COMMENTARY

Reflections: The Category of Us

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Nurse X is young and tall. A mop of untidy brown hair frames her angular face, and I practically need to hyperextend my neck to look her in the eye. Kids like mine, the ones with extensive, expansive, unbelievable medical histories, need lots of orientation. They're tricky, and the only way to make accurate assessments is to learn as much as possible from the parents. It is Nurse X's first job. She's been a nurse for 20 minutes, and she's just as many years my junior. But here I am, attempting to go over essential parts of Josh's medical history, the nuances of his behaviors that must inform his nursing assessments, and ways to keep him content. But she doesn't care about any of that.

"Listen," she says, with the commanding and familiar air of putting me in my place, "I'm the nurse here, and you're just the mom."

There it is again, the divine hierarchy nature intended.

I call the agency to express concern—this sort of attitude among home care nurses almost always ends in an unplanned hospitalization. The agency defends Nurse X's indiscretion. Interruption in care—and reimbursement dollars—is sometimes a far greater evil than the skewed dynamic of experiencing racism in one's own home.

"She's from a small town, and she's not used to people like you," the agency says.

"Like us? Suburbanites?"

"No."

"People with advanced degrees?"

"Um, no."

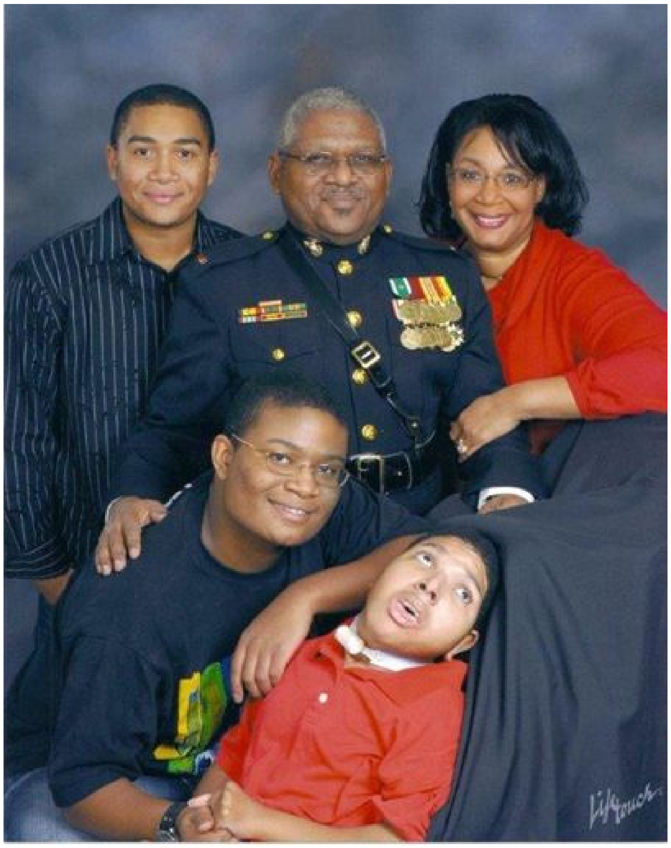
"Military families?"

"Black people. She's just not used to being around Black people. It makes her uncomfortable."

They ask that I be patient, teach her, allow her to allay any fears. But I am emotionally exhausted after years of varied versions of the same scenario. I'm kind of sick of it. And this is my house.

So, I decide that it's simply too much to ask of me. Nurse X isn't welcomed back.

The Category of Us reflects how a family learns to take life 20 minutes at a time, with an awkward kind of gratefulness that embraces every moment of calm and chaos therein. It is told as a juxtaposition of past and present, showing vignettes of an arduous but wondrously fulfilling journey. Our story is that of an African American family in the southern suburbs of the Twin Cities metropolitan area of Minnesota. It brings up difficult questions about implicit bias in health care, ableism, and racism—questions that most of us prefer to avoid.



We are part of a demographic that cares for children who are medically complex with a host of disabilities, coaxing them toward adulthood against all odds. Meanwhile, we face our mortality and the morbidities brought on by unrelenting stress and discrimination. This story reflects on a pregnancy that ends unexpectedly with a traumatic birth—a birth that continues to raise concerns about bias in the U.S. maternal and infant health care system and the subsequent, irreparable guilt that burdens far too many African American mothers. It shows the hurtful, often tragic, outcomes at the frightening intersection where racism meets ableism, with its adjacent nuances, and how that junction can lead to the undoing of countless families who do not have adequate support.

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Josh was our third pregnancy, the youngest of our three boys. Prior to Josh's birth, we had already experienced meningoencephalitis, scarlet fever, a mysterious autoimmune disorder, and had one Neonatal ICU graduate challenged with reflux and projectile vomiting. We knew how to be polite, compliant—whatever it took to try to dispel any bias within a very homogeneous community that might affect the care of our children.

But we also knew that behavior, performance, acquiescence—whatever we could do to make everyone else comfortable with us—could not transcend hard-wired predispositions toward race, ethnicity, gender, or disability.

Surviving the morbidities of prematurity forces families onto a roller-coaster of challenges, emotions, perplexities, and yes, even joys. It is at times a stormy voyage, not for the faint of heart. Thus, I began a journey my family and I could have scarcely imagined. It raised questions about how practitioners, community, family—a society in general—value disability. It asks how bias affects access to medical care and the quality thereof—especially when implicit notions of race, ethnicity, and socioeconomic status come into play. It questions how judgments interfere with decisions about which families can care for a child with complex medical needs—questions that should involve those families first. Finally, and perhaps the most devastating, is how the intersectionality of the above can throw a virtual grenade into the trajectory of our very existence.

But suffering often emerges into an outpouring of empathy, and perception evolves into something beautifully humane when shaped by the artful teacher of experience. Healing and wholeness come in many vastly different ways; therein lies the gift of being a part of the Category of Us.

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I knew a foster mother who dedicated her life to providing the highest quality complex care to her client. But the adjacent challenges of caregiving ultimately embittered her. She loved her charge but dealing with Medicaid and case managers and social workers and therapists and doctors and home health agencies and supply vendors—the list is long—was too much for her. She was an African American woman, heavy-set, middle-aged, with physical scars from a difficult life. Ripe for bias and stereotyping. Thus, she was always under speculation, thought to be scamming the system. Too lazy to find a real job. Infantilizing her ward by buying her fuzzy animal slippers and matching furry hats. Her motivations endlessly questioned, she fought back with humor and sarcasm. When she had to speak truth to power finally, she would fall into a deep growl of *laughter and say, "I never used to be like this." And then, slowly, deliberately, like an infamous line from some movie, "Y'all made me this way!"*

Our journey made me an advocate, a family leader, a parent representative on two biomedical ethics committees…Pediatric ICU Experience Team…hospital diversity committee…host to medical residents in our home…the board chair of our Arc chapter…peer-to-peer mentor…an expert panel participant for medical research studies…speaker at state and national meetings…a family systems specialist for our state Family Voices organization…a Director on the board for The Arc U.S…and many other volunteer activities that I cannot imagine having had the time to pursue. But so much *more* significantly, this journey has taught me that the most effective way to leave a legacy is to leave a story.

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Joshua was born at 31.8 weeks gestation. Every single day, every minute short of *what should have been* means something to me, so I never say 32 weeks gestation when asked. Joshua and I have earned every moment of that slighted time in the most challenging way. With advances in neonatal medicine, even over 20 years ago, Josh was not considered incredibly premature. But he had had a Grade IV intraventricular and subdural brain hemorrhage at birth and was considered the sickest baby in the neonatal intensive care unit. Despite all the mitigating factors that should have placed us in a category with access to quality and early prenatal health care, a generous health insurance policy, and being compliant parents—the outcome for us at the time was devastating.

According to the 2018 California Listening to Black Mothers Survey, in almost every aspect of pregnancy in the U.S. health care system, far too many African American mothers believe they are rendered invisible because of the color of their skin. Communication with their maternity providers is lacking, overlooking vital concerns. Treatment by nursing staff during labor and delivery is reported as detached, harsh, and insensitive, more so than that of their white peers. Finally, Black women often feel judged or maltreated.[1]

The data corroborating these perceptions is as real as it is compelling. According to the Centers for Disease Control and Prevention (CDC), in 2018, the rate of premature births for African American women, at about 14 percent, was 50 percent higher than that of their white peers.[2]

In a 7-Minute Listen for NPR, Rhitu Chatterjee and Rebecca Davis give credence to many stories like my own. They reference James David, a neonatologist at the University of Illinois of Chicago. David found that low-birthweight babies were often born to African American women, much more so than white women of their age—mainly because of disparities in education and wealth. In the U.S., Black women are more likely to be poor and not as well educated. For many reasons, some reach back to a history rife with racism that systemically blocked access and opportunity. However, David's research with James Collins, a colleague from Northwestern University Medical School, showed that older Black women with higher degrees and upper-middle-class neighborhoods were at more risk of giving birth prematurely than less-educated white women. And, with all confounding variables accounted for, discrimination in access and delivery of their maternity care—and the stress it so insidiously cultivates—appears to be the reason.[3]

LISTEN

I wait for my baby to come alive in a way that I am accustomed to; to bounce, jump, and frolic in my womb, as typical babies do. But something is wrong. In the quietness of the hour, I am alone with this unborn child, who seems to cling only tenuously to life. Hungry for more sound, movement, anything to lighten the darkness of my womb, I pick up the boys' Playskool tape player and stretch the curly cord of its bright red microphone across my small belly. I smooth on globs of cold Dippity Doo hair gel to mimic the science of a real sonogram, then turn the volume up. A simple rhythm, the slightest encouragement of sound, would make life right again, push away this dark premonition that has haunted me, clouded the excitement of the holidays, and dampened the anticipation of new life.

Silence.

A few days later, I am throwing up blood. Thick beads of sweat dot my forehead as I try to will food down. The little bit of food I had been able to muster comes first, followed by blood. The cold running water from the faucet splatters from the bowl to my face, its coolness my only relief. Blood and food mix into a gruesome swirl that chokes the drain. I raise my head slowly and recoil from the colorless ghost that confronts me in the mirror.

I am barely seven months pregnant, but something ethereal assures me that my time has come.

If I don't deliver this baby soon, we'll both die.

I pick up the phone and again reach the physician on call. It is close to the holidays, and my physician is still out of town. His partners are attending a holiday party. Tears well up, overflow, and my voice trembles. "There is something wrong with my baby."

I do my best to explain my history. I recognize the physician's name; he is well-known in the African American community. He tells me that if the mother says something is wrong, he believes her, and he will meet us at the hospital shortly.

My husband drops me off at the hospital's front entry and then must move the car, so security doesn't question him. I walk into the darkened, cavernous lobby, terrified. It's late, and the guy at the desk barely looks up from whatever he's reading. I tell him I'm in early labor, so I expect him to be alarmed. He tips his head toward the bank of elevators and mumbles something about the 2nd floor. I wait for a moment, thinking that perhaps I shouldn't be walking around the hospital…that he will offer me a wheelchair. I think maybe I don't look pregnant enough. The reception guy is done with me, brushes me off with the side-eyed, no-baby-daddy look. So, I walk the long corridors to Labor & Delivery, bleeding, cramping, and alone.

Soon after admission, the on-call physician orders a bi-level ultrasound and finds that the baby's head is deep into the pelvis and looks a bit large, the cord close to his tiny neck. After a serious talk with my husband and myself, he hurriedly summons a perinatologist, and they prepare for an emergency delivery.

But just as quickly, the partners from my clinic return from the holiday party, dismiss the on-call physician, and cancel the surgery.

"It's Saturday," they say. "We'll wait till Monday when more departments are open."

The following evening, the baby goes into distress. My labor and delivery nurse had left her post to visit with a friend early in the shift. I could hear echoes of their laughter from far down the hallway as I watched the monitor tape loop in big paper ribbons on the floor. I twisted and turned, trying to escape the pulsating pain radiating from my lower back. The doctor walks in, and the irritation she tries to mask as she scoops the streams of monitor tape from the floor quickly turn to alarm. She rushes from the room.

Soon, the nurse is at my bedside, crying. Not for me and how life for my family is about to change forever, but for herself. For being scolded. Perhaps for being a part of the travesty of neglect and missed opportunity that is about to unfold.

"Call your family," she bleats through barely muffled tears. "The baby has to come out now."

Afraid and confused, I struggle against the unexpected oppression of cold hands and the sudden panic of suffocation as the wayward nurse pushes an oxygen mask against my face with no further warning.

OXYGEN

I feel helpless here in the operating room, vulnerable, and too aware of death. The icy cold air and the room's emptiness produce a kind of whir that overtakes the place. Hushed voices puncture the rhythm of the constant echo in my ears, and I look up to see only bowed heads bobbing busily in blue elasticized caps.

The doctor looks over the blue drape separating me from the lower half of my body, my baby, and my future. He smiles, and I plead in silence.

Help my baby.

I hear drilling, buzzing, and feel a strange pulling. In my mind, I am lifting myself, reaching to pull my soul back to my body, to save myself from an untimely death. I imagine our two boys at home, without a mother, and I feel ashamed at my lack of courage as this new baby tries fitfully to live and breathe.

The sound of a vacuum cuts through my thoughts, and I learn later that amniotic fluid is leaking into the surrounding tissue. The surgeons scramble to contain it, and silence stifles the room. The baby does not cry.

Someone calls out Apgar scores, but in whispers.

A nurse sits tenuously on a low stool and leans in close to me. His large hand gently strokes my head, and the opaque surgical cap that gathers his hair looks like a halo around his delicate face. He shifts his gaze as a tiny creature rolls by, encased within the transparent warming walls of an incubator. My baby is white, like blank writing paper, and his head lies large and swollen atop his small, still body.

"How is my baby?" I look up at the nurse, my eyes searching his.

The nurse's voice quivers as he fixes his eyes on mine. Then he shakes his head and devastates my world.

I'm watching a man die. He's a large fellow with dark brown skin, like that of one of our three sons. The man's head is pressed flat against a Minneapolis street's dirty asphalt, just miles from where I live, almost underneath a police car. A thick white traffic line permeates the scene, mocking the man, who seems so out of place, lying there like roadkill. A police officer presses his knee deep into the man's neck, his hands in his pockets or something, giving him a casual posture. His knee digs into the man in repetitive movements, smooth and firm like he's kneading bread. The brown of the man's skin turns dusky, as though the dust of the street now shadows his face, but it's not dust. Life seeps from the man's face as his color grays and from his lips as he petitions his mother, and then everything stops. The man isn't moving anymore, and the people around the person taking the video become angered and perplexed, and incredulous. I turn away from the Facebook post, from a tragedy that happened too close to home in every way, and I say to my son, "I think we just watched that man die."

AFTERCARE

Someone rolls me to Labor and Delivery, no baby in my arms.

Mothers like me—the statistical outliers—are strategically placed at the end of a long corridor, far away from the blissful others who have successfully delivered pink, cooing babies. The room is already dark, but the nurse makes sure to snap the door shut behind her and draw the shade. A decadent cocktail of drugs quells the pain that sears across the fresh cut of my abdomen, yet I am aware enough to feel extraordinarily alone.

This nurse's footsteps are heavy and loud, and every action is deliberate, a matter of fact. She presses on the tiny bulge of my stomach to push away blood and fluid. Her fingers smell of stale nicotine, and her voice is rough and raspy.

"Let me know if you need anything," she says, halfway out the door.

But I cannot move. I am left on my back to stare at the ceiling. A thread of light shines through the pulled shade of the door, hinting at life outside of this room. I hear lusty, thirsty screams as newborn babies search for their mothers' breasts, anticipating the warm, sweet colostrum that will soon emerge and comfort them. Tears flow, nothing to catch them, and I feel the cold wetness stream into my ears. I know that wherever my baby is, there is no mother to stroke or cuddle him.

The heavy-footed nurse does not return. I have not moved my body in hours. The pain is too raw, and I am left weak, limp in its wake. My lungs feel weighty and wet. Soft crackles escape with each labored breath. My forehead is hot and damp, but I cannot lift an arm to brush away the sweat. I am a prisoner of this place, of the indifferent, smoking nurse, of actions and decisions not to act that will change our lives forever.

The baby is born at nine minutes to midnight, so my insurance representative counts those nine minutes as one of my three days and discharges me early. ‘There were no complications,’ she said, tears welling in her eyes.

The neurologist later told us that, based upon his scans and the activity of the resorption of the blood, the baby could have highly likely experienced his bleed within a day of delivery, as we lay there in the hospital—’waiting for more departments to open.’ This example corroborates the data at the crux of the mistreatment of African American women in childbirth. Our lives play out the rest of the story, the difficult part of being Black in America. The invisibility when it is needed. Too much visibility when it is not. And the lasting repercussions.

THE CATEGORY OF US

It's the beginning of initiatives to learn about cultural competency in health care, and an employee is trialing a project in the PICU for a graduate studies program. Unique cards are slipped into the charts of individual patients, randomly identified by race or ethnicity. Josh's says that he's Black or African American. It says he's likely to be Baptist with roots in Voodoo practices and that he likes fried chicken and watermelon. No one has asked us anything.

The truth is that Josh can digest only Pregestimil at this time, carefully titrated through a feeding pump; fried chicken and watermelon are out of the question. Not all African Americans are Baptist, and I've always disliked the taste of watermelon. Once, a physician said he'd come by the E.D. to check Josh for a shunt malfunction only if he looked like "one of those kids with watermelon heads." Otherwise, based on his scans, he said Josh wasn't worth the trip. Sometimes the bias is not even close to implicit.

In *Caring for Children with Severe Neurological Impairment*, Dr. Julie Hauer shows the relative percentage of children in the category of severe neurological impairment as compared to other special health care needs. Consider them all marginalized populations, beginning with children and youth with special health care needs, the most general category, a smorgasbord of sorts. The circles narrow as one considers the larger demographic to the smallest: children with special health care needs, children with complex chronic conditions, and children with neuromuscular disorders. Our children emerge as titans if nothing but for their small numbers and the families, home care nurses, and the wide range of medical specialists dedicated to their intense care. While the natural and practical inclination might be to stop there, Dr. Hauer goes further, introducing yet another but very tiny circle to the graph: children with severe neurological impairment.[4]

You will find us here, in the Outer Limits of the most marginalized of populations. We are the families of those kids who were not expected to live a decade or two ago, whose prognosis boxes on their care plans were marked as Poor or, at best, Guarded. If our children have survived into their teens or young adulthood, they have entered a sort of Fifth Dimension, a special place where the tacit understanding is that no one discusses prognosis any longer. Living well, without pain, and being loved is the grand prize when there never was a predictable pathway nor a diagnostic tree that could accommodate so many unexpected turns anyway.

EMPATHY MATTERS

The NICU is not a fair playing field, with its uneven terrain, unexpected potholes, and the mountains that emerge suddenly, out of nowhere, often just in time to dampen the anticipation of discharge. Or perhaps it is fair. It is preparation for a life re-imagined, a difficult but more circumspect one that teaches gratitude, perspective, and a life-changer—empathy.

The NICU was an extraordinarily grievous time for us because it seemed personal. We could not determine if it was something about us or about Joshua and the assumption that, if he lived, he would have severe disabilities—too much for us (or the world) to handle. Perhaps, it was a combination of the two.

Surgeons told us to forego a shunt, an internal tube that manages the build-up of cerebrospinal fluid around Josh's brain. Instead, they inserted a temporary reservoir, which they continuously tapped to take off the accumulating fluid, a supposedly less heroic measure. But the continuous access caused virulent infections that ultimately led to sepsis. Josh's floppy airway, the outcome of the failed mechanics from his severe neurological impairment, suffocated him when he was placed on his back, exacerbated by the inflammation of any upper airway infection. Rather than a tracheotomy initially, which I eventually insisted upon after a kind resident intervened and told me it would be an otherwise "stupid way to die," we were offered the choice to have Joshua's tongue sewn to the front of his mouth. A different resident told me to stop pumping my breast milk—the only thing I had left to feel like I was doing something as a mother—because "infants often have bleeds like this because the mother has AIDS." He realized the absurdity of his presumption a few days later, but by then, my milk had mostly dried from the grief, exhaustion, the added emotion, and stress, and I had lost yet another connection to my child.

When Joshua finally graduated from the NICU, we were told to call the coroner, "so when he dies, they won't think you killed him." He was given two months to live, which was just as unaffectedly revised to two weeks.

The home care nursing agency told our first primary nurse that Josh would not last long. There was no need for training, nothing more than a phone orientation.

"He's just trach and a g-tube," they told her. She was sure to be assigned a new case soon.

Yet, Nurse S cared for Josh in our home for 18 years.

Our family sought continued nursing coverage from the military when Victor was activated for military duty after 9/11. The care manager heard the list of Joshua's medical diagnoses, including disabling conditions. Even though Joshua had qualified for home nursing care his entire life through our private insurance, the military's care manager denied coverage based upon his disabilities. "I'm sorry," she said, as I mentally prepared to meet the next 18 months of my husband's activation and deployment alone, "but we don't pay for kids who can't be fixed."

Josh is labeled nonverbal, but for those who get to know him, he's exceptionally communicative. He vocalizes in context, and sometimes all of us burst out laughing at *something he "says." He has excellent receptive language skills, and he loves to watch Rachel Maddow. But when strangers see him—surrounded by the trappings of a candy-purple wheelchair, portable O2, the animated lights of the portable oximeter, a feeding bag swinging from a pop-up IV pole, and an emergency bag for any potential apocalyptic event—they don't see a viable person. Josh answers yes and no questions by mouthing signs and shaking his head, says uh-uh when something he doesn't like is happening and raises his arm to emphasize an answer. He soaks up audiobooks and follows movies steadfastly, from beginning to end. He idolizes his brothers and calms to a peaceful sleep as soon as he hears my voice. But if he were to be judged by his initial head scans, as many have been wont to do throughout his young life, he'd be dismissed as merely a financial burden on an already strained health care system. A non-contributor.*

Dr. Hauer wisely talks about the importance of separating a child's medical condition from his or her disability, avoiding labels, and focusing on contributions—through every individual's unique way of communicating—rather than their deficits. It is music to a parent's ears—the following quote, as the verse of a song:[4]

> Too commonly, these two worlds get mixed up and misunderstood. To avoid confusion, which can lead to misunderstanding, it is helpful to recognize different groups with overlapping challenges and needs. Considering such groups serves to illustrate differences, yet it is critical to consider an individual beyond the points illustrated by each group. An individual is always so much more than what any label can convey.

Several years ago, I read an outstanding book written by Dr. William Bonadio, a pediatric emergency physician who once worked at our local children's hospital and treated my son. *Julia's Mother: Life Lessons in the Pediatric E.R.* recounts stories of tragedy and triumph from a very personal perspective that is rarely revealed to the public. With a traditional mandate to remain professional and distant to practice the science of medicine most efficiently, Dr.

Bonadio closes the gap between doctor and patient in what is described as his "personal notebook." He departs from the typical medical model's constructs and infuses a heavy dose of humanity into the narrative. In the end, he has learned that doctors and patients have more similarities than differences, and acknowledges of what must become a new paradigm in medicine: humanizing the care delivered and rendering better clinical and psychosocial outcomes.[5]

Before the Josh-years, I was turned away from the E.D. in the middle of the night with our eldest son, a stiff, wailing three-month-old, whose temperature had reached 105 degrees. My mother, a tall, stately woman, accompanied me. My husband was away on active duty for a short time with the United States Marine Corps. The resident in charge had been awakened and was not pleased. She gave us both a quick once-over and decided not to get involved.

"I don't know what it is," she said, trying to stifle a yawn, but not so much her blatant irritation. "You'll just have to take him back home until something presents itself."

We arrived as soon as the clinic opened early in the morning, and a physician greeted us who was willing to truly 'see' us, ultimately diagnosed meningoencephalitis. That physician rallied for our family through the raising of three sons, as well as other family members. He taught us to navigate the world; we had to learn to live within and understand critical diagnostic, treatment, and prognostic questions. He saved us.

We learned from our parents that we must perform twice the capacity to get half the recognition as African Americans in America. It isn't a victim mentality. It's just life. Look poor, act uneducated—barely surviving is the expectation—thriving borders on intimidation. Systemic racism and the bias that stirs it up into uncomfortable daily interactions is real, something to prepare for as part of our day. So, I dress nicely for E.D. visits, brush my hair, and swipe on a bit of makeup, even though I'm dying inside. Experience has shown me that anything less puts me into a category that threatens the quality of my son's care, the credibility of my assessment, the integrity of our home.

Still, far too often, we have been dismissed by other physicians, therapists, teachers, social workers. Their actions or inaction can be deadly, can result in the success or failure of the family's ability to endure this journey. Upon Joshua's first admission to the PICU, the medical social worker approached me at the bedside and laid out the unwelcome mat for our future.

"You know, I hear the scuttlebutt around the hospital, and most people around here just don't agree with your decisions about Josh."

My husband and I had not determined Josh's care in a vacuum. We were part of an influential and professional team of active participants. No heroic measures had been taken, merely humane ones. This woman had used her power and position to annihilate a vulnerable parent emotionally, and I would never forget her cruelty.

Oma and Papa raised us to value moral integrity and to treat others as we would like to be treated—possibly even better. It doesn't always matter, though. As an African American woman, I still get bullied when I go for a walk, increasingly so after George Floyd's death and the tensions that mounted around the presidential election. Malcontents in our neighborhood are emboldened enough to edit the Black Lives Matter signs of allies to read Black People Suck instead. Bias and outright prejudice are real, no matter what the skeptics say—as familiar to me as an old winter coat. Its tentacles, not at all insidious, permeate every aspect of our lives, inform my advocacy, and frankly, wear me out. Throw in a giant dose of ableism and living through the intersection of the two in a society that values sameness, independence, entitlement—it gets rough out here.

A NEW NORMAL

The trouble with initially beating the odds, living the life of a statistical anomaly, is that it is relentless. While it might not be uncommon in the Category of Us to bring up our child's 45-plus surgeries and procedures as a side remark, or to laugh inappropriately during a parent-panel discussion when we mistakenly add the one diagnosis he managed to avoid, it is the stuff of sensationalism for the rest of the world.

Humor becomes a way to cope with the anxiety of delivering eight pages of scheduled medications three times a day, including “as needed” medications and just as many treatments. That does not begin to consider daily living activities, which are made more difficult with high spasticity, scoliosis, kyphosis, or as the child grows and the parent ages. For Josh, it is essential to include passive range of motion and therapeutic massage to retain muscle mobility and reduce pain. Sometimes, we have an order for physical therapy as well—the attempt at active movement, positioning, and exercise maintains his baseline and helps keep his lungs healthy.

Interventions and assessments are necessary to stave off heart rates of 34 beats per minute and 180 beats per minute in our autonomically dysfunctional young adult—often, all within the same afternoon. Environmental conditions can trigger copious secretions, requiring Olympic level oral and tracheal suctioning (sterile technique—no cross-contamination—switch out catheters—repeat) that no amount of medication can tame (though surgery has reduced a bit).

Bed baths three times a day, full-immersion baths with jets to help relax tone using the ceiling lift, three times a week—with the panic button ready to call Life-Link, oral cares, peri-cares, trach cares, scheduled meds, three times daily, not counting "as needed", explosive stools, change all of the bedding, do it again, feeding-tube cares, 24-hour continuous feedings, oximetry, titrate O_2*, reposition every two hours, take your hand off of your vent tubing…you'll pull your trach out… There's a storm coming, Jon; go downstairs and unplug your brother.*

Uneventful days are welcome retreats from the difficult ones. We hate the Red Zone on the respiratory chart and how it is a precursor to a challenging 14 days of steroidal proportions. If it does not lead to hospitalization, it might mean dragging the cough assist machine out of the storage room, searching for the needle syringes to puncture expensive vials of Tobramycin, and switching over to old-fashioned oxygen tanks, because the O2 concentrator, no matter how many liters it attempts to pump out, is not powerful enough to bleed into the heated humidity system, tackle the ventilator and find its way to oxygenate a very sick kid. It means that the typical 24-hour care becomes *scary* 24-hour care, making a moment seem like a lifetime.

George Floyd's murder is changing our lives in unexpected ways. We're already in a shut-down, so only essential personnel are supposed to travel. Josh's nurses have

official letters to keep in their cars that say they care for a person who is medically fragile. The world erupts in reaction Floyd's murder, its indignation as palpable as Josh's racing heartbeats during an autonomic storm. Riots prevail in the Twin Cities and reach into the suburbs. Parts of the street where my brother lives begin to burn. The risk to my brother's safety outweighs the additional risk of COVID-19 he might bring at this moment, so he quickly leaves his apartment to stay with us. The night nurse comes in early to make the Governor's newly mandated curfew and avoid driving in the Cities at nightfall.

The National Guard paces in front of the boarded windows of the children's hospital, and I'm wondering where he'll go if Josh gets sick. We ration gloves at home, which are in short supply from the vendor—three boxes a month for peri cares, gastrostomy cares, trach cares, oral cares: family and staff, 24 hours a day. They tell us that home care is at the bottom of the list of priorities. Change out the vent tubing every two weeks instead of every week—the tubing needs to go to the front lines. Vent settings are checked by a modem now instead of a respiratory therapist, which is a good thing, I guess—one less invader.

I think it isn't easy to manage complex care when it seems like the end of the world as we know it, but I'm determined to do it anyway. We've done it before.

In "Effects of Caregiving on Families of Children and Adults with Disabilities," the authors cite research describing some of the chronic conditions parents face with the stress of diagnosis and care of their children. Lower back pain, chronic migraines, gastrointestinal ailments, as well as stressors from disruptions in employment, finances, and childcare exacerbate already challenged lives. And, while the authors encourage practitioners to be sensitive to how each family group processes this "new normal"—considering culture, gender, socioeconomic status, and religion, for example—it is important to avoid bias and presumption in the assessment.[6]

The PICU nurse looks down at Josh and then back at me as she strokes his curly black hair. "What tribe are you from?" she asks.

"Excuse me?" I'm exhausted. I haven't been outside in days. Every PICU stay is like being in the front seat of a roller coaster with the safety bar unlatched. The climbs and dips never stop—we just get dumped out at the end. Maybe I didn't hear her right.

"You know. What tribe are you from in Africa? Washing his hair is like watching the water roll off a duck's back." She was trying to relate, I guess.

"Um, we're from the Southern suburbs of the Twin Cities. Africa's a large continent. We didn't get much information about any of that on the way over."

I hate being mean, but sometimes I want to be the mom, like all the others here. Sometimes, I don't want to have to be The Black Mom.

As was our family's experience, dismissive assumptions are much more harmful than thoughtful inquiry. We are already living customized versions of Edward Lorenz' deterministic chaos: "[W]hen the present determines the future, but the approximate present does not approximately determine the future."[7]

The anxiety of this pandemic is tearing me to pieces. Early on, I couldn't decide whether to keep nurses in our home or not—it makes us so vulnerable. Every contact they make outside of here is ultimately a contact Josh makes. Hospital policies around caregivers for people with disabilities who are nonverbal are new and inconsistent at best. I don't want him in an ICU, dying alone. He's never been alone.

I stalk our home care nurses on social media to see what they're up to out there in a world I dare not access. I don't care if it's invasive because the risk of exposure that follows them whenever they walk through my door makes them feel like invaders. Dangerously useful invaders.

Our middle son says he wants to go running one day, but his dark brown skin and defensive-end build don't bode well for outdoor exercise in our conservative, middle-class suburb. We've been cramped up in this house for months since the pandemic, and we all need some air. But it's post George Floyd in Minnesota and a young Black man running for what others would see as no apparent reason—it feels like a death sentence.

Families of children and youth with complex medical needs and severe neurological impairment live in the kind of "approximate present" Lorenz describes. We become the expert guides of the chaos that has become the ever-moving, consistently unstable foundation of our child's existence.[7] Still, we see a beautiful person long before we see any notion of a complex medical condition.

This life, the isolation, the loneliness, the amazement, its work, the pain of it—Papa always said that life is 80 percent bad things and 20 percent good things. You trudge through the 80 percent to enjoy the 20 percent. Then he changed it to 90/10. That didn't seem fair. But he said life isn't about being fair. No sense in dwelling on that, Papa said. Just a waste of time.

Dr. Hauer reconciles two disparate worlds in the best way: "Families of children who have severe neurological impairment (SNI) are the heart and soul of their child's care. They navigate a world of emotion and uncertainty and are asked to enter the medical world of logic and reason. The two worlds can, at times, seem at odds, and yet both worlds want what is best for the child."[4]

THE POWER OF WORDS

William Carlos Williams, poet and pediatrician of the late 19th and early 20th centuries, said, "It is difficult to get the news from poems, yet men die miserably every day for lack of what is found there."[8] Williams implies that there is something about the literary arts that affects the empirical nature of things; that perhaps we could enhance science if we wrapped it in the lifeblood of the humanities. Narrative medicine is a creative composition genre that talks about the complicated journeys of healing and disease and the extraordinary relationships formed along the way.[8]

In the article "Narrative medicine in the literature classroom: ethical pedagogy and

Mark Haddon's *The Curious Incident of the Dog in the Night-Time*," the author Dr. Shannon Wooden extols the extraordinary potential of both the process and product of composition to humanize the science of medicine. Writing about the difficult experiences encountered in the practice can help to make sense of them, Dr. Wooden shows, while recounting how she has learned and taught others how to use writing to express a special kind of humanity that does not fit as tidily into other modalities of communication.[9]

Narrative medicine promises to have a positive impact on the scientific community. Rather than approaching illness and disability as opposing conditions of ability, Dr. Wooden suggests that learners will discover that health, ability, illness, and disability occupy nebulous places on a spectrum that, at one time or another, any one of us might experience. Writers whose work leads them to see the commonalities of our existences will learn a more thoughtful and respectful language to address differences.[9]

My mother passed away in 2007, just hours after I facilitated her arriving home from the hospital. We thought we were bringing her home on hospice and that we would care for her there, perhaps for up to three months, as we shared memories and said our goodbyes. It was as though she were hanging on to return to the place where she was comfortable, loved, and had enhanced the lives of so many others through her wise heart and extraordinary gift of hospitality. The pain of my mother's death tore through my heart like a dagger, and I was confident that I would remember every word, every touch, every glance that sealed the closing of our time together. At the same time, I wanted to escape to the pen, to write it all down so that when I had the strength and courage sometime in the future, I could revisit those words and savor the gift of my creation. I wished to empty my heart into a letter to myself, my mother, or posterity. But memories fade too quickly, even the most significant ones, and it is not easy to recreate the truth of a matter as the routine artifact of life skews the pictures once so evident in our minds. Writing pulls something memorable out of the soul. It threatened to take my mother away from me permanently. Writing can be so powerful that writing about my son in the present pushes my anticipatory grief up against the portal to a future I cannot bear to see.

No one talks about prognosis anymore. After we made it past the two weeks, then two months, then two years, nobody knew what to say to us. Instead, we count our blessings. But we also watch the friends we've made along the way lose their kids who are complex, one by one. We cry for *them. Then, we watch them disappear quietly into the shadowy corners of our lives, trying to find themselves again without the fiery pace of distraction we all count on to calm the anxiety of anticipatory grief. We go about the business of guarding our hearts, and shutting our eyes, and keeping ourselves way too busy attending to medical things—the special needs version of Waiting for Godot.*

And we hope we're not next.

REFLECTIONS

At a pivotal point in our journey, our pastor took me aside and said, "Don't lose yourself in all of this. Continue to play your flute. Write when you can."

His words were like a slap. It had not occurred to me in years to pay attention to myself—to the person I used to be, nor to consider who I should become. Like many mothers of children with complex medical needs and disabilities, my body became a surrogate for my child. I became his arms, his legs, his voice. I spent days, weeks, months with him in the hospital, every day by his side; nights, either a few doors away in a parent room next to the PICU or on a vinyl pull-out sofa in the medical-surgical unit, vulnerable and exposed. I became beyond exhausted from helping staff with his care all three shifts for days on end. At times, I never so much as stepped outside for a breath of unfiltered air, from the first agonizing hours of stabilization in the E.D., then inpatient admission, to discharge, days or weeks later. My husband met the other boys' needs, school, their sports practices and games, his job, and then their late evening visits to check on their brother. When they were younger, and my husband was away, on active duty as an officer with the U.S. Marine Corps, I would travel back and forth, stuff the boys beneath the large metal cribs that furnished the PICU at that time and have Child Life provide toys and books to keep them busy. We were not easy to forget.

We have managed a parade of home care nurses, a handful with the heart and soul for a job that is at once brutal and delicate, but others who treated Joshua as “a trach and a g-tube, on a vent.” One, shocked to see an African American woman answer the door of a single-family home in a typically white suburb at one of the meet-and-greets I finally insisted upon, quickly demanded that I go and fetch Mrs. Harris for her. Another told me that the area inside of Josh’s room was her territory, and mine was on the other side of the door, which she then deliberately shut in my face. Yet another insisted upon shutting off all lights, monitors, and equipment and sitting in the dark. She had physician’s orders to do otherwise and could not clinically assess the patient without actually visualizing him; she accused me of questioning her organic nursing skills and announced that only one of us in the room was an adult. I asked her to leave promptly, and the adult in the room took over the night shift around 2 am. Another, one of the most memorable, arrived late to the night shift, streams of blood actively running down his face from open injuries atop his bald head. He told me that his roommate’s toucan has escaped its cage and tried to peck him to death. He disregarded my pleas to contain the bloody mess and headed to the nursing area to work.

Josh is mesmerized by the cinematic works of Uncle Miko’s gallery this evening. They combine paintings with the technology of projection animation, light, and music to tell life stories. Layers of preparation went into this short ‘by-appointment-only’ visit to keep Josh safe from exposure to the novel coronavirus. The production is titled “Just Us.” It features Black people from the surrounding community, just six square blocks from where George Floyd was killed. Children play in front of a painted replica of the mural at Floyd’s memorial site as a screened animation features a child running from a floating gun—a target on his back. Josh stares at the flushing waters of real footage of the Pacific Ocean, perfectly fused onto a painting of Blind Lady Justice—animated splashes of fire projected onto her tentatively balanced scales, through the magic of math and physics.[11]

The small gallery, tucked into a neighborhood whose homes and businesses were recently boarded up from the fires of riots and despair after Floyd's death, became a space of joy and restoration. When it opened, the many in the community stood outside its windows and cried.

I have grown since those nursing incidents that chipped away at my dignity, but more seriously, threatened my child's safety and the quality of life of our family. We promised Josh that we would never allow anyone into our home again that made any of us feel unsafe. While that means reduced staff in a time of already critical nursing shortages, so be it. My husband uses a spreadsheet to manage medication orders, as well as disposable supplies. We have delegated monthly enteral supplies to the primary day nurse, who comes four days each week and every other Sunday. We mix and blend the formula daily to add additional nutrients and protein because of Josh's extreme milk allergy. I purchase miscellaneous supplies and PPE monthly, anything not covered by insurance, and help the primary nurse make corrections to the home medical and treatment records. I regularly update the military program case manager who approves nursing hours. I train and oversee paid family caregivers who supplement hours not covered by nursing staff. My husband uses a spreadsheet to organize a monthly schedule covering all three shifts for 24 hours each day, our three nurses, ourselves, and our two sons, who also help. I manage all communication with the county regarding federal waiver resources that provide modifications, additional nursing incentives, and assistive technology. All of it is a full-time job, in addition to caring for Joshua.

So, when Pastor Foye suggested that I play the flute and write a bit, it seemed nonsensical considering our new normal.

There is no me *any longer. Like the book, Julia's Mother, I have simply become "Joshua's mother".*[5]

Looking back, from the precarious perch from which I know one day I will surely tumble, I recognize the wisdom of Pastor Foye's words. He was trying to prevent me from losing myself, from burning out, and waking up one day, only to question what became of my life. While this is in no way a complaint regarding the place this journey has led us–we are grateful for every day, and no longer concern ourselves with *what should have been*– it is an honest expression of truth. I have seen my child through countless surgeries and innumerable hospitalizations; endured nurses who have disrespected us and loved nurses who have loved us; cared for our sons alone for a cumulative three years while my husband was deployed overseas, many times within death's path himself. I had suffered the loss of loved ones when it seemed neither fair nor bearable; I watched Joshua's brothers embrace him as the love of their lives. Life has been challenging but also wondrously full of purpose and joy.

Pastor Foye died today. Glioblastoma. I suspected, but they didn't want to tell me. Two of the people dearest to me in the world have been taken by this ugly brain cancer—first, my sister-in-law, leaving behind my brother, who has M.S., and my two nieces. Now, Pastor Foye. He was our biggest cheerleader; showed us how to put faith to work. Our world is getting smaller. Pastor Foye loved Josh tremendously. He called him his Trooper. Josh cried. It came straight from his heart and pushed like a breathy stab, right out of his trach.

Reflection at this point in the narrative leads to recognition of a tone of resolve in place of what could have been a declaration of defeat. My son will never ambulate or speak the way that we do, but he is lovely, and vibrant, and alive—and loved. And, where I had unsuccessfully begged to have my voice heard at the beginning of this unlikely journey, his unique voice is heard today, in the most amazing and unanticipated ways.

Josh voted today. Curbside, COVID-19 precautions. Safely inside his accessible van with his dad, brother, and the home care nurse. He signed his ballot, hand-over-hand with an X, and he knew just whom he wanted to vote for and verified it with witnesses. I'd asked him a couple of weeks before if he wanted to vote while he was absorbed in his evening news, and he gave me an enthusiastic sign for Yes. I promised I would make it work, and 20 years of growing as an advocate assured me that it did. I talked with the voter supervisor at our city hall and organized it through the early voting option. One of the most memorable moments of our lives. In his way, our nonverbal son showed the power of his unique voice.

MOVING FORWARD

People die because of prejudice. While social determinants of health play a systemic role in disparities of access to health care and the quality of the care received, the insidiousness of implicit bias is a much less conspicuous killer. Seemingly innocuous assumptions can creep into clinical decisions that can have critical long-term implications for patients and their families.

Patients and families accustomed to being dismissed or diminished—those far too often marginalized for being different in the first place—have a sixth sense for it. Disdain cannot be hidden, and respect cannot be feigned.

Health care and the policies that support it can be just as reckless when delivered with bias as though not delivered at all. A system that favors the healing of the non-disabled but sees less value in the lives of those who contribute to the world differently can be cruelly destructive.

Josh's waiver budget is pending for no apparent reason. Case management is outsourced from the county to a contracted agency, and we are on our third person in two years. The supervisor has changed midstream. The new case manager is temporary. No one is a nurse, though the waiver is for people with high medical needs. We are two months into the new budget year and stalled. The personal support planner—the person who is supposed to coordinate the budget process, write the revisions, and keep me apprised—has been missing in action for months. She refuses to return any of my emails or calls. It takes me an entire day to do her work and submit it to case management. We have designed a competitive compensation package to keep safe, consistent nursing care for Josh. We have employed full-time nursing staff for over five years, and, since then, Josh has had no unplanned hospitalizations. The new Team Leader continues to ask for more differently-worded criteria, even though everything meets state policy guidelines. She has the whim to do so and the power to carry it through. I am so frustrated. I write her a three-page paper on the importance of family-centered, person-centered care, showing how this is not something that can or should be quantified. Families need to be trusted. I include the practical information requested at least three times—bonus amounts, number of times per year distributed. The Team Leader's suspicion of us—never having met us—is palpable. She threatens in writing to reverse bonuses approved by supervisors of years past for 'inadequate information'. Will we have to pay back the funds? The stress is unbearable. How many shifts on time? How many shifts absent? She stresses antiquated, patriarchal, ableist criteria that let me know she has never had to do this for one day with a loved one. I tell her that, in the past, nurses have come on time for every shift and treated Josh like an animal. Nurses who were always on time have almost killed Joshua. Nurses who were more than willing to pick up extra shifts called him the R-word.

The scenario feels too familiar, another of those times where I wish I hadn't checked the African American box next to Race in the form's demographics area. I want to be wrong but ask for a Zoom call. I want the

Team Leader to see that Josh is not a thug, fully able, issuing kickbacks in the form of bonuses to his homies whom he has hired as staff. This is how we are being treated. This is how I feel. I straighten out my curls and dress professionally for the call. Josh is in his Sleep Safe Bed, on his ventilator. Sweet. Asleep. I turn the camera toward the home care nurse. He is white, millennial, male, handsome. He is wearing his scrubs and stethoscope. He waves and says hello, like a pageant contestant. The team leader smiles at him. She offers to write up the criteria for us. The Zoom call ends. The budget is magically approved.

Stereotypes, biases, and outright prejudices can contribute to decisions and actions (or the lack thereof), creating even more discrimination. My having been dismissed, neglected, and mismanaged during my pregnancy led to my premature birth to a child living with significant disabilities and an uncertain (if any) future. Sadly, Joshua's disabilities raised questions about the worth of a life forever altered by the systemic flaws that caused them.

Conversation infuses humaneness into interactions, initiates a foundation for an effective patient-provider relationship where knowledge can erase inclinations toward bias. Assumptions disappear as relationships are bonded within the guidelines of professional trust. The insensitivity and alienation bred by the arrogance of assumption distills into a safe place, where the diagnostic process becomes more holistic, clinical outcomes improve, and patients, as partners in their care, experience a better quality of life, wherever their healing journey takes them.

We call ourselves the Ordinary Moms of Extraordinary Boys. We've raised our boys who are medically fragile together, the four of us making it through the mid- to later-twenties, a miracle, really. Before COVID-19, we'd try to get together for a plate of nachos, all talking at the same time, every one of us so deprived of company. These evenings—typically every four months until we can synch our ridiculously busy lives—fly by so quickly, before someone must leave to give a bath, relieve the nurse or personal care attendant, or administer evening meds. In the meantime, we roar with laughter, talk about secretions, the best diapers for twenty-something boys, and giggle over the stress of the systems we're certain are designed specifically to torment moms of young men in colorful tilt-in-space wheelchairs.

PRACTICALITIES

While health care practitioners evaluate policies and practices on diversity, it is essential that they also revisit their ethics regarding disability. It is equally important to consider how one values disability before caring for or serving others. Failure to do so threatens to taint all future aspects of the professional relationship and, perhaps, clinical and psychosocial outcomes.

Consider that children in the hospital are at their worst, and they live their best lives elsewhere. The pandemic has ushered in the opportunity for telemedicine to become a sustainable part of care for children and youth with complex medical needs. For some families, the chance to complete a consult visit without the two or three hours of preparation required to get to the clinic can be a welcomed relief. Children and youth can be observed from a perspective that allows them to be treated more circumspectly and holistically when they are comfortable in their homes' familiar environment. The surroundings and equipment can be seen, and care needs more clearly discussed. Nuances in diagnoses might be ascertained as well. Fund-a-need projects, grants, or donations can be directed toward supporting connectivity and resources for devices so that families have equal access to telemedicine services.

At this pivotal moment in history, it is imperative that access to health care be re-evaluated, technologies and cost-structures for remote clinical consultations are being developed, and barriers, stresses, and morbidities due to social determinants of health are being analyzed, that the needs of children and youth with complex medical needs and disabilities are finally brought to the foreground. State legislatures and Congress must become educated on the unique conditions affecting this comparatively marginalized population and their families, and it must begin with the renewed vigor of grassroots advocacy. Quality-of-life issues need to be discussed with families, first anecdotally, through shared stories and goals, and, ultimately, quantitatively, through carefully executed research studies that examine outcomes from scientifically selected criteria.

Ideally, families of children with complex medical needs must have everything work in their favor to make an already difficult situation workable—finances, health, support from extended family and the wider community, and access to a medical home, as well as premier primary care practitioners and specialists. However, because of the shortage in nursing care, absences required from work, exhaustion from days and nights of unrelieved care, frequent hospitalizations, and the isolation that becomes a natural part of the complex care life, support is often a fleeting rarity. States and counties might consider flexibility in waiver programs to render them wholly consumer directed. Allowing families to use funds in a way that best meets the child's needs at home and in the community customizes care in a way that stiffly structured systems cannot; families feel a sense of control over their situation and more independence. Offering parent pay to mitigate lost incomes helps to resolve the almost certain decrease in the standard of living. Finally, allowing families to find caregivers whom they trust and to offer them compensatory wages assuages fears of abuse, harm due to inadequate training, and an uncertain psychosocial dynamic in the home as strangers come and go. States might also consider directing staff to low-cost or no-cost training programs to ensure the quality of care and providing incentives for completing those programs; for example, direct support professionals in Minnesota receive a $500 stipend and a 7.5 percent wage increase for completion of online coursework and CPR or life support training.

Home care nursing must become more sustainable, its wages and benefits competitive with those of facility nurses. Children need continuity and consistency in homecare for adequate assessment and psychosocial well-being. Incentives should be in place to ensure that families in all geographic areas have equal access to quality home care nursing services. Nurses must be educated to provide family-centered, culturally sensitive care and oriented, with licensed supervision, to each client's specific medical needs.

Post-pandemic visits by medical residents, therapy students, and students of the social sciences to homes of children with complex medical needs should be encouraged. Seek families willing to share a day of their lives to educate others about the complex care journey's challenges and joys. The mark the experience leaves is often indelible.

One of the Ordinary Moms wants me to share some of my more shocking experiences regarding race with her church congregation. But it's just after the January 6th Capitol insurrection and people are more divided than ever. My friend's church has thousands of members, but nary a person of color and I've never felt welcomed there. We live in the same neighborhood and I don't know how empathic folks are feeling these days, even with the sacrifice of our personal stories. I'm afraid of becoming a show and tell or being targeted by someone who cannot tolerate the race part of us, or the disability part, or the burden they perceive of the two. Perhaps, I'm simply afraid.

Transition and care coordination to adult medicine for children with complex medical needs is essential. Internal Medicine-Pediatric Physicians interested in complex care of young adult patients must be supported with the administrative, clinical, and financial infrastructure required for this unique population. Currently, adult medicine clinical practices are disincentivized to accommodate this growing demographic. Families struggle as pediatric specialists they have seen for years retire or their children age out of practice. Patients who have been inpatient-only at their local children's hospitals are being directed to adult facilities where their histories are unknown. Because of other medical complexities, technology needs cannot be accommodated. Hospitalists and support staff at adult facilities might not be accustomed to interacting with families who have been so integrally involved in directing the care of a patient for a lifetime and insist on remaining by the bedside for the hospitalization duration. Hospital policies, or at least considerations and accommodations, must be made for families of youth with complex medical needs and disabilities who transition to adult medicine but still count solely on family caregivers for medical advocacy.

Consider Charting the LifeCourse© to 'throw away the box' of thinking about children and youth with complex medical needs and families. The fundamental principles of the framework include “focusing on all people; recognizing the person in the context of their family; the trajectory of life experiences across the lifespan; holistic focus across life domains (daily life and employment, community living, safety and security, healthy living, social and spirituality, advocacy, and engagement); supporting the three buckets of needs (information, connections, goods and services); integrated services and supports across the life course, and transformational policy and systems change.”[10]

The innovation and creativity that goes into truly living our lives—not merely surviving them—is the side of medicine that can be considered art. The part that allows a child with horrible brain scans to delight in his brothers, to become enraptured with a two-hour movie and to insist on watching the news every weeknight, vocalizing for the entire family to be quiet if they begin to talk through his programs, sending us all into fits of laughter, beaming with pride.

With faith, the support of some fine physicians, the love of family—however it is defined—and friends, it is possible to make one’s miracle. It does not require fixing a disability nor deleting a diagnosis. It is realizing that everyone has a contribution to make, then going about living life fully and with gratitude—twenty minutes at a time.

Empathy Matters

There is an abruptness with which life changes,
Like a vapor, but a cold one, with sharp edges.
It renders the strongest man weak,
Dropping him very suddenly to his knees,
His heart failing in disbelief.

This moment is ethereal for everyone,
Like a dream that catches briefly in the throat.
It announces its arrival with a clack.
Even the tallest bend at its beckoning,
And their tears stream like rivers then.

The sorrow remains forever unexplained,
Like nothing touched or sensed before.
It marks the beginning of a rebirth,
One that labors far too many hours to count.
Great men surrender to it, no fight left in them.

There is a joy that springs from this abruptness,
This moment of burden and dagger of sorrow.
It makes the fiercest king childlike and new,
Malleable, willing to give over his rule
To the even the lowliest of subjects.

There is a kindness known only to those few brave hearts
Which have suffered great pain without recourse.
It pumps compassion through their weary veins,
Soaking the very essence of them in compassion.
Their secrets pour out from precious vials,

“Empathy, anyone?” they say.

~Debbi Harris

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