Palliative Medicine, Good Days, and the Angel of Death

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I walked in the large, wooden front door and took my shoes off as the family requested. The attending pediatric palliative physician and I traded pleasantries with the family as we walked across the hardwood floor to sit on the soft, beige couch in the family den. My attention was quickly drawn to the hallway where I watched the team nurse walk in hugging baby Ellie in her arms. Ellie's mother, Gloria, paused in our conversation. Of course, I cannot be sure what her exact thoughts were, but Gloria's contented smile as she watched Ellie giggle spoke volumes to me.

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I sat in quiet astonishment. Ellie had a diagnosis with little hope for many Good Days, yet here she was…giggling and snuggling with Gloria at home, her 3 brothers energetically running around the room. The home was filled with happy, rambunctious chaos. Ellie was 15 months old at the time with a diagnosis of severe lissencephaly, and I was able to witness one of Ellie's Good Days.

Gloria told us about Ellie's recent, not-so-good days the week prior. How Ellie had cried in pain with her back arching due to severe muscle spasms. A small increase in symptom management with methadone had subsequently changed Ellie's whole world for the better. The conversation naturally led to the palliative team's role. A discussion surrounding how to maintain the number of Good Days for Ellie.

This is exactly what palliative medicine does. It may not always be a seemingly simple increase in opioid medication that creates an improved quality of life. Palliative medicine is there in the home to help decipher needs and manage symptoms as well as aid in communication. The team is also there to talk to those families in need through the inevitable decline in Good Days if the patient nears the end of life.

I did not imagine I would ever be working in palliative medicine, yet life-altering experiences happen to us all. We have personal events or patient encounters that seem to change our physician identity completely. In my neonatology fellowship, I had many valuable yet tough experiences in life and death. My perspective on palliative medicine morphed with each experience. Subsequently, I had a bit of permanent ink placed to mark some of these encounters. I chose these marks of remembrance not as a reminder of the babies I could not save, but as a resounding symbol of change these patients brought me.

The moment I decided to complete another fellowship was, in fact, while talking with one such patient family. Baby Allen's family. He had just spent two weeks on ECMO due to acute respiratory failure, and his heart was now failing, getting worse by the day. There were moments of extensive communication failures that happened over the course of one particular day. The very bad news was shared insensitively, hallway conversations were accidentally overheard and misinterpreted which should never have happened in a hallway, to begin with, the list went on. Despite the mishaps, we knew time was running short – we were not sure how much longer baby Allen's heart would continue to beat. A family meeting to discuss the transition of care was a must.

I sat with his parents and grandparents after the family meeting. Anger and a heavy, ineffable sadness filled the room. This day was an unfathomable, unending nightmare for the family.

We talked extensively about what they wanted their last moments with baby Allen to be like. As I turned to leave the room, I hesitated. The grandfather was still staring angrily at the floor. I thought I understood why. No family should have to overhear bad news in the hallway or be told their son has life-threatening heart failure by a rushed specialist walking out of a room. I slowly turned around, faced the grandfather, and extended my hand to offer an apologetic handshake. It felt like several painstaking minutes before he looked at my face or acknowledged my apologies for…well, everything. I shook his hand and promised I would do everything I could to ensure baby Allen's final moments were peaceful. The Grandfather finally reached out to return my handshake speaking words of appreciation as well as a final, surprising request. Would I do whatever it took to ensure other families have a better experience in the life and death of their loved ones? For me, my mind solidified in that moment. Yes, I would – and for me, that promise meant palliative medicine was the next step.

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I have seen everything from bewildered looks of misunderstanding to shocked shouts of anger for the recommendation that palliative medicine should be consulted. This is true in the neonatal world, adult medicine, and even geriatric practice. These heart-wrenching outcries have come equally from medical colleagues, families, and even personal friends. I finished

my pediatric palliative fellowship by working with a physician doing outpatient home visits. Home palliative and hospice visits reminded me why all physicians, nurses, and team members should take a moment to reflect and possibly adjust our perspective.

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How does a doctor who took the Hippocratic oath and is trained to save lives identify with palliative medicine? To me, palliative medicine is an essential part of whole-person care. I make the case that every single physician can identify with at least a small piece of palliative and even hospice medicine. Palliative medicine is not giving up the fight to the Angel of Death and just ensuring good care surrounding end of life. (1) Palliative medicine is relieving suffering. Palliative medicine is ensuring as many Good Days for the patient and family as possible. Palliative medicine is helping families make informed and extremely difficult decisions. (2) Palliative medicine is a resource to help patients and families through a life-threatening medical diagnosis. As Robert Frost once said, "Hope is not found in a way out but in a way through."

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