

## PSYCHOSIS AND IDENTITY

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I am also a woman with chronic schizophrenia. I first became ill in the late '70s. I was given a “very poor” and a “grave” prognosis—expected to be unable to live independently let alone to work.

That has obviously not been the way my life turned out.

I would like in this Article to think about identity, and the complications caused by mental illness in how we think about identity. I am going first briefly to tell the story of my struggles with mental illness; then I will explore the implications posed by mental illness for our notions of identity.

I look in both parts at my own story. I recognize that I am an “n” of only one. I do think, though, that I am fairly representative of so-called “high functioning” people with schizophrenia, and that what I say will resonate with and have meaning for others with mental illness.

I would first like to describe what my psychosis looks like. I hasten to add that everyone becomes psychotic in her or his own way, so this is just *my* psychosis. I have what are called “positive symptoms”<sup>1</sup>: delusions, hallucinations, and disordered speech. For example, I often believe I have killed hundreds of thousands of people with my thoughts. I have had the visual hallucination of a man standing above me with a raised knife.

I have disordered speech as well. For example, I said to my classmates during a breakdown on the roof of the Yale Law School, “Are you having the same thing happening to your cases as I am—words jumping around the pages? I think my copies of the cases have been infiltrated. We’ve got to case the joint. I don’t believe in joints but they do hold your body together.”

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1. See Nancy C. Andreasen et al., *Positive and Negative Symptoms in Schizophrenia: A Critical Reappraisal*, 47 ARCHIVES GEN. PSYCHIATRY 615, 615–16 (1990); Paolo Fusar-Poli et al., *Treatments of Negative Symptoms in Schizophrenia: Meta-Analysis of 168 Randomized Placebo-Controlled Trials*, 41 SCHIZOPHRENIA BULL. 892, 892 (2014).

This is called “loose associations”—putting words together that may sound alike and be related but don’t actually make sense.<sup>2</sup>

Schizophrenia also has what are called “negative symptoms.”<sup>3</sup> These are things like apathy, withdrawal, inability to function, and inability to be in relationships. Except for the first two years I was ill I have been lucky to not have any negative symptoms. A lot of the burden of schizophrenia resides in the negative symptoms, and so I am again fortunate to be spared these.

To give a sense of what an episode of psychosis looks like for me, consider this scene. My New Haven analyst, whom I will call Dr. White, announced that he was going to close his practice in three months, fully two years before I had planned to leave. The news of White’s leaving shattered me. When White gave me this news, my closest friend, Steve, was traveling around the country interviewing for PhD programs in clinical psychology. He had sensed that something was terribly wrong, and he came to New Haven to see me. I describe this encounter in my book:

I opened the door of my studio apartment. Steve would later tell me that for all the times he had seen me psychotic, what he saw that day shocked him. For a week or more I had barely eaten. I was gaunt, and moved as though my legs were wooden. My face looked (and felt) like a mask. Since I’d pulled down all the shades, the apartment (in the middle of the afternoon) was in near total darkness. The air was fetid, the place was a shambles. Steve has worked with many patients who suffer from severe mental illness. To this day he’ll tell me that on that afternoon I looked as bad as any he’d ever seen.

“Hi,” I said, then returned to the couch, where I sat in silence for about five minutes. “Thank you for coming, Steve,” I finally said. “Crumbling world. Word. Voice. Tell the clocks to stop. Time is time has come.”

“White is leaving,” Steve said somberly.

“I’m being pushed into a grave, the situation is grave,” I moaned. “Gravity is pulling me down. They’re all trying to kill me. Tell them to get away. I’m scared.”<sup>4</sup>

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2. See Christine Mohr et al., *Loose but Normal: A Semantic Association Study*, 30 J. PSYCHOLINGUISTIC RES. 475, 476 (2001); Michael Kiang, *Schizotypy and Language: A Review*, 23 J. NEUROLINGUISTICS 193, 197 (2010).

3. Andreasen et al., *supra* note 1, at 615; Fusar-Poli et al., *supra* note 1, at 892.

4. ELYN R. SAKS, *THE CENTER CANNOT HOLD: MY JOURNEY THROUGH MADNESS* 227–28 (2007).

Dr. White actually changed his mind about leaving so soon, and the episode resolved itself.

When I moved to L.A. I got into analysis with a man I will call Kaplan. Kaplan and I developed a way of talking, a sort of heuristic, about my illness, and my relationship to my illness. There were, in our manner of speaking, three me's:

- Elyn;
- Professor Saks; and
- The Lady of the Medical Charts.

I could not integrate these three aspects of myself.

How could I be a thinker of big thoughts, an academic, if my mind was so damaged? How could I be both Professor Saks *and* the Lady of the Medical Charts? And, where did Elyn fit in all this? What took a huge amount of effort, and what was ultimately self-defeating, was to keep them separate.

I wasn't sure who was the real me. This confusion expressed itself in an intense ambivalence toward taking my medication. For many years, my motto was "the less medicine, the less defective." Steve was a virtual saint as he spent literally years of our relationship going through time and time again when I tried to get off my medication with disastrous results. It wasn't simply that I did not like the side effects of my psychiatric medication. The need to take medication reached to the core of my identity. If I could get by without medication, I wasn't really mentally ill, and the Lady of the Charts would disappear. Only Elyn, and the Professor, would be left as the real me. This cycle culminated in one final effort to get off my medication several years after I had been on the faculty at USC.

I decided to make one last effort to get off—I thought I had never really tried hard enough. And so I started the reduction. I hid what I was feeling when I started feeling bad. Quoting from my book:

The days and nights were harder now. The sheer physical effort of containing my body and my thoughts felt like trying to hold back a team of wild horses. Sleep was spotty, and filled with dreams that left me awake and sweating in terror. Nevertheless, I dropped down to two milligrams.

Months before, when I'd been invited to attend a workshop at Oxford, I'd accepted. . . . By the time I boarded the plane for home, I was a complete wreck.

When I walked into Kaplan's office my first day back, I headed straight for the corner, crouched down on the floor, and began to shake. All around me were thoughts of evil beings, poised with

daggers. They'd slice me up in thin slices or make me swallow hot coals. Kaplan would later describe me as "writhing in agony."

"Elyn, you need to increase your meds," he said immediately. "You're acutely and floridly psychotic."

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I was shaking, but I was also shaking my head. I couldn't take more. *The mission is not yet complete.*

Immediately afterward, I went to see [Dr.] Marder [a schizophrenia expert who was following me for a movement disorder caused by the meds called "tardive dyskinesia"]. He'd never seen me ill before; he'd been under the impression (and I hadn't disabused him of it) that I had a mild psychotic illness and that my primary concern was avoiding TD. Once in his office, I sat on his couch, folded over, and began muttering. I was disheveled—I couldn't remember when I'd slept, or what I'd eaten. When had I bathed—in Oxford? Before Oxford? Did it matter, if we were all going to die anyway? Anyone who walked into that room would have thought Marder was treating a schizophrenic street person. Weeks later, he told me that's exactly what I looked like.

"Head explosions and people trying to kill. Is it OK if I totally trash your office?"

"You need to leave if you think you're going to do that," said Marder.

"OK. Small. Fire on ice. Tell them not to kill me. Tell them not to kill me! What have I done wrong? All the explosions. Hundreds of thousands with thoughts. Interdiction."

"Elyn, do you feel you're dangerous to other people? Or to yourself?" he asked.

"That's a trick question," I said. [I don't think you ask a mental health law professor if she meets the statutory criteria for civil commitment in the language of the statute.]

"No, it's not," he said. "I'm serious, I think you need to be in the hospital. I could get you into UCLA right now, and the whole thing could be very discreet."

"Ha ha ha. You're *offering* to put me in the hospital? Hospitals are bad, they're mad, they're sad. One must stay away. I'm God. Or I used to be. I give life and I take it away. Forgive me for I know not what I do." [My husband made a marginal note here: did you as God quit or were you fired?]

"I *really* think a hospital would be a good idea," Marder said.

"No, thank you oh so very much," I said.

"All right, then, but if I were you, I'd stay away from work for a while. You don't want your colleagues to see this."

“Thanks, banks, bang, bye. See you soon.” Oblivious to the look on his face, I left.

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... The next morning, I dragged myself to my office—my hideout, my refuge.

But I ran into Ed McCaffery [my colleague] in the hall.

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... [A]s I got more wound up, he [quickly] figured out what was happening.<sup>5</sup>

Suffice to say that Ed eventually brought me home, showing the good judgment to follow my doctor’s advice rather than tackle me to the ground and take me to the hospital, as others were recommending. Eventually I acceded to everyone’s demand that I take more meds. “I could no longer deny the truth and I could not change it. The wall that kept Elyn and Professor Saks separated from the Lady of the Charts,” the insane woman hospitalized years before, “was smashed and lay in ruins.”<sup>6</sup>

Getting on new meds also had a great impact on me. I had always had the fantasy that everyone’s mind contained the chaos, terror, confusion, and violence that mine did, but they were simply better at managing them than I. My problem was I was socially maladroit, not ill. Getting on meds that actually cleared my mind and my thinking helped me to understand that I indeed had an actual illness—I wasn’t just awkward. Healthy people’s minds were in fact clear, not full of terror and confusion. Ironically, the more I accepted I had a mental illness the less the illness defined me. It became, as it were, accident rather than essence. At which point the riptide that had kept sucking me in set me free.

My life today is wonderful. I have a great husband, great friends and family, and a great profession. I think I evaded my grave prognosis because of the excellent treatment I have received together with, again, great relationships and wonderful work.

I would like now to broach the specific topic of this symposium: identity. How does one’s experience of schizophrenia affect the question of identity?

The question of identity for a person with mental illness, particularly episodic mental illness, is fraught. As I noted, there are three aspects of myself: Professor Saks, Elyn, and the Lady of the Charts. Who am I? Am I all three at different times? At the same time—just one more prominent at a given time?

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5. *Id.* at 272–75.

6. *Id.* at 277.

These are not different selves as in the case of multiple personality disorder. They are aspects of who I am. Yet they are often in conflict. And I don't know who is, most fundamentally, the real me.

Not everyone with mental illness has three aspects. But except those who are chronically ill, people with mental illness have their mentally ill self and their mentally healthy self. If you are in this situation, who is the real you?

One complication here is that asking who is the real you may be incomplete. One must rather ask who is the real you for what different purposes? For example, the real you for purposes of receiving treatment may be the ill you. The real you for purposes of going to school may be the student you. The real you for occupational purposes may be the law professor you.

For any of these, reconciling mental illness into one's identity is difficult. At the same time that I denied that mental illness was me or a part of me I also thought it dominated my identity—was my truest, if most horrifying, self. Fighting it made it more central.

Part of my treatment has been trying to come to terms with all the aspects of myself. For example, I worked through the narcissistic injury of having a mental illness and needing meds. Again, once I accepted these aspects they became more tolerable and less toxic—my mental illness ceased defining me. The Lady of the Charts diminished in significance.

There's also an issue about being able to claim an identity of any kind. This has been called the "politics of identity."<sup>7</sup> Can all people diagnosed with mental illness claim that identity? Or do you need to have experienced certain things or have certain aspects of yourself to entitle you to claim an identity as a person with mental illness?

For example, does someone with mild anxiety at times warrant the label of being a person with mental illness? A consumer/survivor? What about mild dysthymia?

I have seen instances where an African-American person was said not really to be black; a deaf person not really deaf.

I myself have been told that I don't really have schizophrenia—I am doing too well. At the very least I am "not representative"—that's the basis on which I was removed from a segment on *60 Minutes*. Some might even claim that I am not authentically mentally ill at all; I function too well for that.

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7. Tobin Siebers, *Disability Studies and the Future of Identity Politics*, in *IDENTITY POLITICS RECONSIDERED* 10, 19 (Linda Martín Alcoff et al. eds., 2006). See generally *CULTURE, POWER, PLACE: EXPLORATIONS IN CRITICAL ANTHROPOLOGY* (Akhil Gupta & James Ferguson eds., 1997); *SOCIAL THEORY AND THE POLITICS OF IDENTITY* (Craig Calhoun ed., 1994).

Still, maybe we should say that anyone who wants to claim the mental illness label should be entitled to it. After all, why would one claim it if one didn't identify with the label given all the disadvantages and stigma?

On the other hand, if most people identify as having a mental illness, it dilutes its impact. This could be good—people are stigmatized less. Or it could be bad—knowing you are on a continuum with people with serious mental illness may make it scarier to people: those on the far end of illness may stand out even more and be even more undesirable/unacceptable. In addition, we may have less commitment to people with serious mental illness if mental illness becomes a more acceptable and less problematic phenomenon.

It's an interesting question *why* people want to claim an identity and exclude others. The idea would be that only people with certain characteristics are, e.g., authentically mentally ill. Only these people can understand being marginalized and stigmatized, and can claim overcoming the stigma. Mildly ill people may be more like the general population than like people with more serious mental illnesses.

In the end, mental illness complicates how we think of a person's identity. At least with acute illnesses, we must decide who is the real self—the self in charge most of the time, the self unmedicated or alternatively medicated? Who gets to choose and are there limits on what they may choose?

With chronic mental illnesses we must say either that the person has been transformed into a different person—the ill person—or that the person's real self is being hidden and is still there. The mentally ill self may then be inauthentic even though it is most often present.

Identity and identity politics raise interesting and challenging issues. It is hoped that discussing these will contribute to our understanding of this most important notion.