A Simple Plea For Honesty

DRUGMAKERS AND DOCTORS ARE CONVINCED OF THEIR RIGHTEOUSNESS. IN MAD MEDICINE, THAT'S ALWAYS BEEN A PRESCRIPTION FOR DISASTER

By Robert Whitaker

The story of how we as a society have historically treated those we call "mad" clearly is a troubled history, one that begs to be better known. There are, perhaps, many lessons that can be drawn from it, but one seems to stand out above all others. Any hope of reforming our care of those with "mental illness" will require us to rediscover, in our science, a capacity for humility and candor.

There is one moment in the past where we can find such humility. It can be seen in moral therapy as practiced in its most ideal form, by, for example, the Quakers in York, England, in the early 19th century. In their writings, the York Quakers regularly confessed that they understood little about any possible physical causes of madness. But what they did see clearly was "brethren" who were suffering and needed comfort. That was the understanding that drove their care, and so they sought to run their asylum in a way that was best for their patients, rather than in a way that was best for them, as managers of the asylum. They also perceived of their patients as having a God-given capacity for recovery, and thus simply tried to "assist Nature" in helping them heal. It was care that was at once humanitarian and optimistic, and it did help many get well. But equally important, the York Quakers were quite willing to accept that many of their brethren would continue in their crazy ways. That was all right, too. They would provide a refuge for those who could not regain their mental health and at least make sure they had warm shelter and good food.

In the 1960s, as the United States set out to reform its care, it did look back to moral treatment for inspiration. President John Kennedy and the Joint Commission on Mental Illness and Mental Health spoke of the need for American society to see those who were distraught in mind as part of the human family, and deserving of empathy. Eugenics had stirred America to treat the severely mentally ill with scorn and neglect, and it was time to change our ways. We would welcome the mentally ill back into society. Asylums would be replaced with community care. But the design of that reform also rested on a medical notion of the most unusual sort, that neuroleptic drugs "might be described as moral treatment in pill form." The confusion in that perception was profound: neuroleptics were a medical treatment with roots in frontal lobotomy and the brain-damaging therapeutics of the eugenics era.[1] Our vision for reform and the medical treatment that would be the cornerstone of that reform were hopelessly at odds.

Something had to give, and the moment of choice occurred very early on. The research study that launched the emptying of the state hospitals was the six-week trial conducted by the National Institute of Mental Health in the early 1960s, which concluded that neuroleptics were safe and antischizophrenic. But then, a very short while later, the NIMH found in a follow-up study that the patients who had been treated with neuroleptics were more likely than the placebo patients to have been rehospitalized. Something clearly was amiss. A choice was presented to psychiatry. Would it hold to the original vision of reform, which called for the provision of care that would promote recovery? If so, it would clearly need to rethink the

1 The modern era of medical treatments for schizophrenia is always traced back to a specific date: May 1954. That month, Smith, Kline & French introduced chlorpromazine into the US market, selling it as Thorazine. The drug was the first "antipsychotic" medication to be developed, and it is typically remembered today as dramatically different in kind from lobotomy and the other brain-disabling therapies that preceded it. But that was not at all how chlorpromazine was viewed in 1954. It was seen at that time as a pill that hindered brain function, much in the same manner that lobotomy did. It took a decade of modern-day alchemy to turn it into the "antipsychotic" medication we recall today.

merits of neuroleptics. Or would it cast aside questions of recovery and instead defend the drugs?

There can be no doubt today about which choice American psychiatry made. Evidence of the harm caused by the drugs was simply allowed to pile up and up, then pushed away in the corner where it wouldn't be seen.

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It is not difficult today to put together a wish list for reform. An obvious place to start would be to revisit the work of Emil Kraepelin. Were many of his psychotic patients actually suffering from encephalitis lethargica,[2] and has that led to an overly pessimistic view of schizophrenia? The next step would be to investigate what the poor countries are doing right. How are the "mad" treated in India and Nigeria? What are the secrets of care – beyond not keeping patients regularly medicated – that help so many people in those countries get well?[3] Closer to home, any number of studies would be welcome. A study that compares neuroleptics to sedatives would be helpful. How would conventional treatment stack up against care that provided "delusional" people with a safe place to live, food, and the use of sedatives to help restore their sleep-wake cycles? Or how about an NIMH-funded experiment modeled on the work of Finnish investigators? There, physicians led by Yrjö Alanen at the University of Turku have developed a treatment program that combines social support, family therapy, vocational therapy, and the selective use of antipsychotics. They are picking apart differences in patient types and have found that some patients do better with low doses of antipsychotics, and others with no drugs at all. They are reporting great results – a majority of patients so treated are remaining well for years, and holding jobs – so why not try it here?

At the top of this wish list, though, would be a simple plea for honesty. Stop telling those diagnosed with schizophrenia that they suffer from too much dopamine or serotonin activity and that the drugs put these brain chemicals back into "balance." That whole spiel is a form of medical fraud, and it is impossible to imagine any other group of patients – ill, say, with cancer or cardiovascular disease – being deceived in this way.

If we wanted to be candid today in our talk about schizophrenia, we would admit to this: little is known about what causes schizophrenia. Antipsychotic drugs do not fix any known brain abnormality, nor do they put brain chemistry back into balance. What they do is alter brain function in a manner that diminishes certain characteristic symptoms. We also know that they cause an increase in dopamine receptors, which is a change associated both with tardive dyskinesia[4] and an increased biological vulnerability to psychosis, and that long-term outcomes are much better in countries where such medications are less frequently used. Although such candor might be humbling to our sense of medical prowess, it might also lead us to rethink what we, as a society, should do to help those who struggle with "madness."

But none of this, I'm afraid, is going to happen. The antipsychotic drug olanzapine is now Eli Lilly's top-selling drug, surpassing even Prozac. There will be no rethinking of the merits of a form of care that is bringing profits to so many. Indeed, it is hard to be optimistic that the future will bring any break with the past. There is no evidence of any budding humility in American psychiatry that might stir the introspection that would be a necessary first step toward reform. At least in the public arena, all we usually hear about are advancements in knowledge and treatment, as if the march of progress is certain. Eli Lilly and Janssen have even teamed up with leaders of US mental-health advocacy groups to mount "educational" missions to poor countries in East Asia, so that we can export our model of care to them. Hubris is everywhere, and in mad medicine, that has always been a prescription for disaster. In fact, if the past is any guide to the future, today we can be certain of only one thing: the day will come when people will look back at our current medicines for schizophrenia and the stories we tell to patients about their abnormal brain chemistry, and they will shake their heads in utter disbelief.

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2 The invention of schizophrenia, as a diagnostic term, can be traced back to the work of German psychiatrist Emil Kraepelin. In the late 1800s, when Kraepelin was doing his pioneering work, encephalitis lethargica was not a known disease. Anybody suffering from it would have been dumped into the pool of lunatics housed in asylums. This was the patient pool that Kraepelin had tried to sort out. Psychiatry has unfortunately never gone back to revisit Kraepelin's work. What would he have concluded about psychotic disorders if people ill with encephalitis lethargica had been removed from the asylum patients he'd studied? Would he still have found a group who had no known organic brain pathology but still commonly had poor long-term outcomes?

3 The World Health Organization first launched a study to compare treatment outcomes in different countries in 1969, a research effort that lasted eight years. The results were mind-boggling. At both two-year and five-year follow-ups, patients in three poor countries – India, Nigeria, and Colombia – were doing dramatically better than patients in the United States and four other developed countries. They were much more likely to be fully recovered and faring well in society – "an exceptionally good social outcome characterized these patients," the WHO researchers wrote – and only a small minority had become chronically sick. At five years, about 64 percent of the patients in the poor countries were asymptomatic and functioning well. Another 12 percent were doing okay, neither fully recovered nor chronically ill, and the final 24 percent were still doing poorly. In contrast, only 18 percent of the patients in the rich countries were asymptomatic and doing well, 17 percent were in the so-so category, and nearly 65 percent had poor outcomes. Madness in impoverished countries ran quite a different course than it did in rich countries, so much so that the WHO researchers concluded that living in a developed nation was a "strong predictor" that a schizophrenic patient would never fully recover.

4 Neuroleptics, by dampening down the dopamine system, produce an immediate pathology in brain function. By 1959, a case report had appeared in the literature suggesting the drugs could also cause permanent brain damage – even if the drugs were withdrawn, motor dysfunction remained. That year, French psychiatrists reported the bizarre symptoms that came to be known as tardive dyskinesia (TD): "The tongue [is] permanently projected forward and backward following a rapid rhythm; at times the projection is to the side, sometimes to the right, sometimes to the left . . . the lips participate in this dyskinesia in the form of stereotyped suction motions, pursing, rolling and incessant champing in synergy with rhythmic contractions of the jaw."