Mental Disorders: Pathways to Hope . . . ?

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On the front page of the *New York Times* ran the headline "5 Disorders Share Genetic Risk Factors, Study Finds" (1), and I thought, as I have many times during the past 50 years, "Here we go again!" Because 50 years ago, when my mother, father, and I would return from visiting my brother, Robert, then an inpatient of Creedmoor Psychiatric Center, a state mental hospital that housed several thousand patients, my mother would invariably cry out, again and again: "It's all chemical! You'll see—some day they'll discover it's all chemical!"

Ah, how wonderful it would be if it were all chemical, I thought then, for if it were all chemical, we could cure it with chemicals, just as, were it all genetic, as the author of the research paper that inspired the *New York Times* article, Dr. Jordan Smoller, suggests, we could find treatments that "might have effects across a [wide] range of disorders."

My brother, Robert, now 70 years old, has been hospitalized for mental illness more than 70 times since age 19, and although he completed two years of college, on scholarship, he has never, since his early 20s, lived outside mental hospitals, psychiatric wards, or halfway houses. While headlines and articles continue to promise the hope that we will find (or have found!) causes and cures for the devastating and cruel conditions we call mental illness, see the fine print four paragraphs into the *New York Times* article that belies its headline, telling us, "there seem to be hundreds of genes involved and the gene variations discovered in the new study *confer only a small risk of psychiatric disease*" (italics added).

Organizations such as the National Alliance on Mental Illness assure us that mental illness is a "no-fault brain disease," whereas others, drug companies most notably, declare that mental illnesses result from "chemical imbalances" that medications will correct. Millions upon millions of dollars are spent to investigate neurotransmitters and genetic markers and to develop new medications. But in the places where people with long-term mental illness live—the underfunded and minimally staffed halfway houses and shelters scattered throughout the land, the notorious adult homes the *New York Times* called "psychiatric flophouses," and the locked wards of state mental hospitals—nothing much changes. Budgets for treatment and housing are slashed repeatedly, and although those on the job—overworked, underpaid, and often undertrained—do the best they can, and although programs and treatments have improved considerably in the past half-century (2), anyone who has had to deal over the long term with systems that provide for a loved one with mental illness knows just how inadequate those systems often are.

When it comes to caring for someone with mental illness, despair becomes the handmaiden to hope. Two years ago, after an incident in Robert's halfway house on New York City's West 47th Street, where he caused a flood by stuffing a toilet with toilet paper, Robert was sent to the emergency psychiatric ward at Bellevue Hospital. Although psychiatrists there declared that Robert was not psychotic (they called his act "mischievous"), his residence, in which he had been living for a half-dozen years, refused to take him back. In the next six months, Robert was shunted about to five hospitals and ten psychiatric wards; he had 13 psychiatrists and at least two dozen social workers. For someone with an already fragile purchase on life, how could he survive such extreme *dis*-continuity of care?

On October 4, 2012, six months after being hospitalized at Bellevue, Robert was transferred to Manhattan Psychiatric Center, a state mental hospital on Ward's Island, where he has lived on various locked wards ever since. Even when Robert is stable and eligible for discharge, halfway houses refuse to accept him because they are not equipped to deal with his multiple medical needs (including drug-induced Parkinsonism, incontinence, and congestive heart failure), and as his general medical problems mount, nursing homes will not take him in because of his psychiatric history.

His situation is not unique. According to Michael B. Friedman, a former Deputy Commissioner of the New York State Office of Mental Health and founder of the Geriatric Mental Health Alliance, Robert represents a large and growing population of those with long-term mental illness for whom there are few facilities that can deal with both their general medical *and* emotional needs.

And the longer Robert stays on locked wards in the state mental hospital, the more his emotional problems increase and intensify. He becomes progressively more agitated, withdrawn, or both. Increasing levels of antipsychotic medications or token reward-and-punishment behavioral programs make no difference for his condition or in his daily life.

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Within two weeks of his arrival at Manhattan Psychiatric Center, however, Robert had become, to the staff's surprise and delight, a new and changed man—alert, calm, clear-headed, warm, funny, and charming—and his psychiatrist called to tell me that the staff was going to prepare him for discharge. But when, during his third or fourth week in the state hospital, Robert was moved to a different ward for safety's sake—there were several "rough" new patients on the ward his psychiatrist thought might give Robert trouble—he decompensated swiftly and completely.

But why did Robert have such quick and extreme changes? My guess is that after being bounced from hospital to hospital and from ward to ward, Robert responded in an almost miraculously positive way because he believed he had reached the end of the line. He was back where he began 50 years ago—on a locked ward in a state mental hospital. Where else could they send him? When I talked with his psychiatrist, I made the suggestion that the staff tell Robert that Manhattan Psychiatric Center was going to be his home for the foreseeable future and that the staff was going to make it as good and as safe a home for him as they could.

The psychiatrist said the staff could not do that, however, because it was state policy that all patients were at the hospital on a provisional basis and had to be moved elsewhere within a finite number of months. The staff was required to do whatever it could to prepare patients (other than those who remained threats to themselves or others) to move along paths of recovery—to prepare them for living in less restricted settings where they would have greater autonomy, greater freedoms, less supervision, and so on. Although I understood that they had the best intentions in wanting to prepare Robert for a new and better life outside a hospital, I told the psychiatrist that to Robert, it was the same old story he had encountered throughout much of his adult life: the places where he lived were simply trying—yet again—to get rid of him and dump him somewhere else.

While Robert and I were visiting together one evening, he started talking on and on, as he often did, about money—telling me about how much he had and would have and about all the "income" he was expecting from Social Security, from Medicare, from his account at his former residence, and so on.

"I have all this income, Jay," he said, "but you know what my real problem is?"

"No," I said. "What's your real problem?"

"No outcome."

So what I've been wondering about again, as I did 50 years ago, is what studies about the possible chemical or genetic bases of mental disorders will do for individuals like my brother? If it turns out that these god-awful conditions—schizophrenia, bipolar disorder, major depression, and autism—do have purely chemical and genetic causes, this may free us from large burdens of guilt and responsibility. What we do or have done (by commission or omission) to our loved ones—and to the environment in which they live, and which we provide—will then not be seen as the cause of their misery or ours. Perhaps. But for this to happen—for us to determine in any definitive way what brings about these disorders and renders them resistant to amelioration or cure—we would also have to have studies that begin to explain why two siblings, born of the same parents and growing up with them in the same household and having much the same genetic and chemical makeup—have turned out to have such very different lives.

Then, too, if we have learned anything in the past 50 years about what may bring about severe mental illness, it is that we know very little. We do not have even rudimentary blood tests or brain scans that allow for anything approaching agreed-upon or reliable diagnoses. There are no simple causes or cures, no magic bullets. To raise false hopes about marvelous discoveries and treatments that are on the horizon—when these hopes continue to go unrealized for people who suffer these conditions, and for those who care for them—becomes itself a kind of cruel burden to lives already grim in the extreme.

References

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