. The baby would need to be fed sitting up, rather than lying down, and the milk should be held at her lips, rather than poured in her mouth. At times, she might require stimulation on her hands or feet to stay awake long enough to swallow the correct quantity. It would be dangerous to feed her if her body temperature were too low. All these tools and techniques take parents time to learn. But once they know them, their child's growth improves, and the chances she will die due to swallowing milk into her lungs decreases dramatically.

When families have a hard time seeing value in health interventions other than medicines and machines, how can nurses convince parents to stay in the hospital long enough to learn how to care for their babies? The nurses we work with have found that it helps to take time to explain each baby's individual needs and progress.

When decision-makers such as fathers and grandparents are given regular updates about their baby's vitals and her progress in terms of gaining weight or developing feeding reflexes, this gives them confidence that their child is getting something in the hospital that she would not get at home. Frequent updates also reduce families' requests for early discharges, which allows doctors to focus on the babies who need them most.

Costs of 'free' care

Even in public hospitals where care is in principle free of cost, the families of low birthweight or premature infants may still incur substantial out-of-pocket expenses and face significant opportunity costs during their hospital stay. Although there is no national data that would allow us to estimate the average cost of a week-long stay in a public hospital with a premature baby, data from the National Family Health Survey (NFHS-5) 2019-21 on the cost of care at birth are informative. Despite the Janani Suraksha Yojana that aims to make deliveries in public health facilities free to families, delivery in a public health facility nevertheless costs on an average of around Rs 2,916 (IIPS and ICF 2021).

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When a family needs to stay in the hospital with a premature or low birthweight baby, they may be asked to buy medicines or supplies. They will likely have to buy food for the attendants and pay transportation costs. If the patient's attendant is an earning member of the family, such as was the case for Shivam's family, staying in the hospital means forgoing income. This can be particularly difficult for families who rely on daily wages, such as construction workers, brick kiln workers, or rickshaw pullers.

Family structure matters

Distinct challenges arise in seeking care for premature and low birthweight babies due to variations in family structures. In nuclear families in which the newborn is not the first child, the couple may have other small children at home. There may not be anyone to care for their other children if they need to stay with the newborn in the hospital for an extended period of time.

Living in a joint family may facilitate hospital stay as there is more likely to be a relative who can be depended upon to care for the other children, or to look after the house or the fields. However, in joint families, the decision-making power often rests with older family members, who may not prioritise the mother's and newborn's health. If the family's decision maker decides not to allow the parents to seek care for their baby, there is little that the couple can do to change the decision. Sometimes, when older members of the family are sick, the young parents spend resources on their treatment that could otherwise be used to invest in the children.

The lack of decision-making power amongst young mothers in many families can also delay care-seeking when the baby falls sick or is not gaining weight appropriately at home. The decision of whether or not to take a sick baby to the hospital is with the baby's father or with the paternal grandmother, rather than with the mother.

Fathers often spend most of the day away from home and when they are home, they are typically not involved in caring for the baby. As a result, they may be unaware of a baby's changing condition. Grandmothers often want a new mother to adhere to traditional beliefs such as spending the weeks following birth in isolation to protect the baby from the evil eye. This separation of the mother and infant from the rest of the family can result in delayed care seeking.

Gender discrimination

Data from successive rounds of the NFHS finds a narrowing gender gap in child mortality in India (Coffey and Spears 2018). However, gender biases remain when it comes to care-seeking for babies with complications, including treatable complications such as low birthweight and prematurity. The UNICEF's assessment of admissions to the government's Special Newborn Care Units in 2012–13 found that for every 100 babies being admitted to an SNCU, only 41 were girls (Ministry of Health and Family Welfare 2013–13).

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The nurses we work with confirm that gender bias in care-seeking for low birthweight and premature babies is common. One of the nurses described interacting with the family of a baby girl who was born with facial nerve palsy. This condition makes it difficult for the baby to feed. The nurse urged the family to stay in the hospital to learn proper feeding techniques and hypothermia prevention. However, the family left against medical advice on the baby's second day of life.

During a follow-up visit to their home, another nurse explained that nerve palsy may improve over time, or may be treated with surgery. The baby's mother's sister said, "*Ladki hai, surgery ka bhi koi guarantee nahi hai. Pura ghar dahej mein leke jaegi, mar jaye to acha hai*." This translates to, "She's a girl, and there's no guarantee even with surgery. She'll take everything we have with her as dowry, so it would be better if she dies."

Other families are less explicit in their discrimination against girl children. However, it is far more common to hear families express ambivalence or resignation about caring for a premature or low birthweight girl than a similarly premature or small boy. For example, Poonam's baby girl was born at 1,538 grams. Despite that babies born at this weight should be cared for in the hospital for at least the first week of their lives, the family opted to take the baby home after only three days.

Poonam's father-in-law told the nurse who visited their home, "*Upar se rassee mazboot hoga to bach jayega, warna tut jayega chahe hospital ho ya ghar*." This means, "If the rope from heaven is strong, then this baby will survive. Otherwise, she'll die, it doesn't matter whether we take her to the hospital or not."

In the context of rural Uttar Pradesh, there are no straightforward ways for a health worker to address gender bias in families' health-seeking behaviour. However, it is important for them to recognise discrimination in the care of girl children and address it in their counselling. If families are unwilling to seek hospital care for girls, nurses can train mothers to improve their newborn care practices at home. Female nurses can point out that they are living examples of how girls are worth the investment. After all, they can grow up to earn money and contribute to their families.

Superstition over healthcare

As in many other parts of the world, some families in Uttar Pradesh place more trust in traditional healers than they do in the health system. They prefer to take low birthweight and premature babies to traditional healers for *jhadphook* rather than seeking hospital care (*jhadphook* roughly translates to "exorcism"). They believe that their children are afflicted by *sukhabayar*, an evil spirit which dries up their vitality.

To ward off evil spirits, traditional healers or *babas* perform rituals which may harm the baby. Some babas rub *chuna* (lime) on babies' backs. This results in burns, which are painful for the babies, and can become infected. Babas may dip a baby's finger in hot oil, which exposes the baby to pain, infection, and in some cases, gangrene. Although local government authorities occasionally take action, babas largely operate with impunity.

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How should healthcare workers who want to promote evidence-based care and protect premature babies from jhadphook navigate the parents' superstitions? Criticising and demeaning their beliefs is unlikely to work (Ranganathan 2014). After all, caring for a sick newborn is an extremely stressful experience for parents. Healthcare workers will be more effective if they remain patient, understanding, and compassionate (Post 2011).

The nurses we support do not challenge parents' beliefs in evil spirits directly. Rather, they request that the parents first get the baby the appropriate hospital care. If the parents are nevertheless intent on jhadphook, the nurses try to convince them not to allow the baba to harm the baby.

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They show pictures of babies who had complications due to burns. They ask the family to continue the care practices that they learnt in the hospital and to restrict the jhadphook to incantations or other exorcism techniques that do not involve touching or feeding the

baby. They invite the family to return to the hospital if they notice danger signs in the baby.

The nurses also recognise that not every superstitious practice is harmful to babies. For example, some people put a jaggery paste on the heads of newborns in the place where the skull has not yet closed. Villagers call this spot *sundabba*. They believe it is possessed by an evil spirit because the baby's pulse is visible there. Because there is no harm to the baby by applying a jaggery paste, the nurses focus their counselling on those things that will make a difference to babies' survival, such as kangaroo care and feeding breast milk rather than cow's or goat's milk.

Conclusions

This article has explored the factors shaping families' demand for healthcare for low birthweight and premature newborns in rural Uttar Pradesh. In addition to increasing the quantity and quality of publicly provided newborn care, national and state governments should also work to communicate to the public the seriousness of low birthweight and prematurity, which is now the most common cause of child death in India.

Governments should also continue to expand programmes such as the Janani Suraksha Yojana and Rashtriya Bal Swasthya Karyakram to make newborn care more affordable for the poor. For example, not only patients, but also attendants could be provided with a place to stay and food to eat when a mother or child is admitted to the hospital. Cash transfers or other support could be offered to the families of low birthweight girls who need hospital care.

Medical training programmes could help nurses and doctors develop a sympathetic understanding of the barriers that families face in seeking care for newborns, and to develop messages for explaining the benefits of seeking appropriate care.

Taha Ibrahim Siddiqui and Nayana Nair are research affiliates at r.i.c.e., a research institute for compassionate economics. Diane Coffey is an assistant professor of sociology and demography at the University of Texas at Austin and co-executive director at r.i.c.e.

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