The Harmony of Disequilibrium

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The narrative of life that is revealed during illness and death exposes the fabric and shapes of the human spirit and the texture of human consciousness. The following three clinical encounters illustrate how tragedy, grief, and despair have no architecture: We collapse on cruel universal scars. There is, however, an unbroken flame that never flickers or goes out that brings harmony within the anarchic disequilibrium of human suffering.

CASE 1. THE IMBALANCE OF HEALTH INEQUITY

K could not answer any of my questions. Her mother, standing at the bedside, informed me that K had a seizure that morning, which was why she brought her to the Emergency Department. K grew up in a rural town in the Deep South of the US. She was able to finish high school but because of economic hardship in her family she began working soon thereafter. K became a single mother of 3 children, now between the ages of 3 and 8 years. She was working 2 different jobs to support her children up until the day before her admission to the hospital. Three years ago, as part of her obstetric screening, she was found to be human immunodeficiency virus (HIV)-seropositive. Except when she received zidovudine intravenously before undergoing a caesarean section that prevented her daughter from becoming HIV infected, she has never received antiretroviral therapy. One year ago, K sought medical attention to initiate treatment with antiretroviral therapy. However, because of the nonnegotiable daily commitments of single motherhood, she could not afford the medication copay. K was 30 years old when I met her.

K doesn’t live in desperate poverty, but she stands at the lower end of the social scale with important disadvantages that eventually led her to poor health. Poverty alone does not produce ill health—social inequality does. Unequal and unfair life opportunities are the result of long-term structural imbalances of social systems. Indeed, the distribution of health is directly related to life opportunities and reduced functional capabilities, including conditions of life that matter such as decent housing, adequate nutrition, social support, access to schools and adequate health care, and many other structural factors. Yet amid the increasing entropy of daily life and as the result of social inequities, life went on for K until her illness struck her ability to care for her children.

K was suffering from intracranial hypertension secondary to cryptococcal meningoencephalitis as a manifestation of advanced HIV-associated immunosuppression. Every evening, after work, K would spend time with her children, assisting them in completing their homework and preparing dinner for them. Despite being a single mother of three and facing substantial financial constraints, she never applied for welfare support or requested food stamps support. Who would take care of her children if she died from this life-threatening fungal infection? And if she died, what were the chances of her children remaining trapped in this social vacuum? K was treated with antifungals and underwent placement of a lumbar drain to continuously release cerebrospinal fluid to reduce her intracranial pressure. After a prolonged hospitalization and rehabilitation process, as of this writing she is receiving daily antiretroviral therapy and remains on oral suppressive antifungal therapy. She has returned once again to helping her children complete their homework after school. She is living on food stamps; however, she is planning to return to work as soon as she recovers her strength. Because of her adherence to antiretroviral medications, her plasma level of HIV ribonucleic acid viral load is now undetectable. Her beautiful smile is the most reliable sign of her recovery.

The narrative of health and illness is inexorably linked to societal factors. Unequal distribution of life chances leads to unequally distributed health outcomes. To understand why K became trapped in a position of social disadvantage, there is a need to understand larger societal factors: The immense inequalities and vastly complex collective histories of the locations where individuals live and grow up have a direct link to our health outcomes. Inequality disempowered this single mother: She lacked opportunities to achieve control of her life. She did not have the financial means and social support to empower her to seek adequate medical care, to afford expensive medications, to improve her nutrition, and ultimately to have a prospect to transform her life outlook. She became vulnerable to acquiring HIV infection, and once she acquired this infection, a perpetual cycle of social injustices ensued. If K had succumbed to this fungal disease, chances are that the life-opportunities of her children would have been severely impacted. Adverse childhood experiences, including a poor socioeconomic environment when losing a parent, have important implications for adult life functioning. However, K’s children have continued to attend school and also care for their mother, ensuring that she continues to improve medically. Despite the obvious societal imbalances in power and personal agency that underlie the social injustices of our times, K’s strength and determination provided a far-reaching equilibrium for her family.

CASE 2. THE ETERNAL FAREWELL

One Friday morning, during clinical rounds, I glanced through the window of room 7 of the intensive care unit. Inside, I watched as a thin, elderly woman placed her arms around her husband’s dead body...
and lifted him to an almost 45-degree angle, where she continued to embrace for the last time the man with whom she had spent the past 63 years of her life. It became apparent that this moment of farewell reflected a life of happiness, sorrow, and joys that this couple had shared. She recruited strength from an unconscious primordial pool to overcome the pain of losing her life partner, which allowed her to lift his heavy, lifeless body with ease. It was the confluence of all emotions summed up into one final act of love.

Life is maintained by preserving a state of energy imbalance through the movement of molecules. This leads to the generation of action potentials that activate living cells, the building of carbon-based molecules, and the production of the energetic currency that fuels cellular life and helps to maintain vital organic functions against the universal slide toward energetic equilibrium. Human nature emanates from this energetic disequilibrium to produce the harmony of living.

Death is biologically programmed into the matrix of life. The force field around the cell stop as the electrons and protons cease to flux through membranes, creating a state of energetic balance. However, when someone we love becomes severely ill and dies, we cannot simply accept that everything gets lost in the molecular and biological flow. Our destiny manifests through a tapestry of emotions including timeless memories and storytelling that go far beyond our life experiences. The narrative of death is as important as the narrative of life. There is sacrifice and dignity in the life of a star. The violent death of an ancient star provided the building elements responsible for our lives. Similarly, M possessed a human spirit capable of courage and sacrifice. In the darkness of reality, his mother’s endurance and compassion shed light and warmth into the life of her son up until his last breath.

CASE 3. THE EQUILIBRIUM OF DYING WELL

M’s mother has cared for him without interruption for almost 2 years, ever since the accident that left him in a persistent vegetative state. A few months after turning 21, M was run over by a car when he stopped on the highway to assist a woman and her child who had been in a car accident in front of him. Since the accident, M has required mechanical ventilatory support through a tracheostomy, a gastrostomy tube for feeding, and 24-hour nursing supportive care. I met M when he presented to the hospital in septic shock precipitated by an episode of ventilator-associated pneumonia. During my initial evaluation, I suggested to M’s mother that she consider palliative and compassionate end-of-life care. After listening to this recommendation, she became visibly upset. At her request, we initiated aggressive antimicrobial and supportive intensive care unit management, and he remained in the intensive care unit for many days. Every night, his mother stayed with him and continued to restlessly care for him during the daytime. One morning I glanced through the glass of his room, and M’s mother stepped outside the room. That day, her silence said everything: She was ready to let him reach the end of his life. She wanted to remember her son as the hero who offered his assistance, and ultimately his life, to an unknown woman and her baby in need in the middle of a busy highway. An hour later, M died in the company of his mother and his sister. The room was surrounded by an unspeakable harmony. His mother’s silence was louder than any word or sound. Her serenity traveled freely through the plumbing of the soul, synchronizing everyone present to an ancestral rhythm.

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RESTORING THE HARMONY

Tragedy and despair split human beings into the raw materials that constitute the human spirit. The spectrum of our biological and existential misfortunes manifests in different forms: As social injustices with unfair distribution of health or as illness and death of a loved one. Yet, during these crucial moments we may discover that, against the tyranny of circumstance, acts of compassion and sacrifice restore a natural sense of cosmic equilibrium to our existence that ripples across past and present.

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References

Do Not Forsake the Sick

Even in the stage of dying the physician should not forsake the sick, for even then he may become a benefactor, and if he cannot save, may at least relieve departing life.

— Joseph W Freer, MD, 1816-1877, American physician and surgeon