MIND TO MIND
Creative writing that explores the abstract side of our profession and our lives

Stephen T. Harvey, M.D., Editor

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Our Grief and Loss

The Hazards of Caring for Critically Ill Children

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Yesterday morning we said goodbye to a beautiful baby who had been with us in PICU for 10 weeks. During this time he had three difficult surgeries and multiple complications, in addition to the anomalies he had been born with. He had been held by his adoring mother just half a dozen times. Clasped to her breast for the last time this morning, never having tasted the breast milk she had devotedly expressed since his arrival. His nurse Maryam and I had been involved in his care in PICU, and I knew that she and the infant's mother had developed a special rapport.

The intensity and intimacy of 12-hour shifts spent in the company of a young mother living through unimaginable sadness and stress builds a strong connection. Maryam said she was glad that he had died on that particular day, when she was there, as she wanted to be present for him and his mum. But as she opened his vest and I placed my stethoscope on his tiny chest to verify that his heart had ceased beating, I could see her hands shake and her chin wobble as she bit hard on her lip. Time slowed and I felt that too familiar lump rise in my throat and pain flood through me. We were both struggling and silent. Too many times in the past we have shared this pause in time, this pain. Our thoughts and emotions must be frantically redirected to the baby's mother - to support her, to offer strength and comfort. To tell her she was a wonderful mother, and that she did nothing wrong.

Carol Wiley Cassella, M.D., served as Handling Editor for this submission.

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Two hours later, the infant and his mother have left the unit, his room has been cleaned and Maryam and I stand waiting for our next post-operative admission to arrive. I notice that she is quietly and efficiently setting up the bed space and preparing the documentation to admit the next child. Before I can say anything, our new admission is wheeled in. A seven-year-old girl who has had a thoracotomy for excision of tumor. Our anesthesiology colleagues handover and we swing smoothly into action again. There is simple comfort in the automaticity of our work - working with our hands to distract our hearts and minds. But when her mother comes into the room we are unmasked. She is distraught at seeing her daughter so pale and small in the bed, and Maryam and I have to dig deep to find the necessary warm energy and reassurance to wrap around her. We know she needs it now more than ever, but an empty vessel can pour no more.

Later in the day, there was a scheduled bereavement meeting, with the parents of an older child we cared for in PICU eight weeks earlier. For two hours we sit together and discuss clinical course, laboratory and radiology results, genetic counseling and bereavement support. There are tears, there is anger, there are questions, and surprisingly there is laughter too. In pediatric critical care units all around the world a similar day plays out, and staff steel themselves to control their own grief and give support and human connection to bewildered and broken parents.

The death of any child is distressing to parents, family, friends and healthcare staff. However, family, parents and friends are allowed the right to grieve by society, as the nature of the relationship with the child is socially validated and recognized. The relationship between the child or infant and the PICU professionals is not publicly observed or acknowledged, although it may span weeks, months or even years. But we the medical and nursing staff involved in a nurturing relationship with a child and their family may mourn the loss deeply. Our own peers and community deem the articulation of this loss less acceptable. There is a name for this unacknowledged pain: disenfranchised grief. Certainly most of us working in critical care do not receive guidance on how to address our own grief. So how do Maryam and I refill the vessel, and allow it to pour again for the next devastated family?

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