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INSIGHTS

Family-flustered care: a case against jargon in the NICU

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Why, may not that be the skull of a lawyer? Where be his quiddities now, his quillities, his cases, his tenures, and his tricks?

From Shakespeare's Hamlet

While poetic, the jargon used by Hamlet as he ponders the skull a gravedigger just tossed toward him may puzzle many people today. Like reading Shakespeare for the first time, for parents in the neonatal intensive care unit (NICU), discussions during family-centered rounds often require deciphering the meaning of unfamiliar terms and archaic language. The following scenario illustrates a prevalent shortcoming of using jargon-laden medical language during family-centered rounds in the NICU.

It was 11 a.m. and the medical team was rounding outside the room of a term baby boy named Ezra who was admitted to the NICU the previous night for therapeutic hypothermia for neonatal encephalopathy. The neonatology fellow was leading rounds, so I listened and watched from the periphery as the team discussed Ezra's medical issues with his parents. The parents, both in their early thirties, stood next to each other in the doorway of Ezra's room surrounded by the medical team, which included a nurse, a neonatal nurse practitioner, a fellow, a medical student, a pharmacist, and a nutritionist, with their respective computer carts. Beyond the doorway, in the dimly lit room, Ezra's small body appeared motionless as he lay on a cooling blanket, draped in wires and tubing, surrounded by machines and monitors. His parents appeared glued to fellow's presentation as she ran through a list of their child's medical issues, lab results, and plans for the day. As I listened, I wrote down medical terms that I thought might be unfamiliar to the parents—44 total. After rounds, I typed up the list of terms and printed them out. I went to Ezra's room and again introduced myself to the parents.

I stared at Ezra who was lying on his back wrapped in a white plastic cooling blanket. His eyes were closed, and a breathing mask covered his nose, secured by straps over his round cheeks. Wisps of golden-brown hair peeked out from the white gauze wrapped around his head like a turban to safeguard the scalp electrodes recording his brain activity.

"Congratulations on your new baby," I said. "I know what happened was unexpected and can be super stressful. How are you coping?"

"Thank you. It was really scary at first," his mother said as she squeezed her husband's hand. "But we are feeling better because he is here."

"That's good to hear," I said and smiled. "One of the challenges of having a baby in the NICU is that there can be uncertainty about exactly how your baby will recover, especially when it comes to predicting how your baby will do in the future," I said and paused. "To avoid adding to the uncertainty, I want to spend some time discussing some of the potentially unfamiliar or confusing medical jargon we use in the NICU."

"I have a medical background and work as a radiology tech," the mother said, "So I'm used to it."

"I do construction work," the father said. "This is all new to me."

"Just so we are all on the same page regarding Ezra's medical condition and care plan, can we discuss some of the terms we used on rounds?" I asked.

They nodded and we sat down next to Ezra's radiant warmer bed. I leaned forward in my chair and handed them the list of terms I had printed. Of the 44 medical terms, they were only able to accurately describe three: therapeutic hypothermia, brain MRI, and ampicillin. The other 41 terms, which included jargon such as NIPPV, clamping down, slit ventricles, base excess, cryo, coags, iCal, TPN, UVC, and 2 MeQs of KCl, were unclear to them. We sat together for about thirty minutes, while I explained each unfamiliar term and made sure I allowed time for additional clarifying questions.

"That was helpful," the father said. "I had not heard of most of those words."

"Yes, thank you," the mother smiled.

A core concept of family-centered care is to share information with families in a way that is affirming and useful. The above example represents an all-too-common reality of how jargon-infused medical information is presented to parents on NICU rounds and yet, despite hearing the discussion, they may not comprehend what was said. Routine inclusion of medical jargon in conversations with parents, whether on rounds, when obtaining consent for a procedure, or explaining study results, risks providing incomplete or inaccurate information. Instead of family-centered care, the use of jargon can lead to parental frustration may promote family-flustered care. If we strive to have parents effectively participate in their baby's care and decision-making, why do we habitually use language that may generate misconceptions or ambiguity, especially when the subject of these crucial conversations is someone's son or daughter who requires care in the NICU?

Parental uncertainty may not be apparent without paying close attention to a parent's reactions during these discussions in the NICU, which is challenging if too much time is spent staring at computer screens. Since some puzzled parents may not provide facial expression clues that reveal their questions or worries, being proactive and respectful and inquiring about their understanding of medical terms, concepts, or care plans is essential. This was the

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case when I asked during a presentation on rounds whether a mother understood what the terms "apnea and bradycardia" meant. "No," she shrugged. Her daughter had been in the hospital for 102 days due to a severe lymphatic disorder, yet the mother was unaware of these common terms that were reported daily on rounds. While I was glad to finally explain the meaning of apnea and bradycardia to the mother, I was also dismayed that over three months had passed before this jargon was decoded for her. What other medical jargon had been used without explanation and how was this impacting the mother's understanding of her daughter's complex life-threatening condition? When talking with families in the NICU, avoiding jargon or explaining it right away may help prevent communication breakdown.

As neonatologists, we have an opportunity to model jargon-free or jargon-lite communication styles to facilitate clarity in discussions with families in the NICU. This requires intentional approaches to avoid medical jargon (e.g., submental erythema), to encourage trainees to use universally understood terminology (e.g., redness under the chin), and the patience to explain jargon in ways that promote clarity. We also need to avoid jargon-trade, which qualifies one confusing term (e.g., the abbreviation ABDs) with additional obscure language (e.g., apnea, bradycardia, and desaturations). Refraining from the use of obscure, unnecessary terminology may help bypass the need to put a parent on the spot in front of a team of medical personnel. We should recognize that the "*Do you have any questions?*" spotlight phrase typically offered after a 10-min computer screen-focused discourse saturated in medical jargon, may be awkward and daunting for a parent. Therefore, a polite parental "No," should not always be interpreted as "*Well, they heard me, so now they know*."

To respectfully include families in rounds, we must strive for better ways to share information with parents that will allow them to actively participate and collaborate in their baby's care. Avoiding medical jargon is an attainable step toward being more inclusive in the NICU. Periodic self- or peer-audits can promote increased awareness of jargon use and allow providers to revamp their vocabulary to help parents better understand medical terms and concepts.[1] If jargon is used, clear explanations should follow and check backs should be used to assess parental understanding.[2] Without taking time to explain our medical terminology, we promote a false sense of successful family-centered rounds in the NICU. As Shakespeare's King Lear proclaimed, "Nothing will come of nothing," (King Lear, Act 1, Scene 1). If we try to refrain from using jargon in the NICU, we can achieve more effective communication with parents, which is at the core of family-centered care.

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ADDITIONAL INFORMATION

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