

A Fight to Be

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A Fight to Be

Introduction

Too brief and infrequent are the moments when thoughts and feelings are stilled and I am just present. Beneath the tall pines, standing in the backyard, I glance over at my son frolicking with our dog and at my wife reading in the sunlight – I breathe deeply and absorb all that I can before ego intervenes and intellectual pride demands answers. Why me? How did this pastoral scene insert itself into the fractured life story of a city boy who sought to find himself in madness? I look upwards at the sky and silently ask, what is guiding me? How was it possible for me to become who I am today? What have I learned from more than forty years spent studying the phenomena known as madness – my own and others?

Whether I am conducting a workshop for professionals, teaching a class of psychology students or speaking to a group of people like myself who have been diagnosed and treated for major mental illness, I am privileged to witness their intense search to find helpful information. Regardless of the venue or the makeup of the participants, the questions have become predictable.

How did you recover from schizophrenia?

Do you take medication now?

What was it like studying to become a psychologist?

How did you become psychotic?

What was the experience of schizophrenia like?

Are you afraid it will happen again?

What was the most helpful therapy?

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What do you think would help me (or the people I work with)?

And the comments from the critics:

You must have been misdiagnosed.

Mental illness is a neurobiological disorder with no cure and can only be controlled with drugs.

What you are saying will discourage people from taking the medications they need.

Your example will only give false hope to the low-functioning people I work with.

My daughter cannot survive unless she is forced into inpatient hospital care.

Most listeners praise me for my courage in sharing such painful private experiences, but I believe that rather than being a matter of courage, it is something I must do. What I share has not become automatic or dull from repetition. My stomach continues to flutter, my hands tremble and my voice at times cracks, as much from my passionate belief in the value of what I am communicating, as from exploring the pain and meaning of my travels through madness, its treatment and my personal journey of transformation.

Not far from Manhattan, on the Jersey side of the Hudson River, there's a clearing among the trees and rocks where Alexander Hamilton fought his fatal duel with Aaron Burr. Years earlier I went there with friends to innocently laugh and enjoy our youthful self-centered exuberance. At night, gazing across the river at the New York skyline, where lights, shapes and imagination taunted reality's constraints, I first encountered that seductive charge of energy and power. Awakened to an emotional state in which excitement and possibility replaced the angst and ennui of extended adolescence, a door opened. The invitation to enter alternate realities and unlimited possibilities was irresistible.

After my release from the hospital, I returned to that spot frequently. Sitting on those once-familiar rocks and staring into the distance, I searched and waited for a feeling or memory to infuse my apathetic body with that mystical power the hospital staff had shocked out of me. There was no magic to be recaptured, no opening of the mind and the senses, just the dull pain of longing for what once was. Along with so many others hoping and praying at their public and private shrines, I joined what Albert Schweitzer called the “brotherhood of those that bear the mark of pain.”

For two and a half years I faithfully went to my twice-a-week psychotherapy sessions. Without questioning their value, I obediently rode the bus from Irvington, New Jersey to the New York Port Authority Building, then two subway trains to the upper East Side of Manhattan. I hated those sessions. Each excruciating minute of awkward silence affirmed my inadequacy. I felt dull, numb and barely capable of short answers to simple questions. I blamed myself for my inability to think of anything to say. I floated in a dense foggy space with no anchors, cut off from past aspirations and not knowing what I believed or valued. No goals, but one all-consuming priority guided me – to stay out of the hospital.

Therapy was supposed to be my shield. Would I forever be this person they said was schizophrenic? Electroshock and insulin coma treatments had left huge holes in my memory. I plodded along and endured the emptiness by stubbornly holding onto the hope that I could find a way to change and become the person I once believed I had the potential to be. The return trip was my respite; nothing more would be expected of me until the next session. The people and places I passed elicited no interest or feeling and I was reassured by their lack of interest in me.

Twenty-three years old, the life I had been leading and the many opportunities I expected to be available were torn from me. Experts preached that it was necessary for me to accept a life sentence of schizophrenia. They warned that my choices were governed by the demands of mental illness and my freedom would be dependent upon my compliance with treatment recommendations. A hopeless and helpless mental patient, I had to surrender my power to those with credentialed authority.

Innocently, I had waded into the sea of madness hoping to find myself. Instead, psychiatry found me. They said I would drown if I did not take the lifeline they threw to me. I heard them shouting at me, but wondered why they were so excited about me playing in the waves. I told them I would just tread water until I learned to swim in the turbulence. They said no. I refused to leave the water. I was too young and naive to know that

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the doctors posed more of a danger than the sea. I was an inexperienced lightweight jutting out my jaw and challenging the mighty, government-sanctioned heavyweight champion. Knocking me out with forty shots of insulin, the doctors dragged my unconscious body to shore and left my spirit in the sea of madness. Psychiatry became my life-long nemesis.

Doctor, you act as if you are far superior to me. You talk down to me. You say I have a sick mind, a brain disease. You try to make me see the world the way you see it. I resist. I don't want to be like you. Yes, I do want to be what I am not. I must strive to be more than I am.

I did not know that my journey would be so painful. You made me suffer with the help you forced upon me. First you subjected me to humiliation and brain washing. This state you call schizophrenia has a vastly different meaning to me. Dangerous, yes, but for those of us who must battle the "disease" of feeling too much, of seeing what others do not see, and not meeting expectations that were never our own, it is ripe with opportunity to transform ourselves.

With so many of us out here, and our numbers increasing all the time, doesn't that make you question what you construe as normal? As the expert, you say you are the most qualified to help people like me. How healthy are you and how sick am I? You put me in the hospital and electrocuted my brain. You thought that by injecting me with insulin and forcing me into forty comas I would learn to accept your reality. You did not approve of the way I searched to find me. My quest to explore other possibilities was unacceptable to you. The unknown makes you uneasy. Control and predictability soothes you.

Doctor, is your ego immune to the searing, soul-searching questions that haunt me? I wonder who I am and what it means to be a human being. Do you? You act as if you have access to a special cache of wisdom, but I don't believe you are as self-assured as you pretend. My dog knows what it means to be a fully realized dog. She moves with natural grace, perfectly attuned to her wants and desires. The sight of food in her bowl inspires a frenzy of tail-wagging pleasure. Perhaps you mistook me for a dog and believed that your psychic and physical abuse would make my irrational mind heel to your commands. I did not respond to your rewards and punishments. If Pavlov had performed his classical conditioning experiments on cats instead of dogs, he would not have observed cats salivating at the sound of his bell. I cannot be a dog.

Every Christmas, *It's a Wonderful Life* returns to television to stir nostalgia in its loyal fans and attract a new generation of viewers. Director

Frank Capra and actor Jimmy Stewart tapped into an archetypal need with their movie's defining theme: No one is born to have a life without meaning.

The right to strive to live one's life with meaning and purpose is not among the mutually agreed upon treatment goals available to the schizophrenic mental patient. The existential questions were considered to be too dangerous for me.

I was no longer eligible to struggle with the dilemma that Walt Whitman pondered:

*I cannot understand the mystery but
I am always conscious of myself as two.
Do I contradict myself?
Very well then I contradict myself,
I am large, I contain multitudes.¹*

Few of us with the diagnosis of schizophrenia are permitted the opportunity to live large. I wanted to dance again with expansive possibility. The experts said safety had to be the first priority. Frozen and vulnerable, I had to heal the wounds, feel the hurt, be angry and shed the dead skin so that I might reclaim me. When safety dictates all the rules, such a journey of reclamation cannot be conducted.

The strange and frightening world of mental illness resists reductionist explanations. It seems as if we automatically seek to distract ourselves from confronting our inevitable mortality. Like children, we crave simple explanations to soothe us after our nightmares. Medical anthropologist and cancer survivor Arthur Frank writes about how life changes when one's being is disrupted by illness. Our capacity to reconstruct our interrupted stories offers transformative opportunities. And when those who survive and thrive bear witness, their testimony helps others move through the experience of an illness-interrupted life.

I remain frustrated that mental health professionals have been slow to accept the value of experience-based knowledge and have not integrated that wisdom into the services they provide. Too many treatment practices remain tethered to physical interventions, and continue to constrict a person's chances for recovery and transformative growth. Intolerance and lack of support for emotional pain and instability leave psychiatric drugs as the primary treatment option. The resulting drug-induced stability may bypass the current pain, but too easily invites that person to take on the role of chronic mental patient. The precipitating crisis may be deflected, but the

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opportunity for personal growth and development is sacrificed. I was fortunate that in the late 1960s and early 1970s when I was being treated, psychiatric drugs had not yet reached the esteemed and heroic status they enjoy today. Unlike many individuals subjected to the prime emphasis of current practice – forcing people to continue taking their psychiatric drugs – I was allowed to follow through in my choice to stop taking drugs.

The treatments that are available for people in extreme emotional states are generally ineffective and often harmful. The search for biochemical solutions has become an obsession. New drugs, rather than decreasing emotional pain, have created more severe iatrogenic problems. According to the professional experts, the number of people with mental disorders is increasing. The types of psychiatric disorders in the American Psychiatric Association's best-selling publication, the *Diagnostic and Statistical Manual of Mental Disorders*, keep expanding. Ironically, long-term research from the World Health Organization has shown that people with schizophrenia who live in developing countries recover at a significantly higher rate than those in the United States.²

Manic-depressive disorder, renamed bipolar disorder and once considered rare, has become the new disease du jour. Recently, a nurse practitioner bragged to me of prescribing Prozac for a three-year-old she had diagnosed as bipolar. With a stunning lack of self-awareness, she was proud to tell me of confirming the validity of the Prozac prescription, much to the surprise of the conscientious pharmacist who called to see if a mistake had been made. I shudder to think of how this child will have to struggle with not only a label that was stuck on her at such an early age, but the unpredictable developmental effects of this psychiatric drug.

The practice of psychiatry is now the practice of drug prescription. Psychiatrists are so busy prescribing drugs that they have found it highly profitable to expand their practice by employing and signing off on the orders of physician assistants and nurse practitioners. Pharmaceutical companies have found that they can increase the demand for psychiatric drugs by advertising directly to the public. Taking very little time to understand their patients' needs and problems, health professionals are prescribing these powerful and often dangerous drugs to help their patients cope with the trials and tribulations of life.

In my psychotherapy practice, I get referrals from family physicians who routinely give depression screening tests. Patients arrive for their first psychotherapy sessions with prescriptions for a combination of antidepressants and anti-anxiety drugs. To be sad has become an intolerable

condition that requires a quick pill remedy. It is certainly legitimate for people who are in severe distress to seek a drug-based solution. What is unacceptable is the misleading promise that the psychiatric drug has been scientifically proven to work for your accurately diagnosed mental disease. Can we find real remedies by simply checking off a list of symptoms and behaviors so that a diagnosis can be identified and the appropriate drug prescribed?

Sometimes a psychiatric drug will effectively work on the immediate problem and sometimes not. Which drug will work on which person is a gamble, an educated guess at best, made after months or even years of painful guesswork – that is, painful for the patient. I am not opposed to using a substance to deal with pain. I am opposed to the subtle coercions, the misrepresentation and lack of full information presented to people who are vulnerable and seeking expert advice. A person in extreme psychic or physical pain will most likely choose to take the quickest, most effective substance for relief. Whether or not it provides temporary relief should not be the only factor that guides the decision. Just as it is dangerous to ignore the guidance that physical pain provides, to anesthetize ourselves from psychic and emotional pain deters us from finding better solutions. Unfortunately, the physical and emotional consequences of our reliance on drugs only emerge and demand attention later.

The psychiatrists did not do very well in predicting my future. Thirty-five years ago, after I was discharged from my second psychiatric hospitalization, I aimlessly walked the streets of New York City. Despair and loneliness were my constant companions. I needed people. I wanted to be around people, but how could I relate to others when my feelings were dominated by fear and embarrassment? Empty, nothing to say, nothing to contribute, only with anonymity's protection could I be around people and not be humiliated by my inadequacies. How well I remember believing that a bleak future with no friends was my destiny. Marriage and children would not be available to me. Dull and slow, devoid of spontaneity, I hardly had the energy to hate my life.

Now, no matter how down I might get, when I consider those bleak days and nights my perspective is always jerked back and the picture becomes clear and bright. My good fortune and hard fought recovery and success have never dimmed my insider's knowledge of what has been done, is being done, in the name of treatment – to and for but rarely with those lacking the power or voice to fight the abuses and keep their basic human rights. I survived and learned how to swim in the sea of my personal

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madness, and with that privilege came the obligation to tell my story and make my experiences available for others to use. I began to enjoy and value being me when I was able to move beyond survival into making it matter how I survived.

This narrative explores the evolution and development of my identity and concludes with an examination of more humane and effective ways of dealing with the extraordinary emotional states labeled as mental illnesses. There have to be more creative options than supportive outpatient clinic visits and, when that is not enough - inpatient hospital treatment. We need a variety of services tailored to meet the specific needs of an individual within a specific context at a specific time and developmental stage of life. All of us have the capacity for excruciating emotional pain; perhaps it is the blessing and curse attached to the expansive forms of consciousness that are unique to human beings. We can do much better in supporting each other.

For the unheard voices of those who have been lost in the labyrinth of the mental health system, for the families, lovers and friends who seek understanding and guidance, for the mental health professionals who genuinely struggle with their own and others' frightening existential plight, and for all those activists who demand the absolute entitlement of dignity and respect for everyone, I offer my voice to inspire hope and to join with them in their continuing *fight to be*.