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Case Report

## An obstetrician's own experience of having an extremely preterm baby: an autoethnography

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### ABSTRACT

Parental stress after the birth of a preterm baby is well known. Being an obstetrician who herself had an extremely premature delivery, the author thought of narrating self-experience regarding delivering a preterm baby. The objective is to engage the reader both cognitively and emotionally regarding aspects of preterm birth that obstetricians often disregard. Autoethnography is a unique form of research that examines an interplay between self and cultural norms. The role of narrating self-experience by the author, though well established in mental health issues, has not been explored much in maternal and child health. Mothers of preterm babies go through a mixed bag of feelings. The feelings of happiness and delight are in no time transformed into anxiety, guilt, sufferance, and sometimes even frank depression. Preventing preterm births as far as possible should be the goal of every obstetrician.

**Keywords:** Autoethnography, Preterm birth, Parental psychology

### INTRODUCTION

Parental stress after the birth of a preterm baby is well known.<sup>1,2</sup> The need to keep the infant in the neonatal intensive care unit for prolonged periods and thereby the inability of the mother to take over the role of primary caregiver adds to the stress. Although numerous studies have analyzed parents' feelings and perceptions after having a preterm baby, these are limited mainly by the fact that mothers and fathers were made to answer a predesigned questionnaire.<sup>3,4</sup> Therefore many feelings and emotions not referred to in the questionnaire were largely missed.

Autoethnography is a unique form of research that examines an interplay between self and the established cultural norms.<sup>5</sup> Elements of human experience that are un-accessible or unspeakable, primarily due to cultural norms, such as shame, guilt, embarrassment, or communication lags, are beautifully highlighted in an

autoethnography. It has its established place in assessing and managing mental health issues, but its role in maternal and child health issues has not been explored much.<sup>6</sup>

Being an obstetrician, who herself had an extremely premature delivery, the author thought of narrating self-experience regarding prematurity. The words 'I' and 'my' in this document are vital as they refer to the author's feelings in particular and may not be the general population's views. The author thought that this could be an excellent way to sensitize the practitioner readers regarding the experience of delivering a preterm baby. The goal is to engage the reader both cognitively and emotionally regarding aspects of preterm birth, often disregarded by obstetricians.

### CASE REPORT

At 36 years of age, this was my second pregnancy after an uneventful first one. Everything started normal, no risk

factors for preeclampsia or fetal growth restriction, level 2 scan, and fetal echo also normal. I was expecting a normal course of my pregnancy thereon. Unexpectedly, the growth scan at 28 weeks showed fetal growth restriction with absent diastolic flow. Even after intense surveillance, I had to undergo cesarean section at 29 weeks five days due to a reverse 'a' wave in ductus venosus. The birth weight of the baby being just 980 grams.'

## DISCUSSION

Never in my life before had I understood the importance of prolonging the pregnancy by 2-3 days when my neonatologist counseled me regarding the prognosis of babies born before and after 30 weeks. Just a meager 20 grams gain in weight would make a lot of difference in the survival rate; as the data says, survival is much better for infants more than 1 kg weight. This was probably the first time I understood deeply the anxiety that parents go through when we counsel them regarding the prognosis of preterm babies. An informed consent form informing all risks, including respiratory distress syndrome, necrotizing enterocolitis, retinopathy of prematurity, hypothermia, hearing and vision problems, dental problems, and more, made the list appear never-ending. Signing it was probably a nightmare.

Immediately after the cesarean section, I was thrilled to see the baby, just like 'mini-me,' though very weak, fragile, and tiny. The transparent skin made blood vessels appear as if they were running on the surface of the body. In the NICU, these babies need multiple 'tubes,' in the form of an oro-gastric tube, peripherally inserted central catheter, and oxygen delivering devices like nasal prongs. Screening for retinopathy of prematurity and hearing through brainstem evoked response audiometry (BERA) is usually a must before discharge. Although I knew very well that my baby would require a prolonged stay in neonatal intensive care unit (NICU), just like a layman, I would ask the pediatrician when my baby could be discharged, hoping that this would allow me to be the primary caregiver.

The first thing that the neonatologist would ask you on rounds is that 'Is the breast milk amount adequate?' adding instructions to keep me mentally relaxed and to take adequate sleep, to keep up the supply. Mothers of premature infants face multiple challenges in establishing and maintaining a proper supply of milk. Delayed secretory activation, insufficient milk volume, and difficulties in milk expression due to stress, anxiety, and inadequate support are a few to mention.<sup>7</sup> Expressing breast milk multiple times a day is required to maintain adequate milk output for a longer duration. Pumping 8-10 times a day exhaust you both physically and mentally. I, too, had a tough time in trying to maintain the supply.

Preterm babies are a challenge to feed. Mine was no different. Immature physiological and neurodevelopmental systems lead to weak suck and difficulty coordinating breathing and swallowing.<sup>8</sup> Very

low birth weight preterm infants are unable to feed directly from the breast. Feeding them through an oro-gastric or nasogastric tube is a norm, but seeing the tube being inserted repeatedly is a trauma beyond imagination. Transitioning from gavage to oral feed is again a challenge. It is not yet clearly recommended that tube feeding can be discontinued in place of oral feeds.<sup>9</sup> This is the time when when you are faced with a double dilemma, on one side that the milk intake should not go less otherwise weight gain would not be adequate and on the other side knowing dangers and complications of gavage feeds, a stress to get rid of the tube as early as possible.<sup>10-12</sup>

Staying in the neonatal intensive care unit makes you obsessed with numbers. How many ml of milk did the baby take? How many grams of weight was gained in the last 24 hours? How many ml of urine did the baby pass? These are the everyday things noted in NICU. After staying for 75 days in NICU with my baby, I had become so used to this that even after discharge, I was not comfortable at home until I made a file to record these things daily, even though my neonatologist advised not to do so. He advised measurements once a week, but somehow, I felt uncomfortable in not doing so. These daily measurements would make me happy and sad disproportionately, as per the favorable or unfavorable nature of these. I even had anxiety in feeding my baby directly at the breast because as I wasn't able to measure the intake, I always feared that she hadn't had enough. I had to take consultation with a lactation expert to resolve such issues. I would, at this time, take a chance to emphasize the role that lactation consultants have in such situations. They should be involved from the beginning so that transition from tube to the breast is smooth and timely.

Premature babies are faced with multiple risks that are often unheard of in full-term babies. Even simple procedures such as routine vaccination need special care and inpatient observation. A few vaccines have a potential risk of precipitating apnea, necessitating respiratory support.<sup>13</sup> When you are mentally relaxed that the baby is now moving towards a more or less normal course, apnea requiring oxygen support just due to vaccination is difficult to accept, even when you are a qualified health professional yourself, with due access to all literature.

A very high rate of depression, anxiety, and post-traumatic stress disorders has been reported in mothers of babies born preterm, having a significant impact on the growth and development of infants.<sup>1,2</sup> Being well versed with all the published data, there was a double conflict in my mind, putting undue pressure on oneself to fight the existing or non-existing psychiatric and psychological imbalance.

The experience changed my practice in a particular way that I would personally think thrice before taking out a preterm baby, review the indication again and counsel future parents in a more considerate and empathetic manner.

## CONCLUSION

Preventing preterm births should be a goal of all practicing obstetricians. Primary prevention strategies such as improving adolescents' health and well-being so that they enter their reproductive age free of preventable complications like anemia, hypertension, obesity, and infectious diseases should be done. Thinking thrice before delivering out a preterm baby as even a few days of prolonging pregnancy can have far-reaching consequences on their survival and prognosis. All couples planning pregnancy should be encouraged to go for pre-conceptual counseling and evaluation to improve modifiable risk factors like smoking, cocaine use, improving nutrition, glycemic control in diabetes, and preventing and timely treating urinary tract infections and sexually transmitted diseases. Medically indicated preterm births, though unavoidable, are probably the group that can be a target for policy framework. An audit into the indications of preterm births in all hospitals, an opinion of two specialists, especially when induction of labor or cesarean section is done at preterm gestation, and involving neonatologists at a stage as early as decision-making are a few measures. Although simple, these could go a long way in improving the outcome.

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