On My Mind: Sanity

Despite the wild fights with her mother, Merle was adored, admired, and doted on by her younger brother, Ken, who thought of her as his best friend. He found her beautiful, uproariously funny, and in the sweetest way, she loved to mother and entertain him. During loud and sometimes physical fights between mother and daughter, Ken would shout at the top of his lungs, briefly producing a cease-fire. By the time that Ken was 14 and Merle was 20, Merle was hearing voices that no one else could hear. She was consumed with anxiety. She imagined conspiracies of strangers who were trying to hurt her.

"She transformed into someone unrecognizable," Ken later wrote. A brief marriage failed. One day, found in a phone booth, "holed up, babbling the high-speed speech of psychosis, clearly terrified by her new sense of reality," she was sent to a psychiatric hospital. Her parents were overwhelmed by Merle's distress in finding herself manhandled and trapped in the hospital, and offended by the psychiatrist's intrusive questions about their sex life. Despite Ken and an older sister's protestations, they took Merle home, against medical advice, after a week. It was in that moment that Ken decided to become a psychiatrist. Less than a

decade later, just as Ken was starting medical school, Merle was found screaming, a tangle of broken bones, on the cement below her second story window.

In his forthcoming book, “Bedlam: An Intimate Journey into America’s Mental Health Crisis,” Ken Rosenberg wonders, “Had voices commanded her to end it all? Did those voices transmit a message of self-loathing — the culmination of four years of family denial that she was sick, of the pain of her annulment, of winding up a college dropout despite all her hard work? Or had she heard something that had spooked her? The sound of our heavy door knocker, perhaps — a salesman or someone asking for directions? Ultimately, maybe she was just beset with what people with her problem constantly face: a world of unimaginable sensory experiences coupled with a complete lack of judgment.”

More decades later, after the deaths of his parents and older sister, Ken, who went on to become a preeminent psychiatrist and a documentary filmmaker, became Merle’s caretaker. Merle lived a life of isolation, disarray, and chronic detachment from reality. For two years, acceding to his mother’s dying wish, Ken did not call the police when Merle stopped answering the phone. But as Ken was planning to move Merle to a group home, after two weeks of no response to phone calls, Ken did call for help. When he traveled from New York City to their childhood home outside Philadelphia and showed up with the EMTs, Merle, at the age of 55, was in her room, dead. She had never gone back to school, never held a job, never had another romantic relationship, and for years before her death had never made another friend. Like her parents, she experienced her illness as an enormous shame, and she avoided psychotherapy, group treatment, psychiatrists, and the rest of the world.

On Wednesday, August 14, the Martha’s Vineyard Film Festival (MVFF) will show Dr. Kenneth Paul Rosenberg’s documentary film, “Bedlam.” It traces his own story and the story of America’s health crisis, in which hundreds of thousands of the homeless mentally ill are left on America’s streets every night; in which one out of three in America’s prisons have a severe mental illness; and in which the country’s three largest psychiatric treatment facilities are our largest jails.

On Thursday, August 15, as part of a series of small weekly discussion groups moderated by Diana Barrett, Ph.D., the MVFF will present a panel on “Sanity,” featuring Barrett, Jake H. Davis, Ph.D., Ken Rosenberg, and me.

Sanity is defined by the dictionary as “the ability to think and behave in a normal and rational manner; sound mental health or reasonable and rational behavior.”

The textbook definition of insanity is a "mental illness of such a severe nature that a person cannot distinguish fantasy from reality, cannot conduct her/his affairs due to psychosis, or is subject to uncontrollable impulsive behavior."

By any definition, Merle's behavior and thought processes were not sane. But perhaps what ultimately made her life insane was not her symptoms but rather her isolation, shame, failed expectations, and subsequent despair. Despite her hallucinations and delusions, could she have dealt with the realities of her life and conducted her affairs in a rational manner — had she lived in a different context? And what is reality, anyway? Don't we all see life through our own particular lenses that are colored by beliefs, culture, and education?

There is an international Hearing Voices Movement, whose basic tenet is that hearing voices is not *in itself* a sign of mental illness. After all, 3 to 10 percent of people will hear voices in their lifetime. Members of the Hearing Voices Movement suggest that learning to accept the voices, befriend them, understand their perspective, put them into the context of one's life, can ultimately be a tool for growth and healing.

As medical director of Island Counseling Center at Martha's Vineyard Community Services, I see a lot of people who hear voices, and at times believe that people can read their minds, or that they can read the minds of others, or that they have supernatural powers. By the definitions above, they are not all insane. Many live rational, meaningful lives that include loving relationships, meaningful work, and healthy life choices. Sometimes medication helps people who hear voices. But so does a healthy support system, calm, kind relationships, and a sense of purpose — as it does for all of us.

Anthropologists T.M. Lurmann and Jocelyn Marrow wrote a book titled "Our Most Troubling Madness: Case Studies in Schizophrenia Across Cultures," in which they present cross-cultural case studies of people who have severe psychotic illnesses. They note that rates of psychotic illnesses are lower in some countries and higher in others, such as ours. They make the case for the notion that "social defeat — the physical or symbolic defeat of one person by another — is a core mechanism in the increased risk for psychotic illness," and that poor care in the U.S. increases the likelihood of social defeat, while more community care in countries such as India diminishes it. There is a reason why immigrants, as well as people exposed to poverty and racism, have higher rates of psychotic illness, and why their illness follows a more severe course.

Lurmann and Marrow suggest seven practical points:

1) *Minimize diagnosis talk and maximize neutrality.* Besides the fact that our diagnostic system is so flawed that the National Institute of Mental Health (NIMH) is not supporting research based on diagnosis, diagnoses can stigmatize, shame, and convey the message to people with severe psychotic symptoms that they are deranged and permanently damaged. The reality is that many will go on to live normal, healthy lives, and their symptoms will resolve.

2) *Focus on behavior rather than on intrapsychic phenomena.* Who is to say that one person's lens is more valid than another's? What is clear is that some behaviors lead people toward dysfunctional and unhappy lives. Perhaps one reason that voices are often so harsh is that as a society we have told people who hear voices that they are sick and crazy. When we address behaviors, we avoid making all-encompassing pronouncements about an individual.

3) *Enable work.* I have heard that Freud said that there are three elements to mental health: healthy love, play, and work. The case studies in "Our Most Troubling Madness" suggest that identifying oneself as productive and effective rather than identifying oneself by diagnosis is a key to health.

4) *Minimize social isolation, and encourage family involvement.* We see this all the time at Island Counseling. Living with someone with a severe psychotic illness can be challenging, but when families learn healthy strategies for engagement such as those taught by the National Alliance for the Mentally Ill's (NAMI's) Family to Family course, everything goes more smoothly, and individuals often need lower doses of medication. (see my article, mvtimes.com/2018/06/06/on-my-mind). The main difference between the care of severe mental illness in the U.S. and India, where patients tend to do better than they do here, is that in India people stay with their families, and their families are involved in their care.

5) *Provide safe and secure housing.* It is hard to imagine a more destructive setting for someone with a mental illness than the streets and prisons displayed in "Bedlam."

6) Rather than trying to consign voices to oblivion, *engage with voices.* People who are able to interact with their voices feel less at their mercy.

7) *Practice compassion and respect for the experience of psychosis and for the person who is experiencing the psychosis.* "Voices and visions are real

experiences … They deserve the same respect and consideration that allow for all emotional experiences like depression."

I wonder whether, if these seven points had been followed with Merle, her life would have followed a different path.

As Jim Gilligan, M.D., a part-time Vineyarder and an expert on prison psychiatry, told me, "We spend more in the U.S. on prisons than we do on colleges and universities." Today we have about the same number of severely mentally ill people living in total institutions as we did 50 years ago. The difference is that then, the institutions were hospitals; now, at a much greater cost, they are prisons. As Ken Roseberg and Jim Gilligan suggests, our mental health system is broken. Untethered from the corporate interests that drive our emphasis on pharmaceutical treatment and imprisonment, the system is eminently fixable. If you have an interest in mental illness and our mental health system, "Bedlam" is a film not to be missed.

The book "Bedlam" will be available Oct. 1, 2019.

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