

Right Brain: We were all once “fixed and dilated”

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I was the child neurology resident on service when we were asked to consult on a 27-week premature baby transferred to the intensive care nursery. The baby had developed *Escherichia coli* meningitis at 1 week of life. The referring pediatrics team described him as having “fixed and dilated” pupils with a “burst suppression” pattern on EEG. They appeared to have given up hope for the baby’s recovery, telling the transport team, “I’m so glad you have an ethics team at your hospital that can help facilitate withdrawal of care.”

I immediately felt the need to protect the baby as I listened to him being described in these terms. I was 26 weeks pregnant at the time. The baby was a gestational peer to my own baby, and I felt he was being profoundly misunderstood. I knew that developing in a darkened uterus, my baby’s pupils were also “fixed and dilated” and his brain wave activity was also “burst suppressed” in appearance. At that age, all babies’ are.

Just like the neocortex, the brainstem develops over the course of gestation. As neurologists, we tend to think of brainstem function as essential to life. However, many core brainstem functions, such as the regulation of breathing and a gag reflex to protect the airway, are unnecessary during fetal life. These abilities mature only in late gestation in preparation for birth. A pupillary response to light, not yet needed in a darkened womb, is almost invariably absent prior to 30 weeks’ gestation.¹ The pupils rest comfortably at 4 mm until then.

Cortical electrical activity also develops and evolves over the course of gestation. At 24 weeks’ gestation, cortical neurons have just barely completed their long migration to the brain’s surface. A pattern of continuous brain wave activity is not present in all behavioral states until at least 35 weeks.² Periods of electrical discontinuity punctuated by brief bursts of electrical activity—what might be called “burst suppression” in a more mature brain—is simply how the premature brain hums along. Pediatric epileptologists describe this normal

premature EEG tracing as “trace discontinue” or “appropriately discontinuous for gestational age,” not “burst suppression.”

Certain labels are emotionally laden in medicine—technical euphemisms for an unsaid but clearly intended deeper truth about a patient’s condition. “Fixed and dilated” and “burst suppression” are certainly among these, connoting severe neurologic dysfunction in an adult, or even a full-term infant. But they have no place in describing the neurologic status of a very premature baby.

The nurses in our neonatal intensive care unit spoke in hushed voices, with eyes lowered, around the baby. Those labels had marked him in their minds as a baby they should take care not to get too attached to. I was grateful that his parents did not overhear their discussions.

As neurologic consultants, we tried to undo the harm this inappropriate labeling had done. He was not a “fixed and dilated baby,” but rather a premature baby with a developmentally appropriate neurologic examination. Further, his EEG was appropriate for gestational age. However, the power of these phrases, and the associated perception of the baby’s condition, persisted. The pediatric residents continued to write “pupils fixed and dilated” in their daily progress notes despite our suggestion that they simply describe what they see: “pupils 4 mm and not reactive.” The nurses would ask us, “But isn’t he in burst suppression? How could he ever recover?” I began to learn how the power of certain neurologic terms, once uttered, biased all subsequent information to the contrary.

Working in the neonatal intensive care unit while pregnant was challenging. There was the understandable fear that my baby might suffer from any of these same conditions. But I found it more frightening to imagine that my healthy baby, if born too early like this baby, could be mistakenly perceived as so neurologically damaged as to be beyond hope. Our role as neurologists in reframing this baby’s prognosis felt far more important to me than our traditional role of

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Disclosure: Author disclosure is provided at the end of the article.

diagnosing neurologic injury. Just as it is often said in law that it is better to let a guilty person go free than to wrongfully imprison an innocent one, it seemed to me a worse medical error to assign neurologic injury where there was none than to miss it where there was. For days his team had talked about him and approached his care as if he were practically brain dead. I wonder how much time, thought, and attention he did not receive because his doctors and nurses had been led astray by the inaccurate use of neurologic terms. Thankfully, the baby continued to do well regardless and after several days of observation returned to the referring hospital to complete his course of IV antibiotics.

Health care providers are often attuned to the subtleties of the language used within their narrow spheres, but these can be lost in translation for others less familiar. As neurologists, for example, we are usually cognizant of how clinical context affects the interpretation of key phrases. “Pupils fixed and di-

lated” may simply mean the patient has just returned from the ophthalmologist’s office. “Burst suppression” may have been intentionally induced for the treatment of status epilepticus. However, for our colleagues outside of neurology, these phrases may be assumed to be synonymous with neurologic devastation. In most circumstances, avoiding the use of coded euphemisms is probably best. When used by others, our responsibility must be to ensure they are interpreted in the proper neurologic context.

DISCLOSURE

Dr. Gelfand serves on the *Neurology*[®] Resident & Fellow Section editorial team.

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Neurology 2010;75;1851-1852

DOI 10.1212/WNL.0b013e3181fd6381

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