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Clinical Decision Science requires doctors to examine their own inner world

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REFLECTION ON CLINICAL DECISION SCIENCE: Clinical Decision Science requires doctors to examine their own inner world

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Clinical Decision Science as explored in this journal involves the social environment of the patient and the patient's family and how that interacts with medical evidence. I realize I am part of the social environment for my patients. We can never forget that our own experiences and actions change the way our patients experience life, and death as they make decisions. That means that Clinical Decision Science requires doctors to explore their own inner world; our thoughts and emotions are part of the therapeutic relationship. With that in mind, I share my experience.

I was told in medical school that you never forget the first patient who dies under your care. I did not expect that that my first death would be a days-old baby. During my pediatric neurology rotation, my team received a consult from the NICU. A seemingly healthy newborn baby girl suddenly developed seizures and became unresponsive. Imaging showed extensive blockage of the blood vessels to the brain, and a diagnosis of cerebral sinovenous thrombosis was made.

Along with the neonatology, hematology, and neurosurgery teams, we held a family meeting. This was the first time the parents were notified of their baby's condition. They were visibly distraught, in shock, and asked the same impossible questions. The mother expressed profound guilt and believed that she was to be blamed for the events. Even though I had just met the parents, their emotional responses were heart-wrenching. When parents learn of traumatic news about their newborn child, a point is reached when information can no longer be absorbed or processed.¹ It is not unusual for them to be in shock or disbelief and to question doctors repeatedly. Families approach pregnancies and birth with hope and optimism, but do not expect tragedy to strike imminently after birth. Thus, these emotions can quickly evolve into fear and guilt.²

Once we had determined that a meaningful survival for our newborn patient was not possible, we provided the baby with palliative care and focused on pain management to provide comfort at the end of her life.³ Moreover, it was crucial to have family meetings to assess available support systems and to include the parents in developing hospice plans.⁴ Studies have shown that parents are more likely to be satisfied with the care received if their baby receives palliative services than those who do not.⁵ After numerous discussions with our patient's family, the parents ultimately decided on home hospice care for their newborn.

This was my first experience being involved in a conversation regarding end-of-life care as a medical student, let alone for a newborn who had appeared to be healthy just hours earlier. Having not had any exposure to palliative or hospice care, I realized I did not know how to approach the subject or how to respond as a healthcare provider. It was emotional for me to witness first-time parents grapple with the impending death of their firstborn child. I observed how challenging it was for the NICU physician to deliver the news and the parents were not comforted by his words. This experience demonstrated the challenges of having difficult conversations with patients and families and the importance of being prepared to do so in any situation in any specialty. It is natural for them to have unexpected reactions, and as healthcare providers, we can provide them with support during difficult times. The physicians and palliative care team were available every day for family meetings and ensured that the family had ample time to process information. They were empathetic, included the family in their discussions, and patiently answered all questions to the best of their abilities.

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In her brief few days of life, my patient had already touched the lives of those around her, including mine. Medicine requires not only the knowledge of pathology or pharmacology, but also requires compassion and comprehension of the tragedy of disease. I am grateful for this lesson, as a physician who will encounter unfavorable situations and need to communicate the outcomes to patients and their families. I will not forget my first death of a patient and what she has taught me. I probably haven't even fully realized how those experiences have changed me as a doctor. I hope this experience helps me make better clinical decisions when faced with a similar clinical situation.

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