

MIND TO MIND

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

Stephen T. Harvey, M.D., Editor

Difficult Social Circumstances

Suzanne Crowe, M.B., F.F.A.R.C.S.I., F.J.F.I.C.M.

Some children and infants admitted to the pediatric intensive care unit are described by the admitting nurse and doctor as having “difficult social circumstances.” The phrase gets under my skin every time I hear it. What are the motives for describing a chaotic or impoverished life with this euphemism? Wherever you work, a similar phrase is bound to be used for patients who appear on your operating list or who are admitted to the emergency department or pediatric intensive care unit. These are the children with the electrocardiogram dots still stuck onto their chest from a procedure a month ago, the infants who had their surgery postponed in the past because their parents forgot the appointment, or the toddler with noticeable dental caries when you perform laryngoscopy.

Clear signs of abuse or neglect must be responded to by anesthesiologists and intensivists. Child safeguarding procedures for all healthcare staff are in place and are mandated by law in many countries, including Ireland. Those children are fortunately quite rare. Many more children arrive into your working day with the label “difficult social circumstances,” and how we react to these children may be very different.

A series of admissions over the winter with bronchiolitis prompted me to consider this further. In particular, Amy, a 5-month-old infant. She arrived into our pediatric intensive care unit with her young mother Julie, and a toddler sibling. Amy was admitted to pediatric intensive care overnight for further management of increased work of breathing and hypoxia. She was a beautiful chubby baby, decked out in pink from head to toe by her doting mother. Standard winter work. As I examined little Amy: chest, heart, abdomen—all was expected for viral bronchiolitis. But oh, no. My heart sank as I glanced over Amy’s perineum, her skin was broken and bleeding, weeping in places. It was all in the diaper area, nowhere else. Her mother, Julie, quietly observed me as I examined her daughter. I looked up at her face after I had opened Amy’s diaper. Her eyes filled with tears and she told me with some hesitation that she could not change Amy’s nappy as often as she wanted to because they were frequently walking around the streets from morning to night. My eye was caught by her admission details on the chart and the patient’s address: Hostel Accommodation, Moving Daily.

Medical advocacy is a concept introduced into the medical school curriculum at an early stage, as medical students learn to understand the history of medicine and where it has brought us today. In the intimate relationship between physician and patient, the physician possesses knowledge of the patient and understanding of healthcare and welfare systems, and has credibility and

From the Pediatric Intensive Care Unit, Our Lady’s Children’s Hospital, Crumlin, Dublin, Ireland. suzanne.crowe@olchc.ie

Permission to reprint granted to the American Society of Anesthesiologists, Inc., and Wolters Kluwer Health, Inc., by copyright author/owner. *Anesthesiology* 2019; 130:851–2

professional standing in society. This privileged position allows the doctor to press for wider change and to clamor for fairness and equity in accessing health care. The doctor as an advocate for their patients' needs is part of the ethical duty of each doctor, in each area of practice.

Throughout anesthesia training, the idea of medical advocacy is not a priority among the tomes of physiology and pharmacology; and then in critical care medicine fellowship there were always more urgent demands. The American Society of Anesthesiologists supports advocacy through a political forum (American Society of Anesthesiologists Political Action Committee). We are trained to be confronted by the specter of accidental trauma and nonaccidental injury, and the horror that accompanies it. We are less prepared to deal with chronic deprivation. Chronic deprivation is less provocative to critical care and anesthesia staff, who may not be prompted to highlight deficiencies and lack of resources to support families in the community. Adults and children who receive care from an anesthesiologist or intensivist have already been "filtered" through admissions, nursing, and social work. So it's not really any concern of ours, is it? This changed when I met Julie. The system did not change, but my attitude to vulnerable children and families caught up in the system, and what I could potentially do for them transformed. And it is why this everyday pediatric intensive care unit story changed from being a narrative of guilt and remorse to a call for empathy and action.

Julie and her two small children were living in hostel accommodation because they were homeless. Without family support, they became homeless when their rent was increased and they could no longer afford to pay. At no point did Julie ask medical and nursing staff in the pediatric intensive care unit for help. We made our standard referral to the hospital social workers and psychology department. Duty discharged, medical care continued.

To speak up for a child admitted into pediatric intensive care unit from homelessness, does the doctor have to be an expert on housing/welfare entitlements/social security? Putting a foot outside our own area of expertise feels frightening, and is a barrier to advocacy. There are other barriers to advocacy, including fear of negative responses or repercussions from employers and colleagues. We know, as humans and as physicians, that investing in the medical and social care of a vulnerable patient in intensive care, and then discharging them into homelessness is not right. It is everyone's job to make this and other difficult situations better. Here are some suggested specific and achievable ways to intervene as an anesthesiologist or critical care physician: asking the patient and their family what we can do for them is possible; engaging the pediatric intensive care unit social worker in a conversation focusing on what you as an individual doctor can do to help is illuminating; writing letters of support to housing agencies, schools, community-based charities, addiction treatment centers, and state bodies is achievable, and does not take a lot of time; and campaigning in our own hospitals for greater in-house family support is definitely realizable. Once you advocate more vocally, two things happen: it gets easier because you get a name for being interested in wider patient welfare; and others join their voices with yours.

By listening to what those affected say, we will learn the ways in which specialists in anesthesia and critical care can assist in improving the mental, emotional, and physical health of children. This tale of an infant, her diaper rash, and her struggling young mother, is a call for action in those medical specialties that exist slightly behind the front line. We need to consider whether our role—as highly trained providers of anesthesia and critical care—encompasses medical advocacy, and consider whether our specialty could benefit from returning to our roots as physicians first and foremost. Skirting on the fringes of compassion fatigue and burnout, it is easy to become depersonalized and disengaged. However, there are some critical care providers who believe that the antidote to burnout is engagement; if this is the case, physician advocacy in anesthesia and critical care could balance realism with idealism and potentially offer benefits for the advocate, too.