Palliative and Supportive Care

cambridge.org/pax

365 Days of Notes

Henry Bair, B.S.

Stanford University School of Medicine, Stanford, CA, USA

Essay/Personal Reflection

Cite this article: Bair H (2020). 365 Days of Notes. *Palliative and Supportive Care* **18**, 621–622. https://doi.org/10.1017/S1478951520000243

Received: 11 February 2020
Revised: 27 February 2020
Accepted: 23 March 2020

Author for correspondence: Henry Bair, 1704 Oak Creek Drive, Unit 403, Palo Alto, CA 94304, USA. E-mail: hbair@stanford.edu

When I met baby Madison on the first day of my clerkship in the pediatric wards, she had more than 1,300 notes in her chart, accumulated over the course of 337 days from birth.

She was born at 23 weeks and weighed a little over one pound. Given the resuscitation efforts she endured in her early hours, few thought she would live past her first day. Even with the latest technologies available in the most well-equipped pediatric hospital settings, only half of all babies born so prematurely survive.

Madison managed to make it to the NICU, somehow. The complications she sustained were straight out of a textbook chapter on prematurity: intraventricular hemorrhage, necrotizing enterocolitis, sepsis, neonatal respiratory distress syndrome, and retinopathy of prematurity. Congenital tracheomalacia led to a tracheotomy tube placement and continuous mechanical ventilation. As if that weren't enough, she had a genetic condition so rare even the pediatric geneticists struggled to identify it; and when they did, the list of associated conditions was extensive and daunting: intellectual disability, growth delay, vision defects, hearing impairment, seizures … the catalog of complications went on and on. Then, she was hit with pneumonia. The doctors would often say, "She's tried hard to die so many times." Some called it a miracle. Others said she shouldn't be alive.

By the time I read through her chart, Madison had seen more specialists in her first year than most adults do in a lifetime: ophthalmology, dermatology, pulmonology, infectious diseases, surgery, cardiology, gastroenterology, neurology, genetics, endocrinology, and even palliative care. And then, there were the numerous times she had coded or come close to it. She spent six months in the NICU before she was stable enough to be transferred to the general pediatrics floor.

Having completed an elective in palliative care, I was no stranger to questions concerning the value of treatments when weighing up the quantity and quality of life … in the context of seriously ill adult patients. I had observed, with great interest, heated arguments among physicians about prolonging life in older patients at all costs when outcomes are uncertain. To think terms of "worth it" for an infant rather than someone in their twilight years, however, was new for me.

I saw Madison every day of my clerkship and soon realized that practically everyone in the hospital knew her. I also discovered that her parents were struggling to participate meaningfully in her care, seemingly ill-equipped to manage the realities of a child with such high needs. Madison would be tracheostomy-dependent, and the tube would need to be monitored and cleaned regularly by her caregivers. The hospital worked diligently to include her parents in care planning discussions, but they consistently failed to follow through or manage the responsibilities that the staff attempted to hand over. Over time, her parents spent less and less time in the hospital. As the social work department struggled to find long-term placement for Madison in a facility or foster care, the staff suddenly found themselves in the role of her family. A regular flow of hospital personnel — nurses, doctors, medical students, social workers, and respiratory therapists — stopped by frequently to bring Madison toys, read to her, play with her, or walk her around the ward at the end of the day in her toy car, from which she waved and beamed at everyone like a beauty queen in a parade. There were fewer mumblings about the soundness of trying to keep her alive.

The last day of my clerkship fell on Madison's first birthday. 365 days in the hospital, and she'd never known another home or seen the world outside our building. She looked so well for having been through so much and come so close on so many occasions to not making it another day. She was alert, she was responsive, and she loved to smile back at nurses and doctors who cooed at her. Yet I cannot recall how many times her future had been the subject of discussions between the medical team, with the phrase "worth it" featuring prominently. Yes, so many resources utilized. Yes, so little reason to be optimistic. Yes, so much further to go with sustainable placement.

The entire department threw her a first birthday party. Like any other one-year-old, Madison wasn't aware of what was happening. She seemed as happy as any other time she was simply interacting with the people who took time out of their days to play with her. But it was tremendously meaningful for us. It was a commemoration of our work together, not just for this child, but for all of our patients. A tangible, concerted celebration of why we all chose to pursue medicine, to begin with, a point often smothered by the grueling tedium of the daily grind in healthcare, in which we spend just as many hours justifying our work as

© Cambridge University Press 2020

CAMBRIDGE UNIVERSITY PRESS

doing it. Madison — her vulnerability and inability to advocate for herself, and her complete reliance on us — brought out our full humanity in ways that warmed us, connected us to each other, and renewed our commitment to the fundamental idea of service to others that lies at the heart of all medicine.

A few weeks after I completed the pediatrics rotation (and contributed 30 progress notes of my own to Madison's chart), I heard from residents that Madison had been transferred out of the hospital to a long-term care facility, and that social work continued to seek placement for her in a foster family.

It seems to me that the "worth it" discussion presupposes a crystal ball that none of us have, and it's probably better that way. Not one of us working in medicine will escape the woulda/shoulda/coulda rumination across the course of our personal or professional lives. We will regret times we didn't invest deeply because it didn't seem *worth it*; we will regret times when we threw ourselves into something that ultimately was for naught.

Perhaps, rather than conceptualizing *worth it* as a function of final result outcomes (i.e., Did the patient die anyway? Did the patient suffer too much? Did the patient have a good life?), we might instead think about *worth it* as a function of exercising values. To *try* is to actionize and live our values regarding what's important, and I'd like to think our values stand irrespective of the outcome. Focusing on our values of caring and service allows us to acknowledge the small yet still important outcomes: that a child such as Madison had an incredible support system she otherwise would not have enjoyed outside the hospital (with or without her medical issues); that she was loved and cared for; that she was thriving far beyond what anyone ever dreamed for her.

There will always be the financial matter of return on investment, the topic of never-ending debates given the myriad subjective economic and social paradigms we each hold. But values are consistent and fulfilling. The value of caring for a vulnerable person, the value of fighting for a life, and the value of giving someone a chance even though they asked for nothing. Living these values is not just life-sustaining for patients in treatment; it is what sustains the internal life of a practitioner.

https://doi.org/10.1017/S1478951520000243 Published online by Cambridge University Press