

## FROM THE FLOOR

By Genevieve M. Clavreul, RN, Ph.D.

# Normal is as Normal Does

*What a rural family taught our PICU about taking a patient history*

**N**ursing professionals are accustomed to performing our tasks within a scope of practice and standard of care. We interpret tests based on ranges of highs and lows that help us determine whether or not our patients are exhibiting symptoms of an illness. We take histories to develop a picture of who our patient is, and thus how best to treat him or her. However, there are times that even with all the facts in hand, we're confronted with a case that seems to defy what we know should be true. These are the moments when the concept of normal, like beauty, is in the eye of the beholder.

Many years ago, I was the head nurse of the Pediatric Intensive Care Unit (PICU) at Columbus Medical Center in Columbus, Georgia. Our public hospital served a large population of patients and families that lived

in rural, and sometimes very isolated, areas of the state.

We got a call one morning that a young girl was being transferred to our unit after being admitted and stabilized in our emergency room. She had suffered head trauma after taking a header off the hayloft in the family's barn. Her parents were older; she had come to them late in their lives. Shortly after she was admitted to our PICU, I met with them and worked on completing some of the assessments that weren't done upon emergency admission but were needed for her stay in our PICU.

We went through the usual litany of questions — childhood illness, allergies, medications and so forth. The family was quite forthcoming, answering each question carefully and responding in the affirmative that their daughter, other than the recent fall, was normal.

### The Urgent Call

A short time later I was paged to the nurse's station to answer a call from the surgeon who was performing the operation on the young girl. I knew instinctively that the call was urgent, since it was rare for a surgery to be interrupted. (Well, there was that doctor who stepped out of a surgery in progress to file his income taxes — but that's another story.)

The surgeon quizzed me on the patient history, apparently concerned about the parents' assertions that their daughter was normal. He then stated bluntly, "she has no corpus callosum and consequently should exhibit noticeable neurological deficits."

The ramifications of his statement sank in, and a moment later I assured him that I would return to the parents and do a more in-depth inquiry into their daughter's behavior at home.

### Detective Work

I walked back to the waiting room to speak with the parents, but stopped near the entrance as I heard them engaged in a discussion with some of the others. Since their children were nearly the same age, the parents were sharing stories about their children, books they liked, games they loved to play, and so forth. I could hear the parents whose daughter was undergoing surgery punctuate the conversation with numerous comments like "oh, our daughter doesn't do that yet."

After listening for a few minutes, I approached the parents and took them to a more private area where



**She was the only child of older parents who was isolated from kids her own age**

we could speak. I started by informing them that the surgery was progressing but that the surgeon needed some additional details about their daughter.

I asked them to describe a typical day in their household. They told me that their closest neighbors were 10 miles away, and town was even further, which wasn't a problem yet as their daughter wasn't school age. I asked about her brothers and sisters, to which they responded

## It became clear the parents lived in blissful ignorance of their daughter's neurological deficits

that there were none; she was their only child. She was "their little blessing" the mother said — her daughter came to them when she thought she was well beyond her childbearing years.

Was she born at home or in a hospital? I asked. "Why a hospital of course," they responded. So I asked them to recount as best they could her birth. Did they remember anything unusual? Could they recall what the doctors and nurses told them about the health of their child the day she was born? No, nothing unusual and she was a healthy baby, born with all her fingers and toes and perfect, they told me with beaming smiles.

I probed further: how did she get along with her friends? They responded that they lived a solitary life, far from town, so it was just their little family. After our exchange it became clear to me that they loved this little girl with all their heart, but had no sense of what milestones their daughter should have reached as she progressed from newborn to toddler to preschooler — thus they had no idea that their little blessing was developmentally delayed. They lived in blissful ignorance of their daughter's neurological deficits. I thoroughly documented our discussion and left a message for the surgeon to call me as soon as he had the opportunity.

### The Surgeon's Response

I can still recall the surgeon's shock. He was incredulous — how in this day and age did a child with no corpus callosum not get diagnosed, how did the parents not realize that their child was not "normal"? We met later with the family to go into greater detail regarding the expected outcomes of the surgery, and to also explain to them the implications of the lack of a corpus callosum.

In layman's terms he explained that agenesis of the corpus callosum (ACC) was a birth defect in which the structure that connects the two hemispheres of the brain (the corpus callosum) is partially or completely absent. There are a spectrum of symptoms associated with ACC

## Healthcare Reform March Update

by Genevieve M. Clavruel, RN, Ph.D.

### The Back Story

On March 23, 2010, President Obama signed the Patient Protection and Affordable Care Act (ACA), a sweeping package of provisions we know as "healthcare reform." Provisions go into effect during the next four years, with most changes taking place in 2014. Enactment of the law is complicated by mounting legal challenges.

Stay tuned as we guide working nurses through the twists and turns, and provide an answer to the question: "What is going on with healthcare reform?"

### States' Rights

On Feb 28, 2011, President Obama announced that he supported changes to the 2010 healthcare law that would allow states to opt-out of certain provisions of the ACA. This new announcement appears to be a White House endorsement of a proposal introduced by a trio of senators late last year to offer increased flexibility to the nation's governors.

The bill, sponsored by Senators Scott Brown (R-Mass.), Mary Landrieu (D-La.) and Ron Wyden (D-Ore.) would accelerate the provision in the law that would allow states to ask federal health officials for "innovation waivers."

Congress must approve the change, and then Health and Human Services officials need to write rules defining specifically how states could meet the criteria for a waiver. Should Congress approve the change, states could apply for "innovation waivers" as early as 2014 instead of in 2017.

### Latest Court Ruling

In the latest round, the controversial individual mandate is ruled constitutional. Senior Judge Gladys Kessler, U.S. District Court in Washington, D.C., threw out a lawsuit brought by five plaintiffs who were represented by the American Center for Law and Justice.

So for those who are keeping track, that makes three courts that have upheld the ACA law (in whole or part) as constitutional, and two courts that have ruled the ACA law (in whole or part) unconstitutional. **WN**

## FROM THE FLOOR

such as seizures, developmental delay, hypotonia, poor motor coordination and a high pain tolerance. There was no standard course of treatment for ACC other than managing symptoms and seizures if they occurred.

The parents seemed completely overwhelmed. When the surgeon asked if they had any questions, they numbly nodded no, and the surgeon patted the father on the shoulder and assured him that all would work out in the end, and left to attend another case.

### Nurses Spring Into Action

I suggested they take a short break, get something to eat, and afterwards we could discuss what the surgeon had told them. I could answer any additional questions they might have, and we would talk about what the future might have in store for their family.

I quickly gathered the nursing team and we developed a care plan and made a list of the other departments we would need to engage in providing care, treatment and support for our patient and her family.

When the parents returned to the PICU they visited their daughter's bedside, where I joined them a short time later. I gave them a brief update on her condition, reassuring them that the surgery had gone well, and even with the diagnosis of no corpus callosum the prognosis wasn't grim. By their own accounts, until the fall from the hayloft their daughter was living the happy and carefree life of a child.

### The Outcome

I would like to say that they all lived happily ever after, but that would not be the case. Several months later, they filed suit against the hospital and treating physician; their contention was that the surgeon had somehow injured their daughter during the surgery, leaving her with developmental delays and neurological deficits.

Needless to say they were not victorious in their lawsuit since that it was the lack of a corpus callosum that was the cause of their daughter's problems, and not the treatment for her head injury.

This nursing experience taught me that when taking a patient's history, it is critical to not just ask the questions in the broad sense, but to also ask questions that can offer context and provide a more accurate picture of the patient, especially when that patient is pediatric. I've never quite forgotten that perfectly "normal" little girl whose parents taught me that the meaning of the word can be quite subjective, and is often entirely in the eye of the beholder. **WN**



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