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ESSAYS/PERSONAL REFLECTIONS

A great divide

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FROM THE EASTERN RIDGE

I met baby Olivia when she was nothing but a 32-week gestational age fetus inside her mother's uterus. Already her family had experienced heartbreak and grief. Olivia's co-twin died in utero, wreaking havoc on Olivia. As they grieved one daughter, they were also on deathwatch for Olivia, warned that her existence was perilous at best, her day-to-day chances of survival questionable, her chances of survival through birth even more grim. Her mom and dad were informed by other experts that she would likely be profoundly impaired, "neurologically devastated."

Given the prognosis, I was asked to see them for palliative care support in the high-risk OB clinic. Olivia's parents had expressed concerns about quality of life for their daughter, unsure how aggressive they wanted medical care to be to save her life. Over the course of a few weeks, I got to know them and the members of their family. I learned about their toddler-age daughter, their faith in God, and the support from their own parents and siblings. We had difficult talks about their daughter's future, and how the medical system might best meet her and their needs. Although they were offered termination of the pregnancy several weeks prior, they continued the pregnancy, wanting to give their daughter a chance, and to place her life and outcome in God's hands. They hoped for a miracle, and defined that miracle as the chance to meet their daughter alive, even if only briefly. Eventually we developed a mantra of "we will let Olivia show us the way," and had an intangible yet mutual understanding of what this would look like in the moments, hours, or even days after her birth. Sadness and fear were palpable during each of our visits, and we faced them together.

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I attended Olivia's delivery, watched her parents' grief and fear increase with each contraction. One rarely witnesses such raw human courage as in a mother giving birth to a child she does not know if she will meet alive. I saw the courage in full array that afternoon. The staff and I prepared for whatever Olivia's condition might be when she was born: dead, alive but unstable with death imminent, alive but unstable with death likely later in the day, or, least likely, alive and vigorous.

Frankly, the latter was tucked far in the back of my mind.

When Olivia was born, she did "show us the way." Her pink tone and loud cries surprised us. She was placed directly on mom's chest, screaming and rooting. Mom embraced her and quickly began nursing her apparently hungry baby. Dad had quiet tears while he held his wife. Mom looked at her baby and said, "thank you for letting us meet you."

As I walked down the hall of labor and delivery to update the rest of the anxiously awaiting family, they could see me through the long glass partition. I tried keeping a neutral look on my face, knowing they were expecting the worst. I came through the heavy double doors, and grandmothers rushed to my side as I told them that Olivia was born crying, was able to go to her mom's chest immediately, and was nursing. Then I let myself smile, or at least became aware of smiling for the first time. Cries of joy and disbelief rose up from them. I told them she had dark hair, which no one could quite believe given the rest of the family's complexions. The grandmothers gave me hugs and their thanks. I wished I could have put love and joy into a package and hand it over to this new life.

She did so well that, when she was just over 24 hours old, baby Olivia, her big sister, and her thrilled parents were home, enjoying their miracle, with home hospice services following.

Not knowing what direction her condition would take, I offered to continue as Olivia's primary

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pediatrician and continue coordinating her hospice care needs. Her parents agreed, and I think we all felt more comfortable knowing there was some element of continuity in what had been an unpredictable course of events.

And that is how I found myself as a primary pediatrician for a baby who was not supposed to live. I found myself "on the other side" of the provider experience. I found a new perspective.

FROM THE WESTERN RIDGE

For weeks, Olivia continued to do remarkably well, considering her prenatal prognosis. Her parents continued to marvel at the time they had with her. Her sister held, fed, and cuddled her little sister, whom she referred to as "my baby."

As her pediatrician, I ordered her routine vaccines, kept track of her weight gain and growth. I addressed her mild thrush, worked with parents on treating her constipation. We talked about referrals for evaluation of her vision and hearing, with the idea that properly identifying sensory losses could aid in her comfort and quality of life.

Eventually, it became clear that Olivia's honeymoon period might be over. Calls from her home hospice nurse were becoming more frequent. On a Friday visit, Olivia was nearly inconsolable unless she was taken outside in the bright light. She wouldn't eat. She seemed less alert. Signs that her neurological injury might be catching up with her, might be progressing, that what we had prepared the family for weeks ago, might now be actualizing.

This might be the descent into the valley.

As I considered the plan of care for that afternoon, I felt torn. As her hospice provider, I knew and understood the goal of focusing on Olivia's quality of life and supporting her family as her condition evolved. I knew that utilizing medications for comfort at home, helping to keep her calm there with her family without increasing medical interventions was most consistent with our plan of care. I knew her neurological prognosis was grim, her quality of life may have seen its zenith, and that, although a few months later than we had expected to enter this phase, focusing on her comfort for the remainder of her life should remain top priority.

This is a familiar plan. A plan often developed with my palliative and hospice teams with and for our patients and families. I have signed off on this plan without doubting it being the right thing, the best thing even, for the patient and family.

On this precipice, though, I stalled with doubts.

Instead of feeling certainty in the plan for comfort, I wanted to tell the hospice nurse, "they need to go to the ER." I considered opening the Pandora's Box of medical evaluation: labs, imaging, interventions, admission, to see if there were treatments that might physically stabilize her.

I desperately wondered *why* this was going on. Why *now*? Why after months at home was she failing?

After discussing the options with the hospice nurse, she said, gently, "I think they will want to keep her at home and try the meds." She must have heard the surprise in my voice when I replied, "Really?" She adeptly took control of the conversation and steered me back to this family's goal: quality of life and comfort for their daughter. They didn't want her medicalized before, nor did they seem to want it now. The family had realistic expectations, had been counseled and guided by a team—a team they had met weeks before Olivia's birth, a team that included a palliative care physician. They had carefully and thoughtfully chosen a path together, and now was not the time for me to have doubts and throw that plan into chaos because of my own needs and curiosities.

"It's not about you," I reminded myself.

Standing at the precipice, I recognized the angst of all the primary physicians caring for patients with life-threatening or definitively terminal conditions. As her primary pediatrician, I developed a bond with her not as a doomed patient, but as a patient with potential. I let myself start to believe maybe she would continue to prove everyone wrong. She would keep developing slowly, but in a forward pattern. She would have enough awareness to form relationships, interact with the world, have a true quality of life. In my dream world, this was achieved through minimal medical interventions. It was a nice picture to have in my mind. In fact, when I first noticed that she wasn't tracking light, I rechecked three times during that appointment just to make sure I wasn't misinterpreting what I was seeing

I've called out my pediatric colleagues before for not having tough talks, and yet I hesitated to say "she's not tracking" to this mother. Frankly, it saddened me to think she may have visual impairment. Saying the words to her mom, despite all of the bad news I had already given her over the prior months, suddenly felt like too much. It was her mom who broke the silence and asked, "Do you think she's tracking? I don't think she has been." Her mother, still the one with the most courage.

IN THE CANYON

Reflecting on my struggle that day, I offered apologies. Apologies to other primary physicians: for judging them when I thought they were blind to the writing on the wall, for getting frustrated when

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they wouldn't hand over more control of the patient's care to my "expert" guidance. Apologies for not respecting the part of the journey they walked with the patient and the family before my arrival on my white horse of palliation.

Then there came other apologies: to the palliative care physician for not respecting the frank and honest conversations she had been able to have with the family; apologies for not acknowledging her expertise and skill at trying to remain objective in the midst of a tragic scenario. Apologies for not respecting the goals of care, and letting the goals drive the plan.

When tension arises between a primary provider, whether a generalist or specialist, and the palliative care team, and that tension leads to discord in the plan of care, it is a failure of the medical teams. The downfall is in not respecting the nuanced relationships we and our colleagues have established and built with a patient and family. The lapse is in letting ourselves believe we know what is best for the patient rather than letting the patient and family help us understand what is best—whether we agree with it or not.

Whether the primary provider or palliative provider, we must hold ourselves and our colleagues accountable for letting the goals of care drive the plan of care, ensuring that those goals are medically realistic and feasible, respecting the well-informed decisions made by patients and their families.

We must always remind ourselves in those moments, "This isn't about me."

In the case of baby Olivia, had I called her parents and told them I felt like we needed to put her through a work-up and to get more information and find some answers, I have no doubt they would have agreed with my suggestions and followed that advice.

But who would it have helped?

These are the moments of pause all providers should take when we find ourselves doubting or disagreeing with a plan of care that has been thoughtfully and carefully developed. It is not the time to yell from one ridge to the other, stand staunchly on our side of the divide and try to force our colleagues to assume our perspective. It is the time when we should invite them off the ridge with us, into the valley, where we can be present with the patient and the family, where we continue to help even when we cannot heal.

EPILOGUE

Olivia died a few weeks later, at home, surrounded by her parents, her sister, her grandparents, her aunts and uncles. Her sister sang her songs as she took her last breaths. At the service to celebrate Olivia's life, her parents again spoke about the miracle her life had been, and as we cried together one more time, I thanked them for letting me be a part of their lives, and a part of their miracle. I left the church at peace, remembering the wise words of Paul Rousseau, M.D.: "In time, with time, things will be okay, they will be as they must."

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