

into our history. What we're witnessing today, though shocking, builds on a legacy that still haunts us. But U.S. physicians can stand up to the demonization and bullying; support, counsel, and nurture resilience in our Latino patients; and advocate for the basic human rights of all immigrants.

Disclosure forms provided by the author are available at NEJM.org.

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## Unsteady Thoughts — Telling the Truth of Psychosis

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“Do you have any children?”

I never know how I will react, how I am going to answer that question. Sometimes I avoid the truth. “No, I don’t have children.” Explaining seems too daunting, too much for one sentence, one breath. Or I tell half-truths: “I have two stepsons.” I don’t like to spring the story on people; seeing the shock and distress on their faces is painful. Divulging the facts feels like a confession: “Both my sons are dead.” Some people are struck silent; some can say only, “I don’t know what to say” — reminding me of Seneca’s words: “Light grief can speak, great ones are dumb.” So when someone stammers inarticulately in response to my revelations, I empathize. *I don’t know what to say either.*

The truth is that Austin and Colin both died in their 20s, 9 months apart, from suicide related to psychotic bipolar disorder. Another truth is that I can speak openly about this reality. Perhaps the emotional, psychological, and spiritual support from which I’ve benefited and my grounding in the biologic nature of psychotic illness free me to

speak. But I can’t do it with everybody, not all the time.

Charity Hospital, a historic fixture in New Orleans, was the oldest continuously operating hospital in the United States until it was shuttered by Hurricane Katrina. After studying engineering and spending a 9-year stretch at home with my sons, I went to medical school and then trained in neurology at Charity. During residency, I evaluated hospitalized patients who were hallucinating. After collecting labs and brain imaging, much of my assessment involved simply talking with the patient.

Our neurology service consulted on the 92-bed inpatient psychiatric unit. The psychiatric illnesses at Charity were in some ways more daunting than traumatic injuries and other medical illnesses. Listening, or trying to listen, to someone describe hallucinations or suicidal thoughts and plans is difficult. I learned this skill by listening to patients during their first bewildering psychotic episode. Despite this background, dealing with my own child in psychosis was a vastly different experience.

Years later, I realized that the

Charity patients had prepared me for communicating with my sons about their psychotic illnesses. Like too many patients with chronic mental illness, they were not helped by medications or other therapies. In the end, it all came down to the solace I could offer through love and attentive listening. When my son Colin first divulged details not just of the voices that tortured him, but also of his suicide plans, my heart raced and sweat rose on my skin. Holding still and quiet, I told myself, *If he can bear living with this, I can bear hearing it.* During his illness, Colin seemed to test me. He revealed pieces of his tale and checked my reactions. If I seemed trustworthy, he disclosed another fragment.

Our journey with psychosis was not yet complete. Three years later, when psychotic illness overtook Austin, my older son, it opened another rift in the continuity of our lives. Austin had been unwell for some time, suffering from depression and substance abuse. Still, the speed and extent of his mental deterioration was heart-wrenching. When I first felt, heard, and saw his mind become unhinged and separate from our

shared reality, my world quaked. Although there was a family history of bipolar disorder, and as a doctor I understood my son's risk for the illness, it still felt intolerable. The premise of our story, the truth as I understood it, was shifted — simultaneously altered, augmented, and reduced.

Austin shared little of his inner world — his experience perhaps ineffable. “My mind is so unsteady and fragile,” he said. “It spins off and it's impossible to keep my balance.” Because of the details Colin had revealed, I recognized the seriousness of Austin's hints.

Psychotic pain is formidable. How alone must one feel trying to stand up to voices attacking from within? As close as we were, I felt afraid to approach such suffering. All my inner resources were required to hold steady and be truly present with my sons. When treatment does not adequately diminish a patient's pain, perhaps comfort and even a kind of healing may be found by resting in the depths of others' presence.

Psychosis is a primitive agony that arises from the deepest part of the brain, unregulated by considered thought. People who have lived through psychosis describe it as raw, visceral, and turbulent. Functional MRIs, PET scans, and collection and analysis of genetic metadata have opened up a map of networks and puzzles of psychosis. Much of the territory, however, remains uncharted.

When the brain's brakes malfunction and dynamic equilibrium is lost, psychosis manifests. Regulation runs amok, and perception separates from reality. Shattering and shattered, channels open, courses are carved, new pathways form. The brain rewires, circuits emerge and energize. In a psychotic state, a person sees, hears, and feels things, exaggerated men-

tal images, that are not there — hallucinations. These images and thoughts, like flashes of lightning, are perilous and unpredictable. Unlike hallucinations arising from medical illnesses, psychotic hallucinations provoke interaction. Voices address the sufferer, accuse, humiliate, seduce, and heckle. Colin said, “Just beside my right ear, a voice criticizes me and shouts, ‘Kill yourself!’” The details of the repetitive secret ordeal are unbearable.

I witnessed Austin and Colin endure chronic bipolar psychosis before their untimely deaths in young manhood. Living with their illnesses and death struggles was a primitive agony for me. My arms ache as only a mother's do, longing for two lost children. My body still craves to nurture and hold my babies. I sometimes imagine a future with them that will not be. The pain of their absence resonates to my animal core.

My confrontation with the irrational, impassioned face of psychosis has altered my understanding of the brain, free will, and perceptions of reality. Brain science, although evolving, is still in its infancy and limited in many facets. Afflicted patients are frightened and sick and sometimes provide slim information about their condition. For myriad reasons, patients often remain too little known to their doctors. And those doctors are fallible, as they chase ever-evolving information.

Over the course of 5 years, from 2010 to 2015, my sons and I experienced revolving-door hospitalizations, and our existence filled with frantic phone calls, harsh medications, tears, desperation, visions, and voices. They drifted, and against their will, they molted and transformed. Known and treasured qualities of

my sons disappeared. Our treatment experiences ran the gamut: the finest care that money could buy at private psychiatric hospitals; dysfunctional local-hospital care; absence of community structures; irrational insurance reimbursement; and finally, medically unresponsive lethal brain illness. Our experience may be a kind of touchstone for the state of mental health care during this epoch.

After Austin and Colin died, my heart held a dagger. I wondered how to avoid a second self-inflicted wound, the destructive impulse of anger and jealousy that destroys the present. *How can I lessen my suffering and the suffering of others?* With help, I discovered a medicine for the wound — empathetic joy. The wheel of life turns, and new possibilities enter. My husband and I nurture my precious stepsons, Jake and Michael. I devote myself to my patients. I donated my sons' DNA to the Johns Hopkins Genome-Wide Association Study on psychotic bipolar disorder. At the time of my death, I plan to donate my brain for study at the Harvard Brain Tissue Resource Center.

Through my actions, I hope to speak for my sons, describe our experience, and help those who follow our path. I hope to embody the direction of my spiritual advisor: “You did your job as a mother; now it is complete. Live well in their honor.”

Yet at times, in my mind, I hear the echoes of their voices and laughter, I recall the Cheshire-cat smiles and pranks. And my arms still ache and yearn.

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