

## Palliative Care in Rural India: Lessons from Hemalkasa

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### Opinion

Deep in the heart of the Indian Subcontinent is a rural health clinic called Hemalkasa. Six hours by bumpy road away from the nearest city, the doctors at Hemalkasa serve an impoverished tribal people, whose villages are scattered yet farther from the lone road. Amidst lush forests, Hemalkasa has grown in stature and capability over the past 30 years. From humble beginnings, the clinic now boasts three operating rooms, hospital wards, and even incubators and ventilators. Beyond the impressive medical care provided at Hemalkasa, the clinic serves as an economic engine for the region. There is a school educating hundreds of children, most from the surrounding tribal villages, there are jobs for workers in arenas as diverse as construction to farming, and there is nutritious food and clean water for the many who live within and around the clinic. Much publicity has come to their doorsteps following release of a movie depicting the pioneer husband and wife physician couple who dedicated their lives to the care of some of India's most neglected peoples.

The so called "tribal" people, a government designation for a heterogeneous group who share the common characteristic of being the aboriginal people of South India, are simple and hardworking. Their villages often lack electricity, running water, telecommunication, and sewage. Most speak a language that shares no roots with other Indian languages, making communication a challenge.

One can imagine that the health outcomes of these tribal people are poor. Most deliver babies in their homes, though some are coming to deliver their babies at Hemalkasa. Children have high rates of malnutrition and infection. Consanguinity is commonplace in the small villages, owing to high rates of intellectual disability, anemia, hypertension, and other diseases. Trust in allopathic medical providers is low, as is health literacy, owing to poor compliance even when they are able to access medical care.

A gradual cultural shift has taken place over time, due to the diligent outreach and trust-building efforts made by providers from Hemalkasa. Now, patients come to Hemalkasa's door, sometimes in extremis, dying of common conditions for which we have had cures for decades. People come to the clinic to have their hernias fixed and their babies delivered. They come for traumatic injuries sustained on the farm or for chronic low back pain. Some of the school children have graduated from the Hemalkasa school and work at the clinic, translating between their native languages and the ones spoken by the staff at the clinic, helping mediate between their old world and their new one.

One of the tribal women who had decided to deliver at Hemalkasa came to the clinic at full term with her husband and mother. She was in her 20s, petite, wore a bright orange sari, and was adorned with her village's distinctive piercings and tattoos. She was not in labor at the time of her initial assessment, so she waited patiently until her contractions began. A few days after we first met her, we were asked to

urgently come to her room. My wife, an OB/GYN resident, quickly noted that the patient had prolapsed the umbilical cord. She pushed her hand into the woman's vagina to elevate the baby's head and relieve the pressure on the cord. She gave me a slew of instructions to uproot me from my glacial stance in the corner of the room. "The pulse is thready. Start the timer. Call the attendings, tell them we need to do a stat C section!". The patient was writhing in agony, as her contractions had commenced with great force. My wife left to scrub and I was instructed to place my hand inside the patient's vagina and hold the baby's head up. With each contraction, I could feel the head descending, compressing the cord and ablating the pulse. The staff mobilized, prepping the operating room for its first emergency surgery.

Twenty minutes later, the baby was delivered, limp, dusky, without respiratory effort, but with a faint pulse. I took the baby to the incubator and began to provide ventilation through a bag-valve mask. Seeing no improvement in the respiratory effort, I realized that I would have to intubate the baby. There was one neonatal endotracheal tube, a laryngoscope with a dim light bulb, and no suction. I intubated the esophagus twice, but succeeded on the third try. Immediately after the intubation, the baby gasped and began to breathe on his own, becoming more pink with each breath. I grew anxious about how long the resuscitation had taken, about how long the baby had been without oxygen. There were also no neonatal ventilators, so our only option for the baby was to bag him until he reliably was breathing on his own. For a tense hour, I stood there bagging him, gradually weaning him off to see if he would suck air through the tube, which he gradually began to do. When I pulled the tube out, I thought about how unheard of this would be in the United States, about the luxuries, like the neonatal ICU, I've taken for granted during my Pediatrics training. Remarkably, the baby survived. We were able to bring him to the incubator, and concoct some IV fluids to get him through his first night. I will never forget the father's face or the characteristic one-handed "namaste" he gave me when he first laid eyes on his son. He was so grateful for everything we had done, and I was wracked with guilt that I lacked the ability to communicate the baby's prognosis to him.

The baby developed severe tremors and seizures in the subsequent days. His family was confused because he wouldn't eat, though it was evident to me that his spasticity would preclude him from being able to latch and suck. There were no feeding tubes, so the only thing we could do was spoon feed some formula into the baby's mouth, hoping that some would trickle into his esophagus. We knew that even the formula was a short term solution, as there was no commercially available infant formula that the family would be able to continue at home. We had enough to help the baby survive, but not much more than that.

I was moved by the empathy the nurses and doctors displayed as they interacted with the parents and the baby. Though they were far away from their native village and their support structure, they were treated with dignity at Hemalkasa, and supported through this difficult time. Through non-verbal gestures, we were able to illustrate that we

had not abandoned the family as they cared for their newborn. The ethos of palliative care is to share a journey with a patient and family as they navigate the end-of-life. Despite being unable to provide this baby with the breadth of medical resources that I had become accustomed in the US, I witnessed the nurses and doctors providing what I felt was the essential tenet of palliative care: being there.

Many months since these intense moments, I still think about the baby and his family. I often wonder if it would have been ethically permissible to have forgone the resuscitation so that the family could cherish their newborn for those precious first few minutes, allowing for a peaceful, natural death. In the absence of therapies that can change the ultimate outcome, the concept of minimizing suffering appeals to me. However, I hesitate to invoke our Western cultural norms to this situation as the parents may not harbor these same values. For one, the tribal population holds the birth of a baby boy in higher esteem than having a girl. It's difficult to project the importance that birthing a male child had on their sense of self-worth. Furthermore, attempting to prognosticate neurological outcome is fraught with limitations, especially in the absence of sophisticated neuro-imaging. Though I had a sense of the baby's ultimate prognosis, I don't know whether the family will have weeks or months or more with their child. And, more importantly, what would this time together look like? Ensnared in the glow of parenthood, would the family treasure their handsome baby, sharing their traditions with the newborn? Or, would it be a time of duress and confusion, filled with worry about their child's inability to

eat, or his constant seizures? Any parent in this position is sure to have their own unique experience of the situation, and I can only hope that the parents of the baby fell closer to the former end of the spectrum.

I also worried about some of the downstream consequences of this case. We acted with alacrity to save the child's life, but did we fail to uphold the mother's best interests? She was left with a C section scar that may increase her risk for serious complications with subsequent pregnancies, especially if she chooses to deliver at home. Having failed to deliver a healthy baby to this family, did we erode their trust in Hemalkasa and Western medicine? How would other patients come to learn of this and how would it affect their own healthcare decisions? The ripple effects of this child's birth on the relationship between Hemalkasa and the community have yet to declare themselves.

After our sojourn in Hemalkasa, we spent a few days traveling and meeting family in some of India's largest cities. The disparity between the fortunate and less fortunate in India could not have been more apparent. In the cities, patients with influence and money have access to some of the most cutting-edge technology available in the world. However, for me, medicine isn't so much about the interventions or technology as it is about relationships between people. By opening their doors to this population without prejudice, the providers at Hemalkasa have greatly elevated the health of these impoverished communities.